# Community Perceptions and Practices in relation to malaria control in South West Timor Leste

By

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# ATTENSTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made in the acknowledgements.

Date: 28/01/2013

Signed:

Maria Lurdes Gama Soares

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#### **ABSTRACT**

Malaria is still one of the major public health issues. It is one of the World Health Organization's target to combat worldwide. In Timor Leste, malaria is one of the major causes of morbidity and mortality. This disease might be occurred due to factors such as poor sanitation and drainage system. In addition, it might be happened as an impact of other problems such as lack of knowledge about malaria within the community in Timor Leste.

This research was carried out to investigate and explore the perceptions and practices of the rural community in Timor Leste in relation to malaria control. This will also provide some basis for consideration ways in increasing community involvement in malaria control in this country.

This study applied a qualitative descriptive research methodology and it used four methods in conducting the study. The methods applied in this study were conducted three key informant interviews, two focus group discussions, two transect walks and researcher observation. In addition, the thematic analysis was used to analysis the data.

Findings revealed that lack of knowledge, misconception of the cause and the symptoms of malaria and lack of health services lead the community to have no proper diagnosis and treatment. In addition, lack of community involvement also has been identified as one of the causes for reducing malaria morbidity and mortality in Timor Leste.

The study also revealed that the current malaria program mainly used a "top down approach", therefore the community did not involve actively in controlling and preventing malaria disease. Therefore, the current malaria program should take a consideration to develop a community-based program ('bottom up approach') to get community more actively involved in combating malaria in this country. This suggested approach believed to have a positive outcome for the malaria program to move to the elimination stage in the near future.

# CHAPTER ONE INTRODUCTION

This chapter discusses the definition of malaria, the malaria situation worldwide, the situation in South East Asia and the malaria situation in Timor Leste; as well as the policy that has been implemented to prevent and control this disease in that country. The chapter describes the situation in Timor Leste in depth, especially in regards to one of the districts in the Southwest of the country (Maliana), the area chosen by the researcher as the focus of the field study.

#### 1.1 Malaria

Singh, Kim Sung, Matusop, Radhakrishnan, Shamsul, Cos-Singh and Conway (2004) stated that malaria is one of the vector-borne diseases. It is caused by a parasite (Plasmodium). This parasite is transmitted from person to person and it can be passed on to other people by a female mosquito as a result of biting an infected person, then subsequently biting an uninfected person. There are five species of malaria which can cause malaria in humans. Four Plasmodium species are well known, namely: *P. falciparum*; *P. vivax*; *P. ovale*; and *P. malariae*. A fifth one, *P. knowlesi*, has been more recently found to cause human infections in many countries of South East Asia (B. Singh et al., 2004).

### 1.2 Symptoms of Malaria

The symptoms of malaria are uncertain, because although fever is the most common symptom, it may be asymptomatic; and sometimes it presents with fever as the first symptom and may or may not be accompanied by any of the other signs and symptoms such as headache, body and joint pains, feeling cold and sometimes shivering, diarrhea, nausea, vomiting and splenomegaly (enlarged spleen) (Kakkilaya, 2007).

#### 1.3 At-Risk Groups (Vulnerable Groups)

Jamison et al (1993) state that pregnant mothers and children under five are the risk groups that could easily contract malaria. Children under five, from the age of one year and over, no longer have the immunity transferred from their mother and are at risk until they reach the age where they have developed their own immunity. Pregnant women are at risk of getting this disease because their natural immunity is reduced. Pregnant

women are four times more likely to suffer from complications of malaria than non-pregnant women. Malaria is a cause of miscarriage, low birth weight, and neonatal mortality (Jamison et al., 1993). In addition, if a woman is infected with malaria during her pregnancy, this can result in spontaneous abortion, stillbirth, congenital infection or anemia in the unborn child.

Malaria can cause the fetus to grow more slowly (intrauterine growth restriction, IUGR) and thus result in a low birth weight (less than 2500 grams). The cells of placentas infected with *P. falciparum* parasites change in characteristic ways that is believed to inhibit fetal growth. (The Malaria Consortium, 2007, p. 170)

#### 1.4 The Malaria Situation Worldwide

Malaria is still a major global public health problem. Therefore, in terms of at risk geographical areas, the World Health Organization categorizes the world as falling into six regions, which are Africa, America, South-East Asia, Europe, Eastern Mediterranean and Western Pacific. One of these at risk areas is South East Asia. Nearly two and a half million cases of malaria were reported in this region in 2010 (WHO, 2011). In addition, this disease remains one of the worldwide public health issues, therefore, the World Health Organization included reducing mortality from, and incidence of, this disease as one of the Millennium Development Goals (MDGs) (UNDP, 2010). However, the malaria programme is more focused on target 2 (incidence), which is halting and beginning to reverse the incidence of malaria. The specific target to be achieved is to reduce malaria incidence by 45% in 2010 and 60% in 2015 (United Nations Development Program, 2010). The targets being focused on are to reduce the incidence of, and death rates associated with, malaria; to increase the proportion of children under five sleeping under insecticide-treated bed nets; and to increase the proportion of children under five with fever who are treated with appropriate anti-malaria drugs (UNDP, 2010).

It is estimated that in 2010, around 3.3 billion people in the world were at risk of contracting malaria. Malaria occurs in over 100 countries but is mainly found in the poorer, tropical areas of Africa, Asia and Latin America (Kakkilaya, 2007). As can be seen in the following map (Figure 1), the high risk areas of malaria (indicated in dark purple) are located in the African and South-East Asian regions. In addition, the low risk areas (indicated in light purple) are in the Mediterranean region and the white areas

are the areas that have no malaria cases such as Australia, New Zealand etc. (Kakkilaya, 2007).

Figure 1. Global distribution of malaria

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In 2010, there were about 216 million episodes of malaria, and approximately 655,000 malaria deaths (Kakkilaya, 2007). Ninety one percent of deaths occurred in the WHO African Region, 6% in South-East Asia and 3% in the Mediterranean Region. Approximately 86% of deaths worldwide were in children under five years of age (WHO, 2011).

#### 1.5 The Malaria Situation in South East Asia

Malaria is a major public health issue in the South East Asia (SEA) region. Eleven countries are included in this region, namely Bangladesh, Myanmar, the Democratic Republic of Timor Leste, India, Bhutan, Indonesia, Nepal, Thailand, the Democratic People's Republic of Korea, Sri-Lanka and the Maldives. Ten countries out of the 11 in this region are malaria endemic countries. Around 40% of the global population at risk of malaria reside in the SEA Region, and account for 15% of the global reported confirmed cases and around 2.7% of the global mortality due to malaria (WHO, 2012a). As can be seen in the following bar chart (Figure 2), the African region accounts for the highest proportion of malaria cases in the world. The South East Asia Region accounts for the second highest proportion of malaria cases in comparison to regions such as the Western Pacific (0.9%), East Mediterranean (5.7%), American (3.2%) and European (no malaria cases) regions. Moreover, South-East Asia has the second highest proportion of malaria mortality in the world after the African Region. Based on this situation, South East Asia has continuously included malaria as one of their health targets, in order to combat malaria in their region (WHO, 2012a).

Figure 2. Malaria Burden in the South East Asia.

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Most malaria infections occurring in Timor Leste, Bangladesh and Myanmar are caused by *P. falciparum. P vivax* is responsible for infections in Nepal, Sri-Lanka and the Democratic People's Republic of Korea as well as Timor Leste. In 2010, around four billion malaria cases were reported in those countries. However, there were only around two million cases confirmed parasitologically and the rest of the cases might be underreported (WHO, 2011). India, Myanmar and Indonesia accounted for 94% of confirmed cases. In addition, these three countries also have the highest mortality rate in comparison to other South-East countries. According to the World Health Organization (2011), a total of 2,426 malaria death were reported from eight countries, but around 90% of death cases were reported from India, Indonesia and Myanmar. As the World Health Organization (2011) states, between the years 2000 and 2010, malaria cases increased by 70% in Bangladesh, 250% in Myanmar and 216% in Timor Leste. The increase of malaria cases in these three countries might be due to the rise in utilization of diagnostic testing (WHO, 2011).

#### 1.6 The Malaria Situation in Timor Leste

Timor-Leste is located between Indonesia and Australia (Figure 3), on the eastern end of Indonesia and the northwest of Australia (One World-Nation Online, 2011). The island of Timor-Leste is in South East Asia, making this country susceptible to the blood disease, malaria. In Timor-Leste, 100% of the population reside in areas endemic for malaria (Beilby, 2010). The Democratic Republic of Timor Leste is comprised of 13 districts (Aileu, Ainaro, Baucau, Bobonaro, Covalima, Dili, Ermera, Manufahi, Manatuto, Lautem, Liquica, Viqueque and Oecusse). There are 67 sub districts, 498 villages and 2,336 hamlets in Timor Leste, and a population of approximately 1,066,409 million with around 70% (750,323) residing in rural areas. Approximately 30% (316,086) live in urban areas (Diracao Nacional Estatica & UNFPA, 2010).

Figure 3. Location of Timor Leste in the South East Asia.

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In Timor Leste, malaria is a second major health problem after acute upper respiratory (M. Yapabandara, 2011). Five year data (2005 to 2009) of laboratory-confirmed cases of malaria from health centers in Timor Leste reveal there are around 33 to 88 malaria deaths a year. Inpatient cases range from 682 to 1,829 per year (WHO, 2012c). Moreover, malaria remains one of the major public health problems in the country due to a poor surveillance system. Baum (2008, p. 159) states that "in most developed countries, including Australia, the data collection is routine and reliable, but it is not possible in many low-income countries where specific household studies are necessary to gain estimates of mortality rates." Timor Leste is one of the lowest-income countries in the world and this country also has a poor surveillance system, as most of cases are not parasitologically confirmed by the health workers, and the data may not be routinely collected. Therefore some of the cases were not routinely reported to the Timor Leste Ministry of Health.

Malaria is one of the major causes of morbidity and mortality, responsible for more than 40% of deaths annually in Timor Leste (Beilby, 2010). Almost every Timor Leste household is affected by the human suffering and economic hardship caused by malarial illness. It has been estimated that there are around 50-150 deaths per year due to malaria and more than 1,000,000 working days are lost each year as a result of this disease (Democratic Republic of Timor-Leste (Ministry of Health, 2003). Accordingly, in 2003 the Ministry of Health (MoH), through the Communicable Disease Control Department (CDC), established the National Malaria Control Program (NMCP) at a national level to control malaria in 13 districts. The MoH, through the NMCP, has implemented a 'top-down' approach to control malaria; along with another programme using a 'bottom-up' approach. This programme is known as an Integrated Community Health System (SISCa) and includes malaria education as one of its activities. This activity is still carried out in the country until now.

# 1.7 Malaria Transmission

# 1.7.1 Parasitology of malaria.

There are two types of malaria cycles, one which takes place in the human body called shizogony, which takes 9-14 days; and the other occurring in the mosquito's body called sporogony, which takes 8-12 days. Therefore, a complete malaria life cycle will take about a month (M. Yapabandara, 2011). A detailed depiction of malaria transmission can be seen in the following diagram (Figure 4) (Kakkilaya, 2007), and a description of each stage in the mosquito and humans follows in the next section.

Figure 4. Diagram of the malaria life cycle.

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## 1.7.1.1 Malaria development in the mosquito: the sporogony phase.

The initial stages are as follows:

- 1. Female and male gametocytes enter the mosquito stomach with the human blood meal.
- 2. These male and female gametocytes form gametes in the stomach.
- 3. The male and female gametocytes unite and form a zygote (called an ookinete)
- 4. The ookinete penetrate the mid-gut wall and become a round oocyst.

#### In the mosquito body

- The oocysts divide and form a lot of sporozoites;
- the oocysts then burst and release adult sporozoites into the mosquito body cavity;
- after that the sporozoites migrate to the salivary glands;
- finally, sprozoites are injected with saliva when the mosquito feed.

## 1.7.1.2 Malaria development in humans: the schizogony phase.

The initial infection stages in humans are as follows:

- 1. The female anopheline introduces sporozoites into the human blood during the biting.
- 2. Through blood circulation, the sporozoites enter the liver cells after 30-45 minutes.

The schizogony process.

The schizogony process consists of two parts: the liver stage and the blood stage. Each is described below.

The liver stage: in vivax and ovale malaria, there can be a dormant stage. In this stage:

- sporozoites develop into schizonts containing many merozoites;
- after that schizonts rupture and merozoites release into the blood circulation;

• the human host does not have a fever or any illness during the liver phase.

# In the blood stage:

- merozoites go to the blood circulation and enter red blood cells;
- in the red cells merozoites develop into three stages:
  - Trophozoites
  - Schizonts
  - Merozoites
- the infected Red Blood Cells rupture and merozoites invade the other red blood cells and the same cycle continues;
- the merozoite breaks out of the red blood cells and causes the periodic occurrence of signs and symptoms, for example chills, fever and sweating.

A small number of parasites do not undergo schizogony but differentiate into gametocytes which are sexual (either male or female) which help in transmission of the infection to others through the female anopheles mosquitoes.

#### 1.8 Strategies for Addressing Malaria Issues

This section describes the two malaria control strategies adopted in Timor Leste by the Ministry of Health (MoH) (through the National Malaria Control Program (NMCP) as described above), as part of their Integrated Community Health System: the programme-based 'top-down' approach, and the community-based 'bottom-up' approach.

#### 1.8.1 Programme-based approach ('top down').

This approach sets policies at a higher level in the political process, which are then communicated to subordinate levels who are charged with the technical, managerial, and administrative tasks of putting policy into practice (PHAST, 2011). In the context of the malaria programme, this means that the MoH, through the NMCP, has developed a health policy at the national level to address malaria problems in 13 districts.

The NMCP formulated the objective of this programme, which was to reduce the level of malaria infection and consequent death in Timor-Leste by 30% by the year 2007, and

to sustain that improved level of control by 2013 (T. L. MoH, 2003). The health policy for malaria contains four specific strategies including:

- Guarantee all people access to quick and effective treatment, to significantly reduce illness and death from malaria;
- Provide malaria prevention measures (insecticide-treated nets) to young children and pregnant women;
- Ensure use of appropriate vector control methods (for example Larvaciding, indoor residual spraying) to significantly reduce transmission of disease and
- Improve epidemic preparedness and response (T. L. MoH, 2003, p. 2).

The MoH provides free services to the community, and no private health insurance exists in Timor Leste. The MoH has implemented free services mainly using a 'top down' approach, where the prioritization of health care services, particularly the provision of malaria services and long lasting insecticide treated nets (LLITNs), are implemented by the NMCP program (Tuba, Sandoy, Bloch, & Bykov, 2010). These free health services are namely:

- Distributing free bed nets to pregnant women and children under five in high risk areas
- Providing free blood tests for malaria in all levels of the health center
- Providing free malaria treatment to the community
- Providing free malaria health information to the community
- Conducting free indoor residual spraying (IRS) in some high risk areas.

#### 1.8.2 Community-based approach ('bottom up').

This approach recognizes that individuals at subordinate levels are likely to play an active part in the implementation, and may have some discretion to reshape the objectives of the policy and change the way it is implemented. In this context, the policy implementation should involve policy makers, implementers from various levels of government, and other actors; and the policy may change during implementation (PHAST, 2011). So, basically this approach means that the MoH should involve other levels of the community so they take part in the malaria programme implementation. For example, the Ministry of Health has established Integrated Community Health Services (SISCa) in all 13 districts in Timor Leste. This program based on creating a

place in the community for all community members to gather in order to have access to basic integrated health activities. Communities themselves, through *suco* (village) and *aldeia* (hamlets) chiefs, through their own initiatives, mobilize their community members to get access to health services at the village level using their own available resources (MoH, 2009). However, this initiative is not coming from the community, but has been established by the Ministry of Health to expand health services in rural and remote areas. But although this initiative was not created by the community, it does give an opportunity for some community engagement.

#### 1.9 Factors that Contribute to Transmission of Malaria in Timor Leste

Malaria has always been one of the biggest public health problems in Timor-Leste. Both *Plasmodium falciparum* and *Plasmodium vivax* are present in the country, although their precise distribution is unknown. Malaria transmission occurs due to Timor Leste's favorable climatic conditions, with reported cases peaking post-wet season, which is November to April (Martins, Zwi, Martins, & Kelly, 2009). The most common species vectors in Timor Leste are *A. Barbirostris* and the *A. Subpictus*. These two types of mosquitoes mostly bite people during late afternoon to early in the morning (18.00 to 06.00) (M. Yapabandara, 2009).

The peak season of malaria occurs in November to April due to the long monsoon period occurring in Timor Leste. This long rainy season creates floods and it can produce many areas of stagnant water. These situations support the anopheles mosquitoes breeding and produce many new adult mosquitoes. Cases of malaria increase in these months because the rainy season creates better opportunities for mosquitoes to lay their eggs and start to complete their life cycle (McCafferty, 2011). The mosquito's life cycle has four stages (egg, larvae, pupa and adult mosquitoes) as shown in the following diagram (Figure 5) (Kakkilaya, 2007);

#### Figure 5. Mosquito life cycle

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In addition, the long rainy season creates many breeding sites for mosquitoes such as stagnant water around houses, in abandoned agricultural land, and animals' footprints in the forest (M. Yapabandara, 2011). Moreover, the population in rural areas is more likely to contract this disease because they have a high chance of exposure in the irrigated paddy fields and rice fields, where there is a greater potential for anopheles mosquitoes to lay their eggs and produce more adult mosquitoes.

# 1.10 Vector Control, Diagnosis and Treatment Policies in Timor Leste

This section describes the vector control, diagnosis and treatment policies in Timor Leste and begins with an overview of vector control policies worldwide to set these in context.

# 1.10.1 Vector control policies worldwide and in Timor Leste.

The main prevention measure that has been used worldwide is the utilization of a bed net. There are around 82 countries distributing free bed nets to their population, especially in Africa and South East Asia. Some countries distribute bed nets to pregnant mothers and children under five as they are identified as vulnerable groups for getting malaria. However, around 67 out of 82 countries have distributed bed nets free of charge to all age groups (WHO, 2011). In addition, other measures for vector control are also applied, such as spraying liquid insecticide known as indoor residual spraying (IRS) in houses, and larvaciding. Moreover, most people worldwide commonly use personal protection such as using repellant, mosquito coils and anti-mosquito cream as a method to protect themselves from mosquito bites.

In Timor Leste, the NMCP programme has distributed free bed nets to the community in high risk areas to protect them from mosquito bites. Therefore, most of the community uses bed nets as their first method of protecting themselves from mosquito bites. The bed nets are distributed to the wider community, but the target group is children under five and pregnant mothers, as these groups are identified as high risk populations who could easily get malaria and die if they are late in seeking treatment

from a health professional. The policy of bed net distribution is that every pregnant mother or a child who is under five of age is eligible to get one bed net in every household.

## 1.10.2 Diagnosis and treatment policies in Timor Leste.

The following subsections describe the protocols for diagnosis and treatment in Timor Leste.

## 1.10.2.1 Confirming a diagnosis of malaria.

In Timor Leste, the clinical guidelines to diagnose malaria are as follows:

- All clinically suspected malaria cases require laboratory examination and confirmation.
- Only in case where laboratory confirmation is not possible is it advised to start treatment immediately.
- Parasitological confirmation is done by thin-thick blood smear microscopy examination or by dipstick (Rapid Diagnostic Test [RDT]) (MoH, 2007).

# 1.10.2.2 Treatment for malaria.

Currently, the treatment for malaria in Timor Leste follows the standard of the MoH protocol adopted in 2004. The protocol had been implemented in 2004 and prior to that, the MoH and World Health Organization (WHO) made an intensive effort to introduce artemisinin-based combination therapy (ACT) for treating *falciparum* malaria. Treatment of malaria *falciparum* cases is now ACT and all clinically suspected malaria cases are treated with *chloroquine* (one of the malaria drugs to treat malaria *vivax*) (Martins et al., 2009). Details of the MoH protocol for the treatment of Falciparum malaria are outlined below.

#### Treatment of P. falciparum malaria.

The treatment of uncomplicated *P. falciparum* malaria is undertaken after diagnosis of malaria by light microscopy or Dipstick. Patients with positive thin-thick blood smears or dipstick for *P. falciparum* malaria are treated by blisters of Coartem® (artemether 20mg/lumefantrine 120mg) (MoH, 2007).

#### Treatment of P. vivax malaria

The *chloroquine* treatment regime for *P. vivax*. According to the MoH (2007) protocol, resistance of *P. vivax* to chloroquine has not been found in Timor-Leste and *chloroquine* is the drug of choice, as it has few side effects. The MoH protocol states:

- For the radical treatment of *P. vivax* in addition to chloroquine, primaquine is recommended 0.5mg/kg per day for 14 days (primaquine should always be taken with food).
- *Chloroquine* can be given to pregnant women and children.
- *Primaquine* is not recommended for the children under one year and pregnant women.

#### Mixed infection.

If there is a mixed infection (*P. falciparum and P. vivax*) the protocol indicates the patient should be treated with *Coartem* (one of the malaria drugs) (MoH, 2007).

#### 1.11 Malaria Surveillance in Timor Leste

In Timor Leste, malaria surveillance is poor, which makes it difficult to know the exact burden of malaria in that country. With respect to malaria incidence in Timor Leste, it has been estimated that in 2007, nearly 11% of the population were affected by malaria (UNDP, 2010). Recently, the proportion of malaria patients amongst out- and inpatients in Government health facilities has decreased from 16.1% to 8.7% and 1.5% to 0.9% during the years 2008 to 2010 respectively. Malaria deaths declined from 68 in 2006 to 58 in 2010, showing a decrease of 14.7%. As cases are not well documented, this decline may be due to a weak surveillance system mainly in terms of consistency and completeness (WHO, 2012c).

Four out of the 13 districts (Dili, Viqueque, Covalima, and Lautem) report 60% of cases overall. The number of confirmed cases has increased from 15,212 in 2000 to 48,137 in 2010, while the positive slide rate increased from 44% to 50% between the years 2002 and 2008 and finally settled down to 24.6%. The percentage of reported cases attributable to *P. falciparum* increased from 53% to 75% during the period from 2002 to 2010. These changes may reflect a real increase in malaria or could be at least partly attributable to increased efforts at diagnosis, and it might also be that some areas had begun to report cases more consistently (WHO, 2012c).

Based on malaria cases as reported from the health center, the sub-district of Maliana has a low malaria incidence in comparison to other sub-districts. As can be seen in

Table 1, the sub-districts of Maliana and Bobonaro have the same incidence rate of 14 per 1000 population, whereas other sub-districts have a malaria incidence rate ranging from 16 to 111 per 1000 population (MoH, 2011).

*Table 1.* The number of malaria cases in Bobonaro district according to sub district in 2010.

			No.		Co	nfirm	nfirmed cases			
Sub district	Popul ation	Clini cal cases	Blood slides exami nation	No. RDT used	Tot al	<i>Pf</i> 2	Pv 3	Mix	Total cases	IR <sup>1</sup> / 1000 pop
Atabae	10976	1155	247	867	58	17	41	0	1213	111
Balibo	14768	315	191	434	60	57	2	1	375	25
Bobonaro	23108	333	44	323	0	0	0	0	333	14
Cailaco	9460	145	227	160	1	1	0	0	146	15
Lolotoe	7123	113	43	135	0	0	0	0	113	16
Maliana	24352	343	0	444	6	4	2		349	14
Total	89787	2404	752	2363	125	79	45	1	2529	28

#### 1.12 Rationale for the Study

The following section explains the rationale for the study, beginning with the choice of the study community, and followed by a justification of the focus on malaria prevention and control, rather than treatment.

# 1.12.1 Location of the study community.

The study community area is located close to Indonesia. Therefore, this community is potentially at high risk of getting malaria, as the population movement between these two countries is difficult to control because geographically these two countries are only divided by the river.

As can be seen in the following map (Figure 6) (Re-Downloads.Com, 2012), Maliana is located a few kilometers from the Indonesian border.

<sup>&</sup>lt;sup>1</sup> Incidence rate

<sup>&</sup>lt;sup>2</sup> P. falciparum

<sup>&</sup>lt;sup>3</sup> P. Vivax

Figure 6. Maliana sub district.

This image has been removed by the author of this thesis for copyright reasons.

In addition, the researcher chose Maliana because she originally comes from that community, and is aware that the selected community has poor knowledge about malaria. In addition, as described above they are at risk of getting malaria due to this area being close to the border of Timor Leste and Indonesia. Moreover, Indonesia has been identified as a country with one of the highest rates of malaria in South East Asia. In the last five years, almost 350,000 confirmed cases and between 1. 25 million – 2.50 million probable malaria cases have been reported in Indonesia, with 45%–50% of them being cases of *P. falciparum*; and approximately around 500 confirmed malaria deaths are reported every year (WHO, 2012b).

#### 1.12.2 Focus on malaria prevention and control.

The intention behind this study was not to investigate malaria treatment, but was primarily aimed at looking at malaria prevention and control, in order to explore interventions to help prevent malaria from spreading in the community. The researcher believed by preventing this disease in this low endemic district (but high risk district as it is close to Indonesia and this country is one of the South East Asian countries that has a high malaria morbidity and mortality) will reduce the population's chance of contracting malaria. In addition, the researcher also believed that by strengthening the prevention and control measures at the community level can help the NMCP to reduce the malaria burden in Timor Leste.

#### 1.13 Significance of the Study

As shown in the next chapter reviewing the relevant literature, no studies have been carried out to examine the knowledge, attitudes and practices towards malaria control in Timor Leste. Although the highest burden of malaria is in Sub-Saharan Africa, it is also a significant public health problem in countries such as Timor Leste. As surveillance systems in Timor Leste are sub-optimal, and it is unlikely that all cases are reported, so that the true burden of disease in this country is unknown.

Malaria is largely preventable and treatable. Policies have been put in place to manage malaria in Timor Leste since 2003, but the target of reducing malaria by 45 per cent per 1,000 by 2015 is unlikely to be met (Lover, Sutton, Asy, & Wilder-Smith, 2011).

#### 1.14 Study Aims and Research Questions

The aim of this study was to explore community's perceptions and practices in Timor Leste in relation to malaria control. In order to obtain information in regard to the aim of the study then the researcher had five main research questions (themes) that were needed to be answered. The five main research questions (themes) that were addressed in this research, namely:

- What does the community know about malaria disease?
- What are the community current practices to control malaria in their community?
- What does the community know about the national malaria control program?
- What could the community do to participate in malaria control programs?
- How might the community has a greater role to play in malaria control Timor Leste?

#### 1.15 Structure of thesis

This chapter has described how malaria is transmitted, and described the burden of this disease throughout the world. It provided an overview on how malaria was transmitted, how it impacted people worldwide, what preventive measures and treatment had been in placed in response to this disease worldwide. In addition, this chapter also described more specifically about Timor Leste context on how this country overcomes the disease. Moreover, this chapter provided a specific location of the study and the objective of the study. Furthermore, it also stated clearly about the type of information that the researcher would find out in the study by stating the five main questions to address through this study.

The remainder of the thesis is structured in the following way. The next chapter (chapter two) reviews studies on community knowledge, attitudes and practices towards malaria which have taken place in other countries in South East Asia and the South Pacific. Chapter three will discuss the epistemology, the design of methodology and methods used in the study and this chapter will also discuss in detail about the implementation of the methods in the field study and how the data were analyzed after the data were collected. Chapter four will discuss the findings of the study, chapter

five will provide detail information about the findings analysis. Lastly, chapter six will conclude this thesis through the discussion and conclusion of the whole study.

# CHAPTER TWO LITERATURE REVIEW

This chapter describes the research that has already been carried out to investigate what is known about the knowledge, attitudes and practices of communities in South East Asian and Pacific countries towards malaria. It provided the background information and rationale for the topics included in this qualitative study to investigate this issue in Timor Leste.

#### 2.1 Introduction

This study set in Timor Leste because malaria is one of the main public health issues in this country (Martins et al., 2009). There are several reasons why this might be so. One is that malaria programmes sometimes did not change any of their disease control strategies to suit the community, and this situation creates an environment in which it is difficult for people to adopt appropriate health-seeking behaviour. For example, some malaria control programmes mass-distribute free bed nets to the community and their target group are pregnant women and children under five in at-risk areas. This situation could lead to the wrong utilization of the nets, so they are used for other purposes than covering a bed to protect from mosquitoes (e.g., to protect fruit; a fence for the garden) (Lover et al., 2011). This situation happens due to most of the community not having space or room to hang the nets. The result of this is that the utilization of bed nets could be less than would be expected by the malaria programme.

In addition, the extent of the disease might be due to environmental factors (e.g., poor irrigation system or drainage). It might also be due to lack of knowledge about malaria within the community in Timor Leste. Studies pertaining to knowledge, attitudes and practices (KAP) showed that direct interaction with the community plays an important role in circumventing the malaria problem (Tyagi, Roy, & Malhotra, 2005). However, there have not been any specific studies carried out to investigate community perceptions of malaria in Timor Leste and the aim of this study was to fill this gap.

#### 2.2 Literature Review

Although no specific research has been carried out in Timor Leste to investigate knowledge, attitudes and practices towards malaria, there is existing literature from Timor Leste which briefly touches on the knowledge and practices of the community in regards to malaria and the utilization of bed nets. To get a broad understanding of this topic, the researcher reviewed the literature from a few countries in South East Asian and the Pacific region through scanning the reference list that the researcher found and she used the Google Scholar to search the articles, which were suited with the study. The researcher reviewed the literature from a previous Timor Leste study and also reviewed literature from other countries such as Indonesia, India, Sri-Lanka, Vietnam, Lao PDR and Myanmar, Vanuatu and Solomon Islands. These latter countries have a similar climate to Timor Leste, such as a long monsoon season, and malaria is endemic. As explained in the first chapter, malaria is also endemic to countries in South East Asia (Indonesia, India, Sri-Lanka, Vietnam, Lao PDR and Myanmar) (WHO, 2012a). In addition, two countries in the Asia Pacific region (Vanuatu and the Solomon Islands) have a malaria peak season during December to April due to the rainy season (UCSF Global Health Science, 2012). Moreover, in these countries there are still many people living in poor or inappropriate housing conditions (e.g., only one bedroom in the house, no window or ventilation in the house). The researcher has reviewed 15 studies from these nine countries. The methodology, methods and findings of these studies are described briefly in Table 4 (refer Appendix A - Summary of the studies on KAP from the Southeast Asia and the South Pacific).

Many of the studies which have been conducted in the nine countries listed above have applied a quantitative methodology, selecting a random sample of participants and using a survey method (structured questionnaire or close-ended questions). However, some other studies have used a qualitative methodology, using methods such as focus group discussions (FGDs), key informant interviews (KIIs) and transect walks.

The literature review is organized around four main themes: community perception about malaria transmission; personal protection (bed nets, indoor residual spraying,

other preventive measures); health seeking behaviour (diagnosis and treatment); and community beliefs. Each of these themes is addressed in turn in the following sections.

#### 2.3 Malaria Transmission

A range of studies has investigated how study participants believe malaria is transmitted. One common belief is that malaria is transmitted by mosquito. This perception has been documented in a study which was carried out in Myanmar (Oo-do village) by Shein, Tun-Sein, Soe, Ang, Win and Saw-Aye (1998), which stated that most of the participants (63%) stated that mosquito bites could lead to malaria. In addition, Shirayama, Phompida and Kuroiwa (2006) found that in Lao PDR around 52% of the participants believed that mosquitoes can transmit malaria. Another study also revealed that most people believed that malaria is caused by mosquitoes (73%).

Another common (inaccurate) belief is malaria transmitted through dirty water. Although in the studies reviewed, most of the participants believed that malaria is transmitted by mosquito, some people still believed that malaria is transmitted through dirty water. The study from in Myanmar (oo-do village) (Shein et al., 1998)revealed that some people still believed that drinking steam water could cause malaria (37%). In addition, in a study in India, about 98% of tribal people believed it was transmitted by drinking or bathing in contaminated water (N. Singh, Singh, Saxena, Sharma, & Kalra, 1998). A similar perception also has been documented by Anh, Hung, Thuy, Tuy, Caruana, Biggs and Marrow (2005) in a study carried out in Vietnam (Ninh Thuan Province). The study revealed that community members believed that malaria could be transmitted by drinking unboiled water or water taken from a stream. The same perception also has been documented in a study from Lao PDR by Shirayama et al. (2006), which found that that around 36% of the respondents cited that drinking unboiled water could cause malaria and others mentioned evil spirits (5.4%), lack of basic sanitation around houses (39.2%), and food related issues (27.1%).

In contrast, in Vanuatu (Tafea Province), although the initial perception of malaria was that it was a new condition that had only arrived after independence in 1980, upon further questioning the perceived cause was identified as 'sik blong mosquito' (sickness belonging to mosquito). However, the proportion of participants who believed in this kind of perception was not clearly stated due to this study being conducted qualitatively

through focus group interviews (A. Tynan et al., 2011). In Indonesia, Sanjana et al. (2006) have also found that mosquitoes were recognized as a cause of malaria by almost 50% of respondents. A similar finding is also reported by Lover, Sutton, Asy and Wilder-Smit (2011) through their study carried out in Timor Leste, where they found that many areas had a very good knowledge of the cause of malaria. Almost all participants knew mosquitoes caused malaria infections but a wide range of other factors were also believed to cause malaria (for example, trash; flies; faeces) (Lover et al., 2011).

Based on the misconception of the causes of malaria as documented above, rural community is believed to have an insufficient understanding of malaria signs and symptoms. Most of the studies about KAP, which are carried out in South East Asia (Indonesia, India, Lao PDR, Myanmar, Vietnam) and the Asia Pacific region (Vanuatu) have revealed that insufficient knowledge in the community about malaria is somewhat similar among communities in these countries.

Finally, it should be noted that the researchers who carried out the study in Vanuatu (A. Tynan et al., 2011) cannot make a judgment that the community has insufficient knowledge of the signs or symptoms of malaria if the community themselves did not understand about the signs of malaria in their everyday life. It seems that the researchers provided their answer based on their own assumption rather than the information that the community possesses.

#### 2.4 Personal protection

The following sections discuss studies relating to personal protection measures used in South East Asian and Pacific communities against malaria including the use of chemicals and traditional methods, bed nets, and indoor residual spraying (IRS).

#### 2.4.1 Personal protection using chemicals and traditional methods.

Personal protection from mosquito bites can be achieved by using insect repellents or insecticide-treated bed nets. Other personal protection methods available are aerosol sprays, mosquito coils and vaporizing mats (Pates, Lines, Keto, & Miller, 2002). A study carried out in semi-rural areas and bordering areas of east Delhi (India) found that using insecticide commercial aerosol sprays such as Baygon spray was only practiced by factory employees and residents in rural areas (Tyagi et al., 2005). In addition, a similar finding also has been well documented from the Timor Leste study by Lover et

al (2011), where they found that many participants in urban and semi urban areas were commonly used commercial brands of repellent insecticides and coils. In addition, people in Timor Leste also used traditional methods to protect themselves from mosquito bites such as building smoky fires from specific wood or dung.

These two studies report that most people in urban and semi-urban areas commonly used mosquito coils and other commercial brand repellents because they were available and affordable for the community in those areas.

#### **2.4.2** Bed nets.

Bed nets may be commonly used by people as one of the preventive measures towards malaria because they are distributed freely to the community in some countries. With regard to malaria prevention, the WHO (GreenFacts, 2012) recommends the use of mosquito bed nets treated with long lasting insecticide, and indoor spraying, to control the numbers of infected mosquitoes. In addition, the nets are used in many countries in South East Asian and the Western Pacific WHO regions, but in relatively few countries in other WHO regions (GreenFacts, 2012). For example, outside the WHO African Region, treated nets are targeted at populations who are at the highest risk, including children, and therefore only protect a small proportion of the population. The World Health Organization data show that a relatively high coverage was achieved in Bhutan, Papua New Guinea, Solomon Islands and Vanuatu, with more than 20% of all people at risk having access to insecticidal nets (GreenFacts, 2012).

Moreover, some evidence indicating that bed nets are used by people living in areas where they are at risk of acquiring malaria can be found in regards to the South East Asian and the Asia Pacific regions. For example, a study conducted in Lao PDR (Khammouane province) suggests that 93% of respondents used bed nets to protect themselves against malaria (Shirayama et al., 2006). Another study carried out in Ninh Thuan Province in Vietnam found that over 84% of respondents slept under a bed-net regularly, although only around 66% resided in households with the minimum recommended number of nets (one net per two people) (Anh et al., 2005). However this study did not mention clearly how the study identified this percentage or whether the study was conducted through a survey sample or other methods (for example, observational or transect walk) to directly observe the use of bed nets in each household.

The use of bed nets as primary protection from mosquito bites has also been identified in other regions. For example, in a study in the Solomon Islands, most of the participants mentioned that the main reason why LLITNs would be used in comparison to other bed nets was their capacity in preventing mosquito bites and malaria over a long period of time (Atkinson et al., 2009). In this study, the percentage of the participants who mentioned the reason for using bed nets was not stated due to the study using a qualitative approach (not a survey) and it applied few focus group discussions in two provinces (Malaita and Temotu) in the Solomon Islands. In addition, during the discussion in this study each participant was given a chance to examine three different brands of bed nets (Olyset, Permanet and DuraNets). The results showed that the community preferred to use DuraNets as its characteristics found the middle ground between the unfavorable characteristics of Olyset (mesh size too large) and PermaNet (perceived lack of durability) (Atkinson et al., 2009). Moreover, Lover, Sutton, Asy and Wilder-Smith (2011) found a similar finding from a study carried out in Timor Leste, they reported that the motivator for the vast majority of people to use bed nets was to avoid mosquito bites (nuisance effects). Furthermore, this study also found that some people did not like to use bed nets because the nets were too hot, too small and difficult to enter and exit.

To summarize, the studies carried out in Timor Leste, Lao PDR, Vietnam and the Solomon Islands have revealed that although bed nets are commonly used by the community as the primary protection from mosquito bites in the South East Asian and the Western Pacific regions, a few people did not like to use them due to their being too hot, too small and too difficult to enter and exit.

#### 2.4.3 Indoor Residual Spraying.

Indoor residual spraying (IRS) coats the walls of houses and other structures with small amounts of insecticide to repel or kill mosquitoes. These insecticides are typically longacting; however, their effectiveness depends on the area's climate and the building materials used on the structure (Friends of the Global Fight Against Aids, 2009). This mosquito control method must be undertaken by well-trained staff, and as such is not used by community members as a means of personally protecting themselves against malaria. A study carried out in the Purworejo sub district (Indonesia) revealed that although the IRS had been conducted by the government, the regularity with which this

was done was not known by the community. Around 62% of the participants remembered that their houses had been sprayed with an insecticide at one time in the past few years (Sanjana et al., 2006).

The IRS is a method mostly conducted by governments because of the expense of purchasing and implementing IRS in the community. Although community members may be asked to share the cost, this can be prohibitive. A study carried out by Sanjana et al. (2006) found that 99% of one community in Indonesia would agree to have their house sprayed if the service was free of charge.

# 2.5 Health Seeking Behaviour

Health seeking behaviour in this context comprises behaviour around the diagnosis and treatment of malaria, and beliefs that are behind that behaviour, including community beliefs and the use of traditional healers and traditional herbs. The following sections look at studies in South East Asia and the Pacific Each on these aspects.

### 2.5.1 Diagnosis of malaria.

A study carried out in Indonesia (Jepara district) revealed that the community described malaria in their own language as *katisen* or *panas tis* and this disease was considered a common but a minor illness (Utarini, Winkvist, & Ulfa, 2003). They found that some communities in Indonesia (Purwerejo sub district) have better knowledge about malaria because the community could identify the symptoms of malaria. Most of the respondents (93%) were able to describe at least one symptom of malaria and around 65% could mention three symptoms or more. In addition, people in Timor Leste also have their own dialect to describe malaria. The common Tetum (local language) expression for both fever and malaria is *isin manas* (literally, "body hot"). This term is an indication of how fever and malaria are perceived as synonymous and so there is a chance for misdiagnosis, if the same word is used (Lover et al., 2011).

Although in these two countries people can recognize the symptom of malaria, a study from Indonesia has suggested that misconceptions about malaria still exist in the community and this may contribute to delays in illness recognition and treatment (Utarini et al., 2003). In contrast, a study carried out in Timor Leste (Lover et al., 2011) found that most of the participants could list the symptoms of malaria such as fever, headache, chills "feeling trembling", and they also provided some other ambiguous responses, like backaches and stomachaches. Some people in rural areas

recognized the symptoms and they used traditional remedies first; then if the patient did not improve, they would only then seek care at the health center or hospital (Lover et al., 2011).

#### 2.5.2 Treatment

Most of the people in the Jepara district (Indonesia) prefer to seek treatment from a traditional healer as it is easy for them to access treatment because the healer is close to them (Utarini et al., 2003). Health centers may be used, but when treatments did not work, most people would shift back to traditional services due to cost considerations (Utarini et al., 2003). A study carried out on Tanna Island (Vanuatu) found that there were no differences reported in treatment-seeking behaviour between genders or age groups of the people participating in the study (A Tynan et al., 2011). This study discovered that when faced with any fever people use home remedies as a first treatment, and used methods such as washing special leaves boiled in water, steaming people (covered in blankets with a basin of hot steaming water), drinking prepared leaves or having a cold shower or sponge bath (A Tynan et al., 2011). The same behaviour is also practiced by people in Timor Leste, where people in rural areas treat malaria by using paracetamol or herbal remedies, or various leaves "chewed to pieces and mixed with hazelnuts, then boiled an affixed to the forehead" for many symptoms, including fever (Lover et al., 2011, p. 11).

Different practices were found in other communities in Indonesia (Purworejo), where people preferred to purchase medicines in the nearest local shops (Sanjana et al., 2006). This study found that self-treatment was popular in the community because antimalarial drugs were widely available at local shops, pharmacies, and markets throughout Purworejo at a relatively low cost. This study also found that the local pharmacy sold *chloroquine* tablets in packets of four tablets for US \$0.09, *quinine* in packets of 12 tablets for US \$0.42 and *sulfadoxine pyrimethamine* (Fansidar) for US \$1.50 for three tablets. Paracetamol (acetaminophen) costs only US \$0.02 per tablet and is often used to treat fever and headaches. However, despite the accessibility and affordability of various drugs to treat malaria, this study found that most people's complaints (91%) were not cured after getting the treatment, due to the treatment regimens described having been often below the recommended dose as stated in the national treatment guidelines; however the patients and health providers were ignoring this situation (Sanjana et al., 2006).

The same finding also has been outlined in a study in India (Delhi) (Tyagi et al., 2005). This study found that most people prefer self-treatment and use any *Bukhar ki Goli* (tablet used for fever) including some anti-malarials available among the rural population. This led to incomplete doses of possibly inappropriate drugs being used indiscriminately. This situation may be due to the inadequate medical facilities and also due to long distances between medical centers and people's homes (Tyagi et al., 2005). In contrast, another study conducted in another part of India (Boudh district) found that if there is no cure after getting treatment from health providers in public health services, people intend to go to less qualified providers who apply various measures such as injecting analgesics, antibiotics, even sedatives (Das & Ravindran, 2010). These providers have some advantages such as their availability where there is no doctor and flexibility for the people to pay the fees in installments or in kind. At times, people consume *chloroquine* while availing treatment from the less qualified providers simultaneously. Though they get cured due to *chloroquine*, they attribute their cure to the less qualified provider's treatment (Das & Ravindran, 2010).

Overall, studies in Indonesia (Purwerejo), Timor Leste, Vanuatu and India (Delhi and Boudh district) have found that self-treatment was commonly practiced by the community as it is cheap and easy to access in the community. These studies suggest that community members prefer home treatment even though the treatment is not appropriate according to the guidelines of malaria treatment protocol in that country. In addition, self-treatment is also practiced by the community in rural areas due to inadequate health facilities and the need to walk long distances to seek treatment from health providers. People take malaria drugs at home and they also use herbals (leaves) for malaria treatment.

# 2.5.3 Community beliefs and use of traditional healers and traditional herbs.

In India, the practice of *Deshi ilaaj* (traditional healing) has been found to be common among rural respondents (especially farmers and rural women) (Tyagi et al., 2005). The use of *paracetamol*, *disprine* or *aspirin* and any commonly available *Bukhar ki goli* (tablet for fever) and some herbal mixtures containing Basil (*Ocimum basilicum*) was also found to be in common practice in rural and semi-rural areas. Some people used Basil leaves as anti-malarial herbs because most people viewed these leaves as having

medicinal properties, in addition to the religious belief attached to this herb. However, supernatural beliefs and the practice of *Jhar-phunk* (occult or tantric practice) in treating the illness was found to be rare in India (Tyagi et al., 2005).

In contrast, Shirayama et a.1 (2006) stated that supernatural beliefs still feature in treatment in Lao PDR due to the community not recognizing malaria as a disease. This study found that around 5.4% of the respondents believed that malaria is caused by an "evil spirit" or angry "*Phee*" (spirit) of trees and "*Phee*" of ancestors. Therefore, people used a variety of traditional herbal medicines or religious ceremonies such as chanting and animal sacrificing (such as eggs, birds and water buffalos; together with alcohol, tobacco and flowers) as a treatment for malaria (Shirayama et al., 2006).

In Vanuatu, especially in the community in Tanna, people draw a distinction between what they define to be traditional knowledge, practice and object (*kastom*), and what they perceive as foreign or innovative (*nariitoga*, foreign thing: *narumnarime sei nipitoga*, things of foreigners) (A Tynan et al., 2011). Even though health facilities are available in almost all levels of the community in Vanuatu and these facilities are well equipped to provide modern Western style services, *kastom* medicine still thrives, especially on the more remote islands including Tanna. It has been suggested that modern and *kastom* medicine do not compete with one another, instead they are used as complementary systems. Traditional healers (also known as "Clevers") combine plant knowledge with knowledge of the supernatural and operate as true health therapists within their communities (Tynan et al., 2011).

In summary, studies carried out in India, Lao PDR and Vanuatu revealed that some communities in these countries are using traditional healers and traditional herbs to cure malaria because they do not recognize malaria as a disease; rather, it is identified by the community as a condition where the "evil spirit" enters the person's body. Therefore, they prefer to seek treatment from traditional healers and use traditional medicines or religious ceremonies to draw the bad spirit out of the sick person's body.

#### 2.6 Summary of Current Knowledge

Although no specific research has been carried out in Timor Leste to investigate knowledge, attitudes and practices towards malaria, there is an existing piece of recent

literature from Timor Leste, which discussed a little about the knowledge and practices of the community in regards to malaria and utilization of bed nets. To get a broad understanding of this topic, the researcher also reviewed literature from other countries within South East Asia and the Pacific region, such as Indonesia, India, Sri-Lanka, Vietnam, Lao PDR and Myanmar, Vanuatu and Solomon Islands. Some of the communities in these countries had a similar level of understanding about malaria and transmission of malaria and they also had similarities in practices to prevent and control mosquito bites. Most of the people in these mentioned studies preferred to use bed nets as the primary prevention measure as they are freely distributed to the community. In addition, some people still applied traditional methods to prevent malaria and to treat malaria.

Based on the existed study as stated above then the researcher believed that those studies could support the need for a study to explore more about the community perception and practices in preventing and controlling malaria in Timor Leste. This study applied a qualitative methodology using methods including focus group discussions, key informant interviews, direct observations and transect walks, as it was believed to be appropriate for finding more about the ideas, views and practices that the community implements to control malaria. The next chapter will discuss the epistemology, the methodology and the methods that the researcher applied in this study.

#### **CHAPTER THREE**

#### STUDY DESIGN, METHODOLOGY AND METHODS

This chapter focuses on the methodology and the methods that the researcher used to conduct the study. The chapter includes an explanation of the epistemological approach used in this study, the advantages and disadvantages of using a qualitative versus a quantitative methodology, and the rationale for using a qualitative methodology for the study. In addition, the details of the data collection methods used (Transect walk, Focus Group Discussion and Key Informant Interview) are discussed and the data analysis is also described through this chapter.

# 3.1 Epistemology

Before conducting any research, it is important for the researchers to understand the type of epistemology or foundation that informs their studies. The epistemology is the branch of philosophy that "deals with the nature of knowledge, its possibility, scope and general basis. It is concerned with providing philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate" (Crotty, 1998, p. 8). In research there are two epistemological approaches used, namely positivism and constructionism.

# 3.2 Positivism and Quantitative Methodologies

Positivism asserts that there are objective truths that it is the role of researchers to discover. The original position of positivism focuses on the objective value of the study rather than subjective value (Trochim, 2006). Using a positivism approach means that research applies the scientific method to make measurements and test the hypotheses that the researchers create in their study setting. This approach uses a quantitative methodology as a numerical approach to collecting and analyzing the data. This usually involves large-scale empirical studies using social survey techniques to collect data from representative samples of the population drawn from a wide geographical area. The aim is to produce useful factual data from which generalizations, often about the characteristics of the society as a whole, can be made (Gilbert, 2001).

Quantitative research often applies deductive reasoning or logic, which include arguing from a main or general theory to a more specific theory. Theories in quantitative research start by positioning hypotheses, so that they can be tested statistically (Teddlie & Tashakkori, 2009). Deductive reasoning sometimes is informally called a 'top-down' approach. This means first starting with a theory about the topic of interest which then can be narrowed down into more specific hypotheses that can be tested (Trochim, 2006).

The data collection methods commonly used in a positivism, quantitative approach is questionnaires using closed-ended questions (surveys), experimental transect walks, and quasi-experimental studies (Teddlie & Tashakkori, 2009). The data collected is analyzed statistically:

Statistical analysis is the analysis of numeric data using descriptive and inferential techniques. Descriptive statistical analysis is the analysis of numeric data for the purpose of obtaining summary indicators that can effectively describe a group and the relationships among the variables within that group. Inferential statistical analysis may be defined generically as that part of statistical procedures that deal with making inferences from samples to populations. (Teddlie & Tashakkori, 2009, p. 24)

# 3.3 Contructionism and Qualitative Methodology

Constructionism asserts that there are no objective truths, but rather focuses on subjectivity. It explores people's subjective understandings of their everyday lives. Therefore the researcher often starts the study through reviewing other existing studies from other researchers to gain information as baseline data for a new study in any selected community. Such research often applies inductive logic which involves arguing from specific data to general general theory (Teddlie & Tashakkori, 2009). Inductive reasoning works by moving from specific observations to broader generalizations and theories, and thus it is sometimes informally called a 'bottom up' approach. By using inductive reasoning, therefore, researchers begin with specific observations and measures, begin to detect patterns and regularities, formulate some tentative hypotheses that can be explored, and finally end up developing some general conclusions or theories (Trochim, 2006). "Qualitative research provides a micro-level perspective based on case studies or data collected from individuals and groups. Here the emphasis is on smaller-scale studies exploring the meaning that events and situation have for participants" (Gilbert, 2001, p. 34).

The methods commonly used in this approach include "direct observation, interviews, the analysis of texts or documents and the analysis of recorded speech or behavior using audio or video tapes" (Pope & Mays, 2006, p. 7). Group interviews are also used in this research, such as focus group discussions. The type of interviews that are commonly used in this qualitative research are structured interviews, semi-structured interviews and in-depth interviews (Pope & Mays, 2006). Furthermore, most qualitative research uses a type of data analysis such as categorical strategies or contextualizing analysis.

Categorical analysis breaks down narrative data into units to produce categories that rearrange those units to produce categories that facilitate a better understanding of the research question (Teddlie & Tashakkori, 2009, p. 25).

Contextualizing (holistic) strategies interpret narrative data in the context of a coherent whole "text" that include interconnections among the narrative elements (Teddlie & Tashakkori, 2009, p. 25).

# 3.4 Advantages and Disadvantages of Quantitative versus Qualitative Approaches

There are relative advantages and disadvantages to each approach. The following sections address the strengths and weaknesses of firstly, a quantitative approach, and secondly, a qualitative approach.

#### 3.4.1 The quantitative approach.

A quantitative approach is sometimes less time consuming (depending on the sample size) to conduct because a huge amount of information can be obtained from large numbers of participants through using questionnaires and surveys. The weakness of this method is that it uses a very rigid and systematic approach and attempts to measure and control for all of the variables that might influence the findings. This approach arguably makes it inappropriate for the measurement of complex human attitudes (Basset, 2004).

# 3.4.2 The qualitative approach.

The strengths of qualitative approach are that human knowledge, experiences or attitudes can be well understood because it helps the researcher to explore in the study topic in detail in a community. Such a study also can be used as a reference for a future study or any further study that might be undertaken by other researchers. The weakness of a study using this type of approach is that it is often expensive to conduct as some

techniques or methods (for example, in depth interviews or focus group discussions) used require detailed information from the participants. Therefore, it is time consuming to carry out. In addition, the weakness of this method is that it requires a small sample of people, so that the findings of the study cannot be applied in other communities or the findings cannot be generalized (Basset, 2004)

#### 3.5 The Methodology used in this Research

In this study (community perceptions and practices in relation to malaria control), the researcher preferred to use a qualitative research approach because the topic that researcher selected for this study is about peoples' perceptions, attitudes and practices. Therefore, this study mainly involved talking to people and listening to people's ideas, so that it was not appropriate to use a quantitative approach as it primarily deals with numbers, and such an approach cannot explain the reasons behind people's ideas, attitudes or knowledge (Basset, 2004). In addition, qualitative research explores people's subjective understanding of their everyday lives through the use of in-depth data collection techniques:

Although the different social science disciplines use qualitative methods in slightly different ways, broadly speaking, the methods used in qualitative research include direct observation, interviews, the analysis of texts or documents and the analysis of recorded speech or behavior using audio or video tapes. (Pope & Mays, 2006, pp. 6-7)

Moreover, it was decided that a qualitative research approach was the most suitable, because the researcher could explore people's knowledge, attitudes and practices through applying the research methods of in-depth interviews, focus group discussions and observations (Hennink, Hutter, & Bailey, 2011). Furthermore, a qualitative approach can help the researcher to obtain various perspectives and views on the specific topics of interest (Basset, 2004).

As outlined in the Introduction chapter, in this research there were five main research questions (themes) that were addressed:

- What does the community know about malaria disease?
- What are the community current practices to control malaria in their community?
- What does the community know about the national malaria control programme?
- What could the community do to participate in malaria control programs?
- How might the community has a greater role to play in malaria control Timor Leste?

In order to find out in depth about these five main themes, the researcher applied four methods for collecting the data from the community. The researcher was intended to select a total of 18 people to participate in this study. The researcher believed that this total number of people would be sufficient for this study. This study included two Focus Group Discussions (FGDs) with the total participants of 14 people (7 people per each group). The Key Informant Interviews (KIIs) were conducted with four people (2 hamlets leaders and 2 traditional healers) and informal observation was conducted during the transect walk and the interviews (the researcher also kept a diary as a field journal). In addition, transect walks were also carried out in two study communities, where the researcher was accompanied by a key informant (head of the village or hamlet). The researcher conducted all the observations and documentation of any information that relates to the study (Atkinson et al., 2010).

There are potentially four types of qualitative interview techniques that can be used to collect data, including focus group discussions, structured interviews (usually with a structured questionnaire), semi-structured interviews (open ended questions) and indepth interviews (one or two issues covered in great detail and questions are based on what the interviewee says) (Pope & Mays, 2006).

However, the researcher chose to use the semi-structured interview as it was believed to be relevant for this study.

Semi-structured interviews are conducted on the basis of a loose structure consisting of open-ended questions that define the area to be explored, at least initially, and from which the interviewer or interviewee may diverge to pursue an idea or response in more detail (Pope & Mays, 2006, p. 13).

This study applied qualitative descriptive inquiry primarily because the research aimed to investigate the participants' subjective perceptions and practices in regards to controlling malaria, and their views on what their community will do to support health professionals to control malaria in Timor Leste. The data involved their understanding about malaria disease and their recent practices to control malaria. The data were also analyzed to identify common themes raise in the interviews to build up a broad picture of their perception and practices. The methods of this study involved talking to four key informants and carrying out two focus group discussions (seven people in each group). Also, a 'transect walk' used by the researcher. This involved walking through the study

community to observe physical aspects which may be relevant to malaria control, such as housing, water sources and agricultural practices (Keller, 2011).

# 3.6 Methods used in the Study

In this study, the researcher applied four methods to collect the data from the selected community (the transect walk, researcher observation, focus group discussions, and indepth interviews) and used an interview guide (Appendix B) for asking the participants questions in the FGDs and KIIs. In addition, she applied a thematic analysis for analyzing the data. A detailed explanation of these methods is presented in the following sections.

#### 3.6.1 The transect walk.

This was done by accompanying a key informant to observe the current situation with respect to malaria control in the community. The aim was to gain information about any environmental issues that may impact on malaria control in the community. A transect walk is a systematic walk with the community members through the village observing, discussing, and identifying the problem. In addition, it also helped the researcher to draw a rough map of the location of the health center and other services in the community. As used by Abedi and Badragheh (cited in Holandand et al, 1998) (2011) people employed ground, or flipcharts to map and draw the different aspects of their village. In this thesis the researcher conducted the transect walk with the focus on the environmental issues that are relevant to health problems in the community, especially malaria.

#### 3.6.2 Researcher Observation

Patton (1990) argues that observational data are used for the purpose of description of settings, activities and people in the study community, and the meanings of what is observed from the perspective of the participants. Therefore, in this study, the researcher thinks that it is important to make an observation during conducting the study. The researcher conducted an observation of the study community through recording any information that she observed during transect walks, focus group discussions and the key informant interviews. This observation helped the researcher to have a deeper understanding than interviews alone. In addition, remembering events or information from the observation was difficult. Therefore, she used the researcher diary to keep or making a rough note to record the information (Pope & Mays, 2006)

### 3.6.3 The focus group discussions (FGDs).

This method was used for this study because its aim was to find information from various perspectives about the knowledge, attitudes and practices in regards to malaria from community members. The focus group method applied in this study as the group could potentially help each other to explore and clarify their ideas. A group discussion was believed to be an appropriate method to use in this study because the researcher used semi structure or open-ended questions and the researcher believed that this method could open the opportunity for participants to explore freely their ideas in their own words (Pope & Mays, 2006). In addition, focus group discussion can be described as:

a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment, where participants share and respond comments, ideas and perceptions. It is important that those taking part finding the discussion comfortable and enjoyable, do not feel pressurized to make decisions or reach consensus, and are encouraged to express different points of view. (Litosseliti, 2003, pp. 1-2)

#### 3.6.4 The key informant interviews (KIIs).

There is only one village chief in each village, therefore it was not regarded to be appropriate to carry out focus group discussions. In addition, the village chiefs are powerful people in the community, therefore the researcher chose to do KIIs because in order to interview them alone so that the researcher could find out more about their knowledge and attitudes in detail. In addition, these KIIs aimed to find detailed information on some specific topics, which may have arisen during the group discussions:

The aim of the qualitative interview is to explore the participants' own perceptions and meanings, and the researchers must attempt to avoid imposing their own structures and assumptions onto the participants' account (Holloway, 2005, p. 44).

#### 3.6.4 Data analysis.

A thematic analysis was used to analyze the data. Thematic analysis often includes themes that are anticipated (for example, through reviewing the literature the researcher might be prompted to ask about particular issues) as well as those that emerge (that is, that arise directly or indirectly during the fieldwork) (Pope & Mays, 2006, p. 70).

This study used the analytical methods proposed by Marshall and Rossman (2011), who stated that;

typical analytic procedures fall into seven phases: organizing the data; immersion in the data; generating categories and themes; coding the data; offering interpretation through analytic memos; searching for alternative understanding; writing the report or format for presenting the study (Marshall & Rossman, 2011, p. 209).

# 3.7 Implementation of the methods in the study.

The research was carried out during August and September 2012. This involved a period of consultation at national and local levels, followed by the recruitment of study participants. According to the research design, it was intended to recruit 18 people from two hamlets. There were to be four semi-structured interviews with the key informants (2 head of hamlets and 2 traditional healers). However, when this study was conducted, there were only 17 participants, as there was no traditional healer in one of the selected communities. Table 2 shows the actual total participants in the study.

*Table 2.* Total participants in the study (n=17).

Hamlet	Key informant	Focus Group	
		Discussion (FGD)	
First hamlet	1	7	
Second hamlet	2	7	
Total	3	14	

The following sections discuss the methods that the researcher used in conducting this study, beginning with a description of the consultation process used, followed by an explanation of the data collection procedures using the four methods of transect walks, focus group interviews, semi-structured interviews with key informants, and researcher observation. Finally, an outline of data security measures is given.

#### 3.7.1 Consultation Process

First, upon on arrival in Dili (Capital city of Timor Leste), the researcher arranged a meeting with the Manager of the National Control Program (NMCP), Ministry of Health to inform him about the study and arrange a meeting with him and two of his colleagues (Malaria Adviser from the Ministry of Health and the WHO Malaria Adviser). This was to obtain advice and support for the study. This support was obtained.

Secondly the researcher contacted District Health Services (DHS) Director to gain support for the study. A meeting was conducted with the Director and the Deputy Director to get support from the staff at the district level and obtain the name of the local health volunteer of the hamlets where the study would be conducted. Verbal support for the study was gained and the researcher gave a letter from the Ethics Committee of AUT University approving the study to the deputy of DHS as an archival record of the DHS Ethics Committee at district level.

Thirdly, after getting a verbal approval from the district level then the researcher continued to do the consultation directly at the hamlet level. The researcher contacted the health volunteer to support the researcher in getting contact with the head of the hamlet. After getting contact with the chief of the hamlet then the researcher informed these chiefs about the study.

#### 3.7.2 Data Collection

#### 3.7.2.1 Transect walks

Permission to carry out the transect walk was obtained from each head of the hamlet, who each provided a guide to accompany the researcher. Each guide was a local health volunteer, who lived in the village.

The transect walks were conducted in August. One was conducted in the morning, the other in the afternoon. Each transect walk took approximately one hour. A camera was used to take pictures of the local environment, and examples of the houses of villagers. Permission to take pictures was gained from the chief of the hamlet. Notes were made during the transect walk which were used to draw a map of the area later in the same day.

#### 3.7.2.2 Focus Group Discussions

Local community health volunteers were asked to announce to the community that the focus groups were taking place, and to encourage participation. Those who were

interested in taking part in the study were recommended to contact the hamlet's leader or any health volunteer from the study community. The reason for involving hamlet leaders and health volunteers in the recruitment system was because of local cultural practices: firstly, potential participants should not be approached directly, and secondly, the hamlet leader should know about anything that happens in their community. The contact details of these potential participants were given to the researcher by the health volunteer by telephone.

Potential participants were informed by the researcher about the purpose of the study and given a week to decide if they wished to take part. Recruitment took one week to complete. One focus group was conducted in the local school and the other in the home of the hamlet chief. These were centrally located.

All participants were given an information sheet (Appendix C and Appendix D) and a consent form (Appendix E and Appendix F) before the interview was conducted. As some of the participants were illiterate, the researcher provided an oral explanation about the reason for the study. It was emphasized to all participants that they may withdraw from the study at any time up to the completion of data collection. The researcher also ensured that participants understood that their participation would remain confidential and anonymous, and there would be no harm to them by participating in this study.

#### 3.7.2.3 Semi-structured Interviews with three Key Informants

Although the researcher intended to interview four key informants, there were only three interviews carried out because there was no traditional healer in one of the selected communities. Therefore the interviews were carried out with three key informants: two hamlet leaders and one traditional healer. Each interview was carried out in the home of the key informant. The interviews of the key informants ran for about an hour and were digitally recorded. However, one key informant was not comfortable with the presence of the recorder; therefore the researcher took notes during the interview.

#### 3.7.2.4 Researcher Observations

Every day the researcher always brought her diary for making a note from any discussion and interviews as well as writing down the information that she observed through the transect walks. The aimed of keeping this diary was to record any important information that she observed during the transect walk, group discussion and individual

interviews with the key informants. For example; the rough map was produced during conducting two transect walks in the two selected communities, and some information was recorded through talking to the two key informants during transect walks. In addition, participant's attitude towards others and the researcher were also recorded during group discussion and the interview of the key informants.

#### 3.7.2.5 Data Security

Finally, after conducting all of the interviews and observations (transect walks; group discussions; interviews of the key informants; researcher observations) then the researcher kept all of the details and the recorder in a folder and kept it in a secure bag during the course of the fieldwork taking place. And all the completed consent forms are securely stored in locked filing cabinets in the second thesis supervisor's office for six years, after which time they will be destroyed complying with the Auckland University Ethics Committee (AUTEC) protocol. This aim of this activity was to keep all of the information safe and confidential.

#### 3.8 Data Analysis

All interviews were recorded using a digital recorder and the information was transcribed and translated verbatim (word by word). Having the original recordings or documents was important for the researcher to double check the data when needed. In this study, the researcher used about two to four hours to do the transcribing and around two hours for translation (Tetum to English).

The researcher used a thematic analysis to analyze the information after gathering data from the field. The researcher grouped the data into three main themes: perception or knowledge; practices; and attitudes; and examined all the cases in the study to make sure that all the manifestations of each theme had been accounted for and compared. The purpose of this study is exploratory, therefore thematic groupings were simply reported or described at this stage. In this way thematic analysis can be used to develop classifications that express the connections between themes.

In this study, all open-ended questionnaire responses were coded for identification of particular thematic trends and individual variation in perception or knowledge, and their experiences of controlling malaria through their common practices in the community.

The code used for each main theme were as follows:

- *K/P* for knowledge and perception;
- *PR* for practices;
- Att for attitudes.

In addition, under these main themes, the researcher developed sub categories with specific codes under each main theme. For example: symptoms, transmission or cause of malaria were used under knowledge or perception (*K/P*); prevention and control measures were used under practices (**PR**); and access to services and seeking treatment were used under attitudes (**Att**). All participants were anonymous, therefore the researcher also used specific code for the participants from the two focus group discussions and key informant interviews. The focus group participants and the key informant participants were all given codes to preserve their anonymity. Those from the first focus group were labelled **FG1** to **FG7**, those from the second focus group were labelled **FG 8** to **FG14**. The codes that the researcher used for the key informants were as follows;

- *CH1* for the first key informant
- *CH2* for the second key informant
- *TH1* for the third key informant

The codes were used for thematic analysis to identify any patterns. Answers and quotes to specific questions were highlighted, sorted and to be re-arranged under appropriate thematic groupings. These groupings were divided for interpretation to identify common characteristics as well as differences in views and opinions that individuals' expressed during the interview. All answers from the interviews were coded for identification of any thematic trends. According to Marshal et al (2011, p. 207), "Qualitative data analysis is a search for general statements about the relationship and underlying themes; it explores and describes and builds grounded theory". Therefore, after data collection, the interview data were transcribed, translated and coded as preparation for doing analysis. The researcher started the data analysis with clustering from a main topic then collating related topics and putting them together under each category or sub clusters (Marshall & Rossman, 2011).

#### 3.9 Summary

In this chapter, the definition of epistemology, positivism and quantitative research, constructionism and qualitative research, advantages and disadvantages of using quantitative and qualitative were described. In addition, the researcher also expanded in detail on how she gained the data from the study community. This chapter also discussed in depth on how the researcher applied the specific methods such as two transect walks, two FGDs and three KIIs in the study community, along with systematic

observation during the whole period of fieldwork. The researcher also analyzed the data by using a thematic analysis. The next chapter presents and discusses the study findings in detail.

# CHAPTER FOUR STUDY FINDINGS

This chapter reports the findings of the fieldwork component of the study, and describes the characteristics of the research participants, followed by the results of data collected from the transect walks, focus group discussions (FGDs) and key informant interviews (KIIs).

# **4.1The Participants**

The participants of this study were male and female farmers, who were aged 20 plus years and lived permanently in two selected hamlets. These farmers lived close to the border, which is located in the South West of Timor Lest and they also lived close to the irrigated rice-field areas. The first focus group discussion was attended by three women and four men and the second group discussion was attended by five women and two men. One key informant participated in an interview from the first hamlet and two from the second hamlet.

The age of the participants of this study ranged from 20 to 70 years of age (nine people were under 30 years of age, four people over 30, one person over 40, one person between 50 and 60 and two people were over 70 years old). In these two hamlets, most family houses consisted of three bedrooms with five occupants per household (the mean number of occupants for the first hamlet was 4.5 and the second hamlet was 5.3).

The next sections present the findings from the transect walks, focus groups and key informant interviews. The observational data are not reported separately but are incorporated into each section.

# 4.2 Findings of the Transect walks

The researcher began the study by conducting two transect walks. They were made on the 26th July (first hamlet) in the afternoon and 27<sup>th</sup> (second hamlet) of July 2012 in the morning. The walks activity were both carried out within an hour. Figures 7 and show

the simple maps which were drawn by the researcher to get a broad idea of the situation of the communities in the two selected hamlets.

Figure 7. Map of the first hamlet

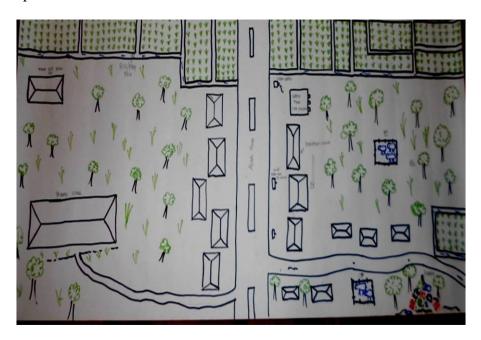


Figure 8. Map of the second hamlet



The following sections describe the observations that were made under the following categories: the suitability of the local environment for mosquito breeding; and the accommodation and protection measures used by households.

### 4.2.1 The suitability of the local environment for mosquito breeding.

There were three environmental factors that could contribute to the burden of malaria in each of the two communities: (a) lack of suitable water supply, drainage and/or sewerage systems; (b) the paddy fields; and (c) the rubbish tips (dumps).

(a) Lack of suitable water supply, drainage and/or sewerage systems.

#### The first hamlet

The first hamlet had three main water sources, which were located close to the community. These water sources were used by 61 households, with a community population of 213. However, these three water sources did not have a proper water tap. This situation caused water to be continuously running and this condition created stagnant water everywhere. In addition, the water could not flow well due to the rubbish dumped around these places (there was no rubbish bin) which caused the water to stop running (no drainage system). This situation potentially created a mosquito breeding ground, and mosquitoes could bite people when they came to take water in this place. The following pictures show the various scenes observed on the walks: the continuous running water (Figure 9); the stagnant water created by the dumped rubbish (Figure 10); and the results of the lack of a drainage system (Figure 11).

Figure 9. No proper water tap, so water continuously running.



Figure 10. The stagnant water and algae.



Figure 11. No drainage system to channel away the water.



# The second hamlet

This hamlet had one well as a source of water for the 81 households, with a population of 395. In this hamlet, most of the community mentioned that no clean water was available in their hamlet, therefore it was hard for them to get clean water for cooking, a bath and for use in their toilets. In addition, some stated that they did not have the toilets. Therefore, they used their backyards as a toilet and some used the river as a toilet. This situation forced them to walk about 5 to 15 km to obtain the water from the river. These conditions might create potential circumstances for them to get malaria because when they walk to find the water sources then they could be bitten by mosquitoes during their trip; and they could also be bitten by mosquitoes on the river as there are many potential sites for mosquitoes to breed there (for example, in stagnant water along side the river, in small irrigation trenches alongside the road). Figure 12 presents a picture of the only well in the hamlet; and Figure 13 show stagnant water beside the river used by the community.

Figure 12. The only well used by the community in the second hamlet.



Figure 13. Stagnant water beside the river.



# (b) Paddy fields.

Many paddy fields were located close to the communities' houses. This environment could also create a potential place for the mosquitoes to breed due to slow moving water and algae in the rice field and small irrigation channels connecting water from the river to rice field could be places where mosquitoes lay their eggs (increasing mosquito density). In addition, people could have a chance to be bitten by the mosquitoes because some farmers also irrigated their rice field during the night. Figure 14 shows two aspects of the paddy fields in the first hamlet, including one picture of a farmer standing in the middle of the water-covered field.

Figure 14. Paddy field in the first hamlet





#### (c) The rubbish tips (dumps).

The rubbish tip was located close to the community in the first hamlet. This condition created many potential sites for mosquitoes to breed because a vast amount of rubbish was dumped in this place. In addition, some people burned their rubbish once they threw it there, but some of the rubbish was non-combustible such as cans, and bottles and other glass (recycling rubbish). Moreover, some people did not burn their rubbish and left them scattered along the side of the road. These potentially malaria-risk situations can be seen in Figure 15 (rubbish tip in the first hamlet) and Figure 16 (results of incomplete burning of rubbish).

Figure 15. The rubbish tip in the first hamlet.

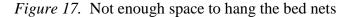


Figure 16. Some dry rubbish were burnt down but the recycle bins were still there.



## 4.2.2 Accommodation and protection measures used by households.

Most of the community had insufficient room to live because most of them had 3 bedrooms in each house, and each was occupied by four to seven people. This meant that there was little room to hang bed nets, as shown in Figure 17.





#### 4.3 Findings of Focus Group Discussions and Key Informant Interviews

FG1 was conducted on 26<sup>th</sup> of July 2012 (in the afternoon) and FGD2 was conducted on 27<sup>th</sup> of July 2012 (in the morning). This discussion was carried out over a period of 90 minutes. In addition, three interviews with the key informants (CH1, CH2 and TH1) were also held in these selected hamlets. CH1 was conducted on the 1st of August 2012, CH2 was conducted on the 2nd of August 2012 and TH1 was carried out on 3<sup>rd</sup> of August 2012. All these interviews were conducted in the morning. The interviews were carried out over 60 minutes per key informant.

In presenting the findings from this study, the researcher presented the data based on the five main questions, which was stated in chapter one. After obtaining the information from the selected community then the researcher categorized the main findings into six main sections to describe the participants' knowledge and behavior relating to malaria in terms of: transmission; avoidance and prevention; causes; symptoms, diagnosis and treatment; and knowledge about the National Malaria Control Program (NMCP) and initiatives from the community to prevent and control malaria. The detail explanation of these main findings as follows;

#### 4.3.1 Malaria transmission.

#### Focus Group Discussions

Some people stated that they did not know how malaria is transmitted. However, some reported they thought that malaria is transmitted through mosquitoes, dust, water from tyres or empty drums; and some thought that they got it because they did not wash their hands when they ate, and that you also could get it through taking a bath in the river. Although some stated that they did not know the causes of malaria, they took measures such as digging a hole to put rubbish in and burned the rubbish afterwards (as shown in Figure 18). Some did not dig a hole but burned their rubbish after sweeping it into a pile (shown in Figure 19).

Figure 18. A hole to throw the rubbish into.



Figure 19. Burned rubbish in front of the community house.



Moreover, most of the participants could identify the peak season of malaria or they mentioned it as the "season of many mosquitoes flying around". Most of the people from these two communities were aware that during the rainy season, there would be many stagnant waters everywhere, therefore those conditions could create a better environment for mosquitoes to thrive:

Malaria occurs during rainy season because heaps of rubbish had been dumped in here. It creates many places for many mosquitoes to live because many stagnant waters, water everywhere and creates places for mosquitoes to breed. (FG1)

#### 4.3.2 Malaria Prevention

The main issues identified by participants relating to malaria prevention included mosquito avoidance and bed nets, and participants' behaviours, knowledge and attitudes to those issues are reported on here. Participants were also asked about problems in taking preventative measures, and the key themes that emerged included no coherent strategy to prevention in their hamlet; difficulty in rubbish disposal; no health facility; and no permanent employment. The views that participants shared on each of those themes is reported on in the next section.

#### **4.3.2.1** *Mosquito avoidance.*

# Focus Group Discussions

Some people recognized that mosquitoes could transmit malaria therefore they protected themselves from mosquito bites through practices such as applying Autan (anti

mosquito cream) and burning Baygon (mosquito coil), if they had the money to buy these products. Some stated that if they had bed nets then they used them. However, for those who could not afford to buy these chemical products then they killed the mosquitoes using the hand (slapping it), and burned tyres, dry cassava and cow dung. They believed that the smoke of these identified materials could chase mosquitoes away. In addition, some people stated that they wore sarongs, long pants and long sleeves for covering their body to protect themselves from mosquito bites.

# **Key Informant Interviews**

The researcher found that the head of hamlet recognized that he had a malaria, therefore he mentioned that to minimize mosquito breeding sites in the community, he announced to the community that they should clean up their houses and back yards, and burn their rubbish after they collected it. In addition, the key informants also identified that their community did similar practices to those that emerged in the focus group discussions to protect themselves from mosquito bites, such as using bed nets and burning dry cassava and tyres.

#### 4.3.2.2 Knowledge about, and use of, bed nets.

Some people understood the benefit of using bed nets. They believed that using bed nets could protect them from mosquito bites. This shows that people could identify the connection of mosquito and bed nets. As one of the community members stated:

At night, sleeping without using bed net could get mosquito biting us and it could make us get malaria. (FG8).

Some people did not have bed nets to protect them from mosquito bites because they did not receive the bed nets, as they were not eligible (bed nets are only distributed to pregnant mothers and children under five). They also said a pregnant mother had received one bed net and two children (under five years of age) received one net.

Some farmers had bed nets but those bed nets were not in good condition due to them having holes in them, and were old and dirty (the existing bed nets were received in the past five years) as shown the following picture (Figure 20).

Figure 20. The big hole in the net used by the inhabitants.



In addition, some people knew that it a net was only provided to some people, and they did not seem to understand the rationale of it:

We do not know because they come here and said that that's the policy from the programme, therefore we do not know, we just follow whatever the government provides, we cannot ask for more. (FG2).

Moreover, they thought they had to be washed (but didn't mention with insecticide) and when they got torn, some people mended them, some people threw them away, and some people didn't know how to sew it.

# 4.3.2.3 Problems in conducting prevention measures

# (a) No coherent strategy (depending on the chief of the hamlet)

Most of the community explained that they were waiting for the chief of the village to take actions in preventing malaria or any disease in the community. They pointed out that community members only do the cleaning up in their community if there was an order from the head of a hamlet. If the initiative came from any of the community members then people will not do it because the order from the head of the hamlet is powerful and trusted by the community. People only believed order from the chief, not from any community members.

#### (b) Difficulty in disposing of rubbish.

The participants from the communities stated that there were no rubbish bins available in their community. Therefore, it was difficult for them to keep their community clean. Although some people dug a hole in their backyard for putting their rubbish in then burnt it, some did not. So this situation was not supporting the community to get rid of the breeding sites of mosquitoes or other insects.

#### d). No permanent income.

Most of the communities' residents were farmers, therefore their source of income was from the crops in the paddy fields that they received once or twice a year. This dependence on a limited and sporadic source of income restricted their choices about taking malaria prevention measures because they only had money when they harvested their paddy fields, otherwise they had to find other methods for earning money such as through selling firewood. However, this income was not enough for sustaining their lives, therefore when they got sick they could not afford go to the hospital, and they also could not afford to buy some chemical products (For example; Autan, Baygon) to protect them from mosquito bites.

#### 4.3.3 Knowledge about the cause of malaria

#### Focus Group Discussions

The participant community members in the second hamlet recognized that the the tipping of rubbish could create breeding sites. They believed rubbish tips could create a place for mosquitoes to live because empty cans or bottles and other rubbish provided a good environment for mosquitoes. Some participants reported that their communities had been used as a place for the rubbish tipping. In addition, one of the community members pointed out that sometimes people burned their rubbish when they dropped it.

# **Key Informants**

The chief of the second hamlet (CH2) said he could recognize malaria because he had had a personal experience of it, however the chief of the first hamlet (CH1) could not describe the symptoms as he did not have it or he might not know if he got it. In addition, the traditional healer (TH1) identified that the community considered getting malaria a result of misdeeds in the past or present and of forgetting family members who had died, so was caused by the spirit of the dead body or not caring for an ancestor:

How malaria feels like, we don't really know about it because we haven't got it therefore we do not know...(CH1)

Malaria is when the spirit of the dead body, our children or our parents, they died and we forgot them, therefore they did such as thing to us and we got malaria, shivering, back pain. (TH1).

It's happening because people are hit by something sacred therefore they get shivers and it's also happening because people are stealing and selling out the sacral accessories inside their own traditional houses; some women do the abortion, or killing unwanted baby. (TH1).

# 4.3.4 Knowledge about the symptoms and diagnosis of malaria, and treatment seeking.

#### 4.3.4.1 Knowledge about symptoms.

Most of the participants could recognize one to three symptoms of malaria. Malaria was known in the community as *be doko* (shivering), along with the other symptoms such as *malirin* (cold), *ulun moras* (headeache) and *isin manas* (fever):

About malaria.... we have a lot of children; we had malaria all the time. Malaria is sometimes fever, shivering, headache, diarrhea and vomiting...(FG3)

Malaria is when we feel hot, cool then hot inside the nose, our mouth/tongue bitter... (FG9)

In addition, some people claimed they did not know about the symptoms of malaria as they did not think they had experienced these, and stated that malaria only affected children and pregnant women.

#### 4.3.4.2 Knowledge about diagnosis.

Not many people understood about the importance of having blood tested for identifying any diseases (for example, malaria) that they might have. Participants said they would diagnose it on the basis of clinical symptoms. One out of 17 participants stated that when she had the symptoms of malaria then she got her blood tested at the hospital:

We got this disease but we don't know, therefore we go to the hospital to get it tested.... if we stayed at home then we didn't know, so go to hospital to get blood tested then we will know...if it's malaria disease. (FG9)

Cold then hot, then cold again, then hot and then felt like shivering.... when I got it...put four blankets on top of me...but feeling not good.... it appears, disappears.... then appears, disappear again.... till I got to the hospital ...taken blood.. (FG9)

#### 4.3.4.3 Treatment seeking

Participants reported that they would get malaria treatment in the following three ways: (a) self treatment; (b) going to the hospital and (c) going to a traditional healer.

# (a) Self treatment.

Most of the people would treat themselves when they thought they had got malaria. They mentioned that if they got malaria then they would boil papaya leaves with noodles (dan aidila tahan ho supermi) and eat it. This treatment was believed by the community as a cure for malaria as the bitterness of it could kill the disease in the body. In addition, some participants reported they purchased medicines, which were available in the nearest small shop in their community. The common medicines that some people used included paracetamol, ampicilin and aspirin. The participants mentioned that self treatment would be their first action because they stated that the health center is far from their community, therefore they could not afford to get there.

We buy medicine at the small shop nearby.... (beside the road) (FG3)

Get malaria go to the hospital, if not...buy medicines such as paracetamol, ampicilin, aspirin 1 dollar...(FG3)

Some eat, when we got fever then we like to boil papaya leaves and put with noodles on it . (FG10)

Some people just eat papaya leaves without putting anything on it because they don't have money.... it's boiled but bitter. (FG11)

#### (b) Going to the hospital.

Some people went to hospital if their condition was getting worse. In addition, most of the participants did not know about the treatment that they would get when the doctor prescribed it for them when they got malaria or any other diseases.

After 2 days then I went ...went there then the doctor got angry with me. Then the next day they taken my blood....when they tested me...my baby was not moving inside my tummy...it's very very hot (refer to her tummy). (FG9)

They gave me the medicine...I was admitted for about 4 days and 4 nights. (FG9)

Moreover, some could not access to hospital due to they do not have enough money to get the transportation to the hospital. Some participants stated that if they did not have money then they will stay at home without doing anything and die.

"No money, we cannot go to hospital, just wait at home..." (FG10)

"If didn't have the money then waiting till die...waiting if God calls us then that's the destiny." (FG11).

Furthermore, most of the participants said that there was no health facility available in their community for them to access when they got sick. The location of health center was far from the community. The distance from people's homes to the health facilities was about 8 to 12 kms. This situation stopped them from seeking help from professional health providers. The distance of the community and the price of the transportation, which were identified by the participants, can be seen in Table 3.

*Table 3.* The distance and price to use transportation.

Name of hamlet	Form of transportation taken (Motorbike)	Distance (km)	Cost of the transportation (return)
First hamlet	Motorbike	12	US\$ 4
Second hamlet	Motorbike	8	US\$ 2

#### (c) Going to a traditional healer.

According to the traditional healer malaria was known to be caused by current or past misdeeds and it was also believed as a result of not caring for an ancestor (for example, forgetting to pray for their souls). Therefore, this traditional healer stated that there was no specific treatment for this disease. Therefore, people could be treated through doing some traditional ceremony (chewing betel nuts and kill some animals) to feed the the dead body's spirit. After carrying out this ceremony then people could get healed:

I didn't treat with some special leaves or using any roots of the trees, but people bring betel nuts, candles, and cigarette for sharing and eating together with the spirit of our family's dead body. (TH1).

Malaria can be treated through bring betel nuts and give it to the spirit of the dead then it will get healed. Kill chicken and feed the spirit of the dead people then we will not get it again. (TH1).

Chewing betel nuts...they (traditional healers) are just chewing betel nuts, let's say using leaves (betel nuts) and killing a chicken/pig to see things wrong with the sick person (known as ta bula-local name for the traditional process of finding

things going on with a sick person) ...through see it on the leaves /liver of chicken or pig then it's alright. (FG12).

# **4.3.5** Knowledge about the National Malaria Control Program (NMCP) and initiatives from the community to prevent and control malaria.

#### Focus Group Discussions

Most of the participants stated that they did not know about the initiatives that the NMCP implemented in their community. However, some stated that based on their knowledge, they understood that the only activity that the malaria programme conducted in their community was bed net distribution. In addition, they also mentioned that they were not involved in this activity (except the selected health volunteers, which are appointed by the head of a hamlet). In addition, they also mentioned that they did not have their own initiatives to do any health activities in their community. Therefore, they were depending on the programme to provide health services in their communities.

#### **Key Informants**

Two out of the three key informants stated that the malaria programme was only distributing bed nets and they did not conduct any other activities in these two hamlets. In addition, one key informant also stated that sometimes some health officers did not inform them about any health programmes that they conducted in their communities (except for bed net distribution). Moreover, the chief of the hamlets also stated that they had their own initiatives to keep their community clean but they did not have specific initiatives for preventing and controlling malaria. The activities that they conducted were things such as announcing to the community to clean their backyards and their homes and burn their rubbish after they disposed of it.

### 4.4 Researcher observation (during conducting the FGDs and KIIs)

The researcher also noticed that during the interviews with the two key informants, one of them refused to use the digital recorder. Therefore, the researcher was taking a note during the interview. In addition, one or two people in the group dominated several discussions and this has an impact on the findings because some people chose to less talk during the discussion taking place.

#### 4.5 Summary

Based on the findings in this study, the main factors that contribute to malaria problems were identified such as not enough space to hang the nets, inappropriate water taps, stagnant water in the river side, no drainage system in place, no rubbish bin in the community and community leaved close to the rubbish tips. In addition, there were also other factors such as limited community knowledge about malaria (cause of malaria, symptoms of malaria) and lack of community initiatives to control and prevent malaria in their community. In addition, lack of health services in the community also other factors that contribute to the community did not have appropriate diagnosis and treatment for malaria. Moreover, transportation issues also became a problem for the community to access to the health services. Furthermore, the researcher also found out that some people could not share their ideas during FGDs because other participants dominated them. The following chapter discusses these findings, how the current situation affects the community, and the impact of this situation on health programme strategies.

#### **CHAPTER FIVE**

#### ANALYSIS OF THE FINDINGS

This research aimed to investigate community perceptions and practices in relation to malaria control in Timor Leste. This chapter presents the qualitative analysis of the findings reported in chapter five on community perceptions and practices, and addresses the following issues identified by study participants regarding malaria: transmission; prevention; symptoms; diagnosis; and treatment. As part of the analysis, the results of this study are also compared with recent findings from other relevant studies reviewed in chapter two.

#### 5.1 Malaria Transmission

The next two sections present the analysis of the findings from the transect walks, discussion groups and key informant interviews.

#### 5.1.1 Analysis of the transect walks.

The findings from the transect walks showed that there were several factors that contributed to the health problems (especially malaria) in the community. Those factors were to do with the way in which people live and worked. Some factors could be controlled by the community, some they could partially control and some factors were beyond their control or outside of their control.

The environmental issues around these two hamlets (first hamlet and the second hamlet) that could be controlled by the community were places where stagnant water lay around the tap water and other clean water sources; that the communities lived near paddy fields and close to a river; and staying in the paddy fields at night. These identified factors increased the risk of malaria transmission. A factor which was partially outside their control was having no rubbish bins available in either two communities. In addition, there were more factors over which they had no control such as the tipping of rubbish, and no means of preventing the taps from dripping. This means people had more chance of getting malaria, because they had to walk to obtain water and during their trip (late afternoon) they could be bitten by mosquitoes because they walked through the places where the breeding sites of mosquitoes were.

#### 5.1.2 Analysis of the FGDs and the KIIs.

Some people understood the reasons for malaria transmission. Common understandings about malaria transmission were similar amongst the participants, where they understood that malaria is transmitted by mosquitoes. This finding is in line with the studies carried out in Indonesia, where Sanjana et al. (2006) found that mosquitoes were recognized as a cause of malaria by almost 50% of respondents. This finding also strongly supported by another study by from Myanmar (Oo-do village), where they found that most of the participants (63%) stated that mosquito bites could lead to malaria (Shein et al., 1998).

In addition, some people still had other perceptions, believing that malaria can be transmitted through dust, and water from tyres or empty drums. This despite the researcher not mentioning dust as one of the causes of malaria. Similar perceptions found in a study from Lao PDR by Shirayama et al. (2006), which found that that around 36% of the respondents cited that a lack of basic sanitation around houses (39.2%) could also cause malaria.

Moreover, some believed that they got malaria because they did not wash their hands when they ate, and that you could also could get malaria through taking a bath in the river. The study in India reviewed in chapter two supported this finding, where they found that about 98% of tribal people believed malaria was transmitted by drinking or bathing in contaminated water (N. Singh et al., 1998). A similar finding also has been documented by Anh et al. (2005) in a study carried out in Vietnam (Ninh Thuan Province). The study revealed that community members believed that malaria could be transmitted by drinking unboiled water or water taken from a stream.

The findings of this study also suggested that the traditional healer (TH) had another etiology about malaria, where he stated that malaria was occurring because of an evil spirit or people forgetting an ancestor; and it happened because of the person's misdeeds in the past and the present life. This finding is similar to the study carried out in Lao PDR by Shirayama et al. (2006) where they report that around 5.4 % of participants were still mentioned evil spirits as a cause of malaria. This situation could lead to the misconception of the cause of malaria and it can also contribute to a delay in getting treatment, as some people might go to traditional healers to get treated traditionally. However, the study findings reported on here found that none of the FGD members thought this. Therefore, although some participants in this study attributed other reasons for malaria transmission, nearly all knew that they had to avoid mosquitoes.

Furthermore, most of the participants could identify the peak season of malaria, where they described the rainy season as the season of many mosquitoes flying around. Most of the people from these two communities were aware that during the rainy season, there will be a lot of stagnant water around, and these conditions could create a better place for mosquitoes live. This finding is in line with the study carried out in Timor Leste by Lover et al (2011, p. 10), where they state that "it was almost universally accepted that malaria was serious during the rainy season in all the studied regions, but many also thought it was year-round." This finding shows that people were aware that during a wet season, people should take some preventive measures to protect themselves from mosquito bites. This means the knowledge about the seasonality of malaria was well recognized by most of the people in the study.

#### **5.2** Preventive Measures

The findings regarding preventive measures analyzed in the following sections include mosquito nets and a number of other preventive measures reported by participants.

#### 5.2.1 Mosquito nets.

The results showed that there were mosquito nets available in many houses, but it was acknowledged that the government policy was that the bed nets were only freely distributed to pregnant women and children under five. Lack of funding to obtain nets independently of government provision meant that participants felt disempowered. This finding is in line with a previous Timor Leste study carried out by Lover et al (2011), where they reported that nets are freely distributed through antenatal clinics; and the National Malaria Control Programme has also partnered with several non-government organizations (NGOs) to deliver nets in other campaigns that specifically target pregnant women and children under-five. This policy will lead to a reduction of the number of people using bed nets because it is only targeting two specific groups. This means that some other people (for example, non-pregnant women, men, elderly, older children) may not have access to, and not use, bed nets, meaning more people are potentially exposed to mosquito bites during the night due to the excluded people sleeping without nets.

In addition, although some people received bed nets, sometimes it was difficult for them to hang the nets because there were not enough places for them to hang from. Thus despite the mass distribution of bed nets to pregnant women and children under five, the utilization of bed nets was poor. This situation was beyond participants' control, so

although they knew that they could get malaria if they did not protect themselves by using bed nets, despite the expectation that they would they could not because the environment was not supporting them to do so.

#### 5.2.1.1 Maintenance of the bed nets.

Some participants from the study communities stated that when the nets were torn or soiled, not all were mended, some threw them away, and not all washed them. This demonstrated that although they had the nets, some did not know how to repair and wash them. This finding suggests that lack of knowledge about maintaining the nets might lead to people not continuing to use the nets because their nets were in very bad condition (e.g big hole in it, old and very dirty). Lover et al (2011) strongly support this finding, where they found that most women stated that they would request for a new net or even burn older nets with holes, and repair was not a common practice in Timor Leste.

In relation to washing the nets, the findings of Lover et al (2011) did not support the findings of this study, because in their study they found that many women reported washing their nets every few months or twice a year and some reported washing their nets every few weeks. Whereas in the study reported here, the researcher found that not many people understood the regularity of washing their nets. Some stated that they washed it every three months and some every six months. Washing the bed nets more than recommended (twice a year) could lead to a reduction in the effectiveness of the insecticide in the nets, which means that mosquitoes are not killed when they fly close to the nets. Thus there is no longer a potent amount of insecticide left in the nets as a result of washing the nets with the wrong detergent or washing them more than twice a year.

#### **5.2.2** Other preventive measures.

Most of the participants stated that they conducted some practices to avoid mosquito bites. These practices include using bed nets, applying Autan (anti mosquito cream) and burning Baygon (mosquito coil). For those who could not afford to buy these chemical products then they killed the mosquitoes using their hand (slapping it); or by burning tyres, dry cassava, and cow dung. They believed that the smoke of these materials could chase mosquitoes away. In addition, some people stated that they wore sarongs, long pants and long sleeves for covering their body to protect from mosquito bites. These reported practices were in line with those in the previous study carried out in Timor

Leste, where many participants used commercial brands of repellent, insecticides, and coils for protecting themselves from mosquito bites, along with building smoky fires using specific types of wood or dung. Moreover, people also wore sarongs, long pants and long sleeves as well as using a blanket to cover up their body (Lover et al., 2011). Furthermore, the findings of the study reported here revealed that some people burned dry cassava and tyres to chase mosquitoes away, and some people burned their rubbish to destroy potential environments for mosquitoes to live.

#### 5.3 Symptoms

In this study, the researcher found that most of the participants could recognize one to two malaria symptoms and they described malaria in their local dialects as *be doko* (shivering). They also mentioned the symptoms of malaria such as *malirin* (cold/chill), *isin manas* (fever) and *ulun moras* (headache). This is in line with the findings of the the study carried out by Lover et al (2011, p. 10), when the participants were asked to list the symptoms of malaria, they gave generally non-specific responses, including a mention of fever, headache, chills, "feeling trembling," along with some ambiguous responses, like naming backaches and stomach aches. They also reported that the common local dialect (Tetum) phrase to express both malaria and fever is *isin manas*, (literally "hot body"), which is an indication that people perceived that fever and malaria are similar.

Moreover, this thesis also found that Timorese people described malaria in the local language as *be doko*. This is similar to the study carried out in Indonesia, where they also found that Indonesian people describe malaria in their own words as *katisen* or *panas tis* (Utarini et al., 2003). In addition, people in these two countries also have the same level of knowledge on malaria, where they could identify the symptoms of malaria. Most of the respondents (93%) were able to describe at least one symptom of malaria and around 65% could mention three symptoms or more. The study reported on in this thesis did not provide specific percentages of people who could describe at least one symptom as the numbers studied were small and this study was conducted qualitatively. However, in this study the researcher found that some people claimed they did not know about the symptoms of malaria as they did not think they had experienced these, and stated that malaria only affects children and pregnant women.

#### 5.4 Diagnosis

Although, the findings in this study indicate participants' knowledge of the symptoms of malaria was reasonable, there was confusion in distinguishing fever or other infections or illness from malaria, which could lead to people delaying getting proper treatment. In addition, not many people understood the importance of having their blood tested for identifying any diseases (for example, malaria) that they might have. This lack of knowledge about the procedure to gain a correct malaria diagnosis could lead to people not getting their blood tested when ill. Participants reported diagnosing malaria on the basis of clinical symptoms. Only one out of 17 participants stated that when she had the symptoms of malaria, she got her blood tested at the hospital. This finding indicated that because people might trust themselves to recognize malaria, not many of them would go to the health center to get their blood tested. This situation would lead to a delay in getting a proper diagnosis and treatment.

This finding contradicts the findings of the previous Timor Leste study (Lover et al., 2011), where they report that in many areas people had very good knowledge of malaria, due to extensive education campaigns from the Ministry of Health; several participants even mentioned "falciparum" and "vivax" specifically, and were knowledgeable about the relative severity of different types of malaria. This recent study totally disagreed with this study because some illiterate communities (e.g. Farmers, not educated people) regardless of the location of they live (urban or rural areas), they did not know about the specific type of malaria.

#### 5.5 Treatment

The different methods of treatment mentioned by participants were self treating, treatment in hospital, and treated by a traditional healer. The analysis of each of these treatment types is reported on in the following sections.

#### 5.5.1 Self treatment.

In this study, self treatment was reported as the most common treatment option. The only reason participants mentioned for treating themselves was because there was no health facility available in their communities. Therefore, when people got malaria, they were boiling papaya leaves with noodles, and purchasing medicine such as paracetamol, ampicilin and aspirin from the nearby shops. These findings are supported by those in the other study carried out in Timor Leste (in rural Manatuto and Covalima) by Lover et

al., (2011), where people mentioned that they used paracetamol or herbal remedies for treating many symptoms, including fever. This finding showed that the traditional remedies were used as a first option, and if people did not get better then they would seek help from the professional health providers at the primary health clinic or hospital.

In addition, the findings of both studies are in line with the study carried out in Indonesia by Utarini et al (2003), where people preferred to purchase medicines at the nearest local shops. Moreover, the findings from the study in India (Delhi) (Tyagi et al., 2005) also support the Timor Leste study. The Indian study found that most people prefer self-treatment and use any *Bukhar ki Goli* (tablet used for fever) including some anti-malarials that were available to the rural population. They found that this led to incomplete doses of drugs being used indiscriminately. This situation may be due to the inadequate medical facilities and also due to the long distance between medical centers and people's homes (Tyagi et al., 2005).

#### 5.5.2 Hospital

Some people noted that they would go to the hospital if their condition were getting worse. Most of the community did not know about the treatment they would get when the doctor prescribed for them when they got malaria or any other disease. Moreover, some could not go to hospital as they did not have enough money to get the transportation to get there. Some participants stated that if they did not have money then they would stay at home without doing anything and die. Moreover, some people said they would choose to visit the traditional healer if they could not afford to go to hospital.

This finding is in line with the study carried out by Lover et al (2011)where they report that some people who live in rural areas spent \$1USD to arrange a motorbike as transportation to a health clinic. Because of the distance between the health facility and their home, it was not possible for people to walk (around two hours walk). Difficulty in getting to a health care facility could delay people in getting treatment. The study reported on in this thesis also found a similar situation, where people could spend around US\$2 to US\$4 hiring a motorbike to get to the health center.

These barriers to seeking treatment at health care facilities could lead to underreporting of cases and an incomplete surveillance system in Timor Leste because any malaria cases occurring at home will not be recorded. This finding supported the researcher's

rationale for conducting the study in the two selected study communities. As stated in chapter one, in the Maliana sub district the number of reported malaria cases were low (the number of clinical cases was 343; confirmed cases were 6) in comparison to other sub districts, but the data was not accurate due to some of the morbidity or mortality cases happening outside the health centers; and sometimes mis-diagnosis of malaria also occurs due to poor laboratory equipment at the village and sub district levels.

Moreover, this study also found that some communities preferred to use the traditional healer because they were close by. This finding is in line with the reported findings from the study in Indonesia (Jepara district), where it was found that people prefer to seek treatment from a traditional healer as it is easy for them to access treatment because the healer is geographically close to them (Utarini et al., 2003).

#### 5.5.3 Traditional healer

The traditional healer believed that Malaria was caused by current or past misdeeds and as a result of not caring for an ancestor (for example, they forgot to pray for their souls). Therefore, this traditional healer stated that there is no specific treatment for this disease. Therefore, people could be treated through doing some traditional ceremony (chewing betel nuts and killing some animals) to feed the dead body's spirit. After carrying out this ceremony then people could get healed.

The Lao PDR study supported these findings, and found that people used a variety of traditional herbal medicines or religious ceremonies such as chanting and animal sacrificing (eggs, birds, water buffalos), together with the presentation of offerings such as alcohol, tobacco and flowers, as a treatment for malaria (Shirayama et al., 2006). Although they have different methods of conducting a traditional ceremony for healing, they have the similarity of using traditional practices to get people cured.

#### 5.6 Summary

The analysis of the study findings and comparison with the other studies reviewed in chapter two shows that most of the communities in Southeast Asia and the South Pacific have similar knowledge, attitudes, beliefs and practices in regards to preventing and controlling malaria. Most of the communities in rural areas have limited knowledge about malaria and how to take proper preventative measures. The findings in this study suggested that most of the community preferred self treatment as their first choice of treatment when they got malaria, and there were substantial barriers to seeking diagnosis and treatment from health care facilities. Based on these findings, the final

chapter of this thesis discusses how to address the malaria problem in Timor Leste and proposes some recommendations to support the MoH, through the delivery of the NMCP programme, in order to address malaria in the country.

#### **CHAPTER SIX**

#### DISCUSSION AND CONCLUSION

This study is one of the knowledge, attitudes and perceptions (KAP) studies undertaken to explore the perceptions, attitudes and practices of the community in regards to malaria in the Southeast Asian and Pacific regions. It is the first KAP study undertaken in Timor Leste and adds to the results from other studies in Indonesia, India, Vietnam, Lao PDR, Vanuatu and the Solomon Islands. This chapter discusses main findings of the study and some recommendations are suggested to improve malaria services and combat malaria in Timor Leste. In addition, the limitations of the study are also reviewed. The chapter ends with the overall conclusions to be drawn from this study.

#### **6.1 Main Findings**

The Timor Leste Ministry of Health (MoH), through the National Malaria Control Program (NMCP), has developed a health policy to address malaria problems throughout the country. As described in chapter one, the health policy consists of four main strategies such as follows;

- Guarantee all people access to quick and effective treatment, to significantly reduce illness and death from malaria;
- Provide malaria prevention measures (insecticide-treated nets) to young children and pregnant women;
- Ensure use of appropriate vector control methods (for example Larvaciding, indoor residual spraying) to significantly reduce transmission of disease and
- Improve epidemic preparedness and response (T. L. MoH, 2003, p. 2).

In order to address malaria problems, the programme provides free services to the community. However, based on the findings from this study, it suggested that there are still some communities who are unable to access the free services. This study has identified six major barriers to the effective tackling of malaria in small rural communities in Timor Leste:

- 1. Difficulty in accessing health services
- 2. Reliance on self-treatment
- 3. Under-reporting of cases: incomplete surveillance systems
- 4. Lack of control over factors impacting on malaria risk

- 5. Lack of understanding of malaria
- 6. Inadequate preventive measures.

Each of these barriers is described in detail in the following sections, in relation to the study findings.

#### 6.1.1 Access to health services.

This study found that a majority of people could not access health services, because health centers are not available in their community. This situation has an impact on the effective diagnosis and treatment because there was not available the diagnosis and treatment centers in the community for people to access when they get sick. People have to walk about eight to twelve kilometers or for around two hours to reach to the health centers. In addition, the cost for using public transportation also had been mentioned by the study participants as another factor that contributes to the difficulty in accessing the health centers (outside of the geographical location of the community). People have to pay around US\$ 2.00 to US4.00 to hire a motorbike as the form of transportation to get to the hospital.

#### 6.1.2 Self treatment.

The study findings suggest that some of the participants chose self treatment as the primary method in getting treatment for malaria. Most of the time people were persistently using traditional remedies (boil papaya leaves) and they believed they could treat any malaria symptoms. In addition, some people purchased malaria drugs from the local shop. This occurred because people had no alternative treatment options, as the health center was far away from their community. These situations bring a negative impact on malaria treatment as it could cause drug resistance in the community because people taken drugs that was not recommended by the NMCP to treat malaria.

#### 6.1.3 Under-reporting of cases.

This study also found that as most of the people in the community could not access the health center, that malaria morbidity and mortality cases were under-reported, as the cases occurred outside the health services. This situation could bring a negative impact on reducing malaria morbidity and mortality in Timor Leste because many cases especially malaria cases in rural or remote areas were not regularly reported due to the cases occurred at people's home and the health staffs could not recorded. This means that health staffs could not produce an accurate malaria data from the community as the

staffs were only recording the data, which was only obtained from the people who came to get a diagnosis and treatment in the health centers. The further problems of this situation will be that the NMCP could not expand their services appropriately to the community who are needed the most but they cannot get to the services as they are left behind due to not accessing the health services as they expected.

#### 6.1.4 Lack of power, control and trust.

This study found that lack of community power to take control over the factors that influence their health is a substantial barrier in effectively preventing and controlling malarial disease. For example, one of the selected communities in the study had a rubbish tip close to where they lived. In addition, there were no drainage and sanitation system in place. This situation could not be controlled by the community because the community did not have the power or any initiative to overcome this situation.

Moreover, in the findings under the "Researcher observation", the study also found that some community members did not trust an outsider (researcher). This situation was observed by the researcher during the FGDs. For example, during the discussion taking place, some people still withheld some information that they wanted to share with the group. This may be because they had a problem with previous people who visited their community, therefore they did not trust any outsider.

#### 6.1.5 Insufficient knowledge about malaria in the community.

The researcher also found that some people still had insufficient knowledge about malaria transmission and vector control in their community. This study found a lack of understanding of the causal link between the mosquito as the etiological agent, the mosquito bite as the mode of transmission, and the malaria as an outcome. Therefore, this study suggests that the NMCP needs to increase community knowledge about the basic epidemiology of malarial disease and the basic knowledge about vector control. By engaging with the community through education, the NMCP can increase community participation to support the programme in controlling and preventing malaria.

#### 6.1.6 Inadequate preventive measures.

This study found that the community relied on two types of preventive measures such as using chemical products and traditional materials. The chemical methods included using various commercial products, as described earlier.

Bed nets were also commonly known by the participants, however the majority of people had no clear clue of the reason of why only the pregnant women and small children used the nets. In addition, the bed nets were also poorly maintained and underused because of not enough space to hang the nets.

Another method was using traditional materials. This method was commonly practiced in the community especially by the people who could not afford to purchase chemical products. These methods employed strategies to create smoke such as burning dung, tyres and dry cassava. While the previous study in Timor Leste by Lover et al (2011) describe the use of other traditional preventive measures (for example, burning specific wood), this study found another, slightly different local practices (for example, burning tyres and dry cassava).

The researcher believes that these factors influencing effective malaria prevention and control in small rural communities found in this study may not have been adequately recognized by the NMCP. This lack of awareness could could substantially hinder the NMCP successfully reaching the Millennium Development Goal. Those mentioned factors could make it difficult for the programme to reach the target of 45% by 2010 and 60% in 2015 (UNDP, 2010).

#### **6.2** Strategies to Address Malaria Issues

In order to address the issues and barriers to effective malaria prevention and control mentioned above, the researcher recommends several actions, which can be implemented by the NMCP as a 'top down' approach to current activities, and the community can also do some activities as the 'bottom up' approach. These two approaches can be carried out by the community and the programme to combat malaria in Timor Leste. The next two sections describe the suggested actions in detail, beginning with those using a 'bottom up' approach.

#### 6.2.1 'Bottom up' approach.

Based on the results of this study the researcher suggests that the NMCP should involve the community in the delivery of the programme.

As has been identified earlier, the community did not have the power, initiative or trust to take control over key influences in their lives, such as their environment, that were affecting their health. This study recognizes that it is important for both the programme and the community to work together in combating malaria. Therefore, this study suggests that the NMCP and the community could do some future work for reducing malarial diseases through applying a Community-Based Participatory Research (CBPR) approach, as described by Israel et al (Israel, Schulz, Parker, & Becker, 1998). This approach is believed to be effective for getting the community involved in addressing malaria issues because

the CBPR is a collaborative, partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process. The partners contribute their expertise and share responsibilities and ownership to increase understanding of a given phenomenon, and incorporate the knowledge gained by action to enhance the health and well-being of community members. (Israel et al., 1998, p. 184)

Furthermore, O'Fallon and Deary (2002, pp. 157-158) state that "by involving community members in every stage of the research process and communicating findings to them in culturally appropriate and understandable terms, CBPR enhances trust between the researcher and the community". This means that if the researcher can get the trust from the community then any activities can be done easily because the community and the researcher are positioning themselves as a working partnership.

This approach might work for future research within the malaria programme. For example, the NMCP could design a study on bed nets preference in the community. This should involve the community at all levels of the study, including at the beginning with the study's design; then its implementation, data collection and determination of appropriate actions based on the results. So, basically the programme and the community will be working together to identify which bed nets will be better used by the community in regards to the bed nets' design, color, size and methods of distribution prefer by the community.

In addition, another activity that the researcher thinks that may work in preventing malaria in the future is a programme called "Community ready to combat malaria" (this idea is created by the researcher). The researcher suggests that the NMCP can create this programme in each village. This type of community-based programme can be prepared to respond to any malaria problems that might occur at the community level. This programme could include activities such as identifying fever cases and treating people earlier with a proper basic treatment. If the illnesses cannot be cured then they have to provide a proper way to refer these people to health centers.

Moreover, another activity would be to set up an entomology team in the community. If implemented by the NMCP, it should increase community knowledge of vector control, so that the community will be ready to support the programme in combating malaria in all levels of that community. This activity can be carried out through the NMCP and involves supporting the community to set up the team, and providing the proper training. This training would be specifically related to the entomology programme. This aim would be to set up an entomology team in the community and it is run by the community. This team would be responsible for controlling malaria vectors such as doing larvaciding (a chemical mosquito eradication method) and using panchax fish as one of the biological methods to reduce mosquito larvae in the community.

Those suggested activities could be added into the existing community-based activities, (SISCa programme) as described in chapter one. Including these activities in the future SISCa programme can only strengthen the programme's impact.

#### 6.2.2 'Top down' approach.

This approach sets the policies at higher levels in the political process which are then communicated to subordinate levels, which are then charged with the technical, managerial, and administrative tasks of putting policy into practice (PHAST, 2011). Based on the findings of this study, the recommendation is that, while the policy is created by the national malaria programme, it needs to be implemented at every level of the community in Timor Leste. The next sections list the specific recommendations regarding a national malaria strategy and policy in Timor Leste.

#### 6.2.2.1 Malaria strategy/policy to address malaria issues.

6.2.2.1.1 Health facility/health staff (malaria programme).

The NMCP should strengthen the health system to increase the availability of malaria diagnostic tests at all levels of the community (hamlet, village, sub district and district). This means the MoH should provide a proper health service at all levels of the community and equip it with sufficient services and sufficient number of the health staffs for the community to access.

#### 6.2.2.1.2 Bed nets distribution.

Pregnant women and children under five are the target groups for receiving bed nets in Timor Leste. This finding of this study has indicated that accordingly, the excluded groups will not be protected by bed nets. The researcher suggests that as Timor Leste is an endemic country, by protecting only the target group this will not support the programme to prevent and control malaria. Therefore, based on these this study findings, it is suggested that the NMCP should put more effort (financially) into obtaining more nets to distribute to the population in the country. The bed nets distribution should be expanded to all populations regardless of their vulnerability to malaria and their level of risks (low, medium, high risk areas). However, the researcher acknowledges that any policies made should take into consideration that most of the community had houses with not enough room or space to hang the nets. In addition, they had also have to be shown to wash and mend the nets, and have full involvement in understanding the rationale for using them.

#### 6.2.2.1.3 Improving the malaria surveillance system.

The researcher acknowledges that the quality of malaria data is poor in Timor Leste. The researcher found that it was very hard to obtain accurate data about the malaria morbidity and mortality from the programme due to the weak surveillance system, with data being incomplete, unreliable and inconsistent. Therefore this study recommends that the NMCP should provide accurate malaria data through improving routine reporting and increasing the number of staff working on the surveillance system at each level of the community (village, sub district, district and national level).

#### 6.3 Timor Leste Could Shift to Malaria Elimination in the Next Few Years

Timor Leste is still at the stage of malaria 'control', because the NMCP has had the objective of reducing the level of malarial infection and consequent death in Timor-Leste by 30% by the year 2007, and to sustain that improved level of control by 2013.

However, Timor Leste could shift to malaria elimination in the next few years if the cessation of malaria transmission can be achieved in the country.

In Timor Leste, the NMCP had implemented some strategies such distribution of insecticide treated bed nets, conducted the indoor residual house spraying, larviciding and strengthening the health system to increase the availability of malaria diagnostic tests. However there are more challenges for Timor Leste to face for it to shift to malaria elimination in the next few years. Therefore, the researcher strongly believes that through applying the CBPR model in the NMCP, it might increase the participation of the community in the effort to reduce malaria morbidity and mortality, or eliminate malaria in the country completely.

#### **6.4** Limitations of the study

Qualitative studies by definition are non-representative and generalizable, and the presence of a tape recorder and outsiders may have affected responses. Two focus group discussions were conducted, however during the interview one or two people in the group dominated several discussions and this has an impact on the findings because some people chose to less talk during the discussion taking place. In addition, three interviews were done with three key informants, however one key informant was not comfortable with the presence of the digital recorder, this is also having an impact on the findings because the researcher had to take notes during the interview and it didn't have sufficient time to record all the information when the discussion was too fast. Lastly, the researcher had no direct control over the recruitment of participants. Focus groups by their nature are not representative of the population as a whole, so responses may be very important social themes, or simply one individual's idea.

#### 6.5 Conclusions

This study explored the knowledge, attitudes and perceptions of the Timorese community of malaria and it aimed to find out the practices that the community do to prevent and control malaria in Timor Leste. In addition, it also aimed to help the NMCP understand the whole KAP of the community. This study has identified some of the barriers preventing the community from being involved actively with the NMCP in combating malaria. Moreover, the researcher believes that identifying the barriers for preventing and controlling malaria might help the NMCP to consider developing specific activities to address malaria problems in the community. The results will be shared with both the Ministry of Health and the National Malaria Control Program, and

will support the programme expansion in rural areas. In addition, this study also provides some recommendations for future malaria elimination in Timor Leste.

Further qualitative and quantitative studies (for example, a KAP study in another part of Timor Leste, and a survey on the effectiveness of utilizing bed nets in the community) will be needed to identify other issues that might not have been identified in this study, as the study's small sample means the findings are not necessarily generalisable to the wider population in Timor Leste. Understanding community perceptions and practices is important to be able to address malaria issues in Timor Leste. Better understanding of the needs of the community and the potential contribution that the community could make towards the malaria programme could support the NMCP in creating a better community-based programme using a 'bottom up' approach. This community-based programme could combine with the existing NMCP to effectively address malaria issues in Timor Leste, so that the country can move towards malaria elimination in the future.

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#### **GLOSSARY**

ACT : Artemisinin-based Combination Therapy

AUT : Auckland University of Technology

AUTEC : Auckland University of Technology Ethics Committee

CBPR : Community Based Participatory Research

CDC : Communicable Disease Control

DHS : District Health Service

FGDs : Focus Group Discussions

KAP : Knowledge, Attitude and Practices

KIIs : Key Informant Interviews

IRS : Indoor Residual Spraying

LLITNs : Long Lasting Treated Nets

MDGs : Millennium Development Goals

MoH : Ministry of Health

NGOs : Non Government Organizations

NMCP : National Malaria Control Program

PHAST : Public Health Action Support Team

RDTs : Rapid Diagnostic Tests

UNDP : United Nation Development Programme

WHO : World Health Organization

#### **APPENDICES**

### Appendix A

# Summary of the studies on KAP from the Southeast Asia and the South Pacific

Paper	Methodology/Method used	Main findings
Indonesia	Used combination of	Insufficient understanding of
Rapid Assessment	quantitative and qualitative	malaria sign and symptoms in
Procedures of malaria in	methodology	the sub villages likely leads to
low endemic countries:		delay in illness recognition
community perception in	Conducted 7 Focus Group	and treatment.
Jepara district, Indonesia	Discussions, 28 In depth	
(Utarini et al., 2003).	interviews and conducted	The health center was used
	few unstructured	but when it did not work,
	observations.	most people would shift back
		to traditional services due to
	Used thematic content	cost considerations.
	analysis.	
	-	Low understanding and
		acceptance of the casual link
		between the mosquito and
		malaria, likely leading to poor
		comprehension of preventive
		activities as well as confusion
		of malaria with dengue fever.
Survey of community		Almost 100% of the
knowledge, attitudes, and	Applied quantitative	respondents were aware of
practices during a malaria	methodology.	malaria.
epidemic in Central Java,		
Indonesia (Sanjana et al.,	Selected the participants	36 % respondents at least
2006).	randomly.	owned one bed net, 92% of
		these had been purchased by
	Used 1000 households	the owners.
	from 50 villages.	
		However, only 36% of
	Used a pre-tested survey	households with bed nets
	instrument consisting of	affirmed their use as a means
	93 questions	of preventing malaria.
		Nearly all respondents
		reported a willingness to
		accept spraying of residual
		insecticides for malaria
		prevention, yet less than 5%
		were willing to pay a nominal
		fee (US \$3) for this service.
		52% of respondents reported

Socioeconomic factors and access to health services for malaria control in Mamuju district, West Sulawesi Indonesia (Amiruddin et al., 2012)	Recruited 739 participants randomly.  Conducted a cross-sectional study.	self-treatment of malaria illness without visiting a health facility.  The study found that around 50% of respondents have low levels of education. Low level of education of respondents caused little attention to malaria control.
	Used observational.  The data were analyzed by using SPSS and Chisquare test and logistic regression.	Based on occupation showed that around 75% respondents was a civil servant. They have done enough malaria prevention to improve malaria control in Mamuju district.
		Based on income, the researcher found that almost 60% of the respondents have low income. Out of this percentage, there was around 47% of the respondents could implement malaria control.
India Knowledge, attitude, beliefs and practice (KABP) study related to malaria and intervention strategies in ethnic tribals of Mandla (Madhya Pradesh) (N. Singh et al., 1998)	Used 200 participants (age of 15 to 50 years old).  Conducted a field survey.	Most of the participants were familiar with malaria but around 98 % did not really know what caused malaria. 50% said that drinking contaminated water could cause malaria.
		25% said that polluted water of stream bed pools could cause malaria.
Knowledge, awareness and practices towards malaria in communities of rural, semi-rural and bordering areas of east Delhi (India) (Tyagi et al., 2005).	Conducted a questionnaire-based survey in various groups including primary school teachers (PST:94), factory employees (FE:336), business group (BG:134), lower economic group (LRP:432), farmer group (FG:50), rural	Practice of using insecticide spray by FE was probably be due to the easy availability of insecticide sprays in their work place.  High usage of commercially available mosquito repellents (mats and coils) by urban respondents and low in rural respondents partially explained the impact

	women (RW:125) and local healers (LH:15).	of socioeconomic conditions.
	Used 1,186 participants (age of 18 to 80 years old).  Applied Focus Group	High malaria incidents in LRP with repeated infection is understandable as these respondents belong to low
	Discussion (FGD).	socioeconomic strata of the society.
		Less malaria infection and low expenditure incurred in teachers' group may be due to better socioeconomic condition, education and knowledge of protection from mosquito bites and better acquaintances with Government hospitals for treatment.
		Practice of Delhi ilaaj (traditional healing) was found to be common among respondents (especially farmers and rural women).
		Some herbal mixture containing basil herbs were found to be in practice in rural and semi rural areas.
Factor affecting treatment-	Used 300 participants.	Most of the participants
seeking for febrile illness in a malaria endemic block in Boudh district,	Conducted a cross- sectional community-	stated that when they got malaria then they sought some sort of treatment e.g.
Orissa, India: policy implications for malaria	based survey.	government health facility (35.7%)
control (Das & Ravindran, 2010)	Data collection was selected through a multistage sampling and interviewed with a pretested and structured	31.3% of the participants sought less qualified providers.
	interview schedule.	24.3%) from community
	Malaria treatment providers were	level health workers and volunteers.
	interviewed in the district to gather their insights on	Almost 60% of participants sought treatment from
	factors associated with prompt and effective treatment through a semi-	appropriate providers within 48 hours of onset of symptoms.

#### structured and open-ended interview Visiting a provider more than guideline. five kilometers were more likely to have delayed or inappropriate treatment. Patients' lack of trust in community volunteers providing treatment led to inappropriate treatment-seeking from the less qualified providers. Used 75 households. Sri-Lanka Participants in the educational Impact of education on intervention were shown to knowledge, Implemented a 20-week agriculture increase use of practices, and community pilot education program environmentally sound to improve community actions for mosquito methods for mosquito control and mosquitoknowledge and mosquito control and disease prevention such as bed net borne disease prevention control with participatory in rice ecosystems and non-chemical use, breeding Srilanka (Yasuoka, approaches site elimination, and was Mangione, Spielman, & developed, environmental cleanup. Levins, 2006). implemented, and evaluated Decreased using preother methods that might educational and posthave a negative influence on educational surveys in two interventions and the two comparisons environment, including villages. insecticide spraying, mosquito coil Targeting rice farmers. use, and jungle clearing. To prevent mosquito breeding reduce mosquito density, rice initiated farmers new agricultural

		practices, including land leveling, canal cleaning and draining, and decreased pesticide use.
Vietnam KAP surveys and malaria control in Vietnam: Findings and cautions about community Research (Anh et al., 2005).	Conducted a cross-sectional study from June-December 2003.  Applied Face-to-Face structured questionnaire with 29 questions.	Almost 73% of the participants were correctly identified that malaria is transmitted by mosquito bites.  Most people correctly identified fever as a symptom of malaria infection.  More than 84% said that they sleep under a bed-net regularly, but only 66% of the households sleep according to the minimum recommended number of nets (1 net per 2 people).  Sources of malaria education around said that they got from health staff, more than 33% through television and radio, 26% mass organizations, and teachers (9.5%).  In answer to which education method made it easiest to understand malaria control, respondents identified posters (28%), videos (21%), radio (18%), public meetings with health staff (17%), and home visits (12%).
Timor Leste An exploratory study of treated-bed nets in Timor Leste: Patterns of intended and alternative usage Lover et al, 2011).	Used an exploratory study.  Conducted nine separate Focus Group Discussion.  Utilized comprehensive	The primary determinants of net usage were a widespread perception that the nets could or should be used by pregnant women and young children.

	quantitative analysis by using open source analysis software.	The availability of sufficient sleeping space under a limited number of nets within households.  The primary motivation of using bed nets was a nuisance biting and disease prevention.  Long term net durability and ease of hanging were seen as key attributes in net design preference.  Very frequent washing cycles were common, potentially degrading the net effectiveness.
Lao PDR Knowledge and behaviour relating to malaria in malaria endemic villages of Khammouane Province, Lao PDR (Uza et al., 2002)	Used a descriptive cross-survey.  Applied structured interview.  Conducted active case detection of malaria in communities was made concurrently with this study. Examined by using the dipstick.  Data was analyzed by using SPSS. Chi-square test was used for comparison of groups and p-values less than 0.01 were defined to be statistically significant.	55% of the illiterate group slept under bed nets, compared to 75.4% of the educated group.  Around 29% of the illiterate group had knowledge about malaria transmission by mosquito bites, compared to 48.8% of the educated group.
Modern medicine and Indigenous health beliefs: Malaria control alongside "Sadsawa-Phee" (Animist belief system) in Lao PDR (Shirayama et al., 2006)	Interviewed 240 heads of household.  Used open-ended question.	Most of the participants recognize the symptoms of malaria but knowledge of malaria were poor.  5.4% of the participants cited that malaria is caused by evil spirits (5.4%).  Around 52% of the participants know the link between mosquito bite and malaria infection.

		36.2% said that malaria is caused by drinking unboiled water.
		27.1% said that malaria is caused by eating.
Myanmar The level of knowledge,	Used descriptive cross- sectional KAP survey.	Almost 70% said that they used bed nets
attitude and practice in relation to malaria in OO-do village, Myanmar (Shein et al., 1998).	Applied structured questionnaire and focus group discussion by using structure questionnaire.	80% of the study subject stated that mosquito bites could lead to malaria
	-	Around 43% of the respondents still have incorrect knowledge that malaria is transmitted by the bite of infected mosquito such as drinking stream water and eating bananas can lead to malaria.
		72% knew the correct symptoms of malaria (fever, chills and rigor).
		Nearly 100% respondents believed that repeated attacks of malaria could affect their family income.
		24% used various indigenous drugs, which they believed to have antimalarial action before going to the forest for wood cutting.
Vanuatu Community participation for malaria elimination in	Conducted 9 FGD and 12 KIIs, 3 transect-walks and 7 participatory workshops.	Use the bed nets was identified by participants as primary protection method.
Tafea Province, Vanuatu: Part I. Maintaining motivation for prevention practices in the context of disappearing disease (Atkinson et al., 2010).		Village, household and personal cleanliness were identified by participants as important for protection against malaria.
		Barriers and influences on bed net use included cultural beliefs and practices, travel,

Solomon Islands A qualitative study on the acceptability and preference of three types of long lasting insecticide-treated bed net in Salomon Islands: implications for malaria elimination (Atkinson et al., 2009).	Conducted 12 focus group discussions (FGDs).	availability of health worker and poor community infrastructure.  Knowledge of malaria and the means to prevent it were not sufficient to guarantee compliance with LLIN use.  Factors such as climate, work and evening social activities impact on the use of bed nets, particularly in men.  The main criterion for bed net acceptability identified by
Community participation for malaria elimination in Tafea province, Vanuatu: Part II. Social and cultural aspects of treatment-seeking behavior (A. Tynan et al., 2011).	Conducted an ethnographic study. Conducted 9 focus group discussions (FGD), 12 key informant interviews (KII) and 7 participatory workshops.	Most communities identified That malaria is a new condition that had only arrived after independence in 1980.  Use of traditional or home practices was common: perceived vulnerability of patient and previous experience with malaria impacted on the time taken to seek treatment at a health facility.  Barriers to health care access and reasons for delay in careseeking including the
		gender roles, seasonality of mosquito nuisance and risk perception. Participants preferred receiving health information through visiting community health promotion teams, health workers, church leaders and village chiefs.

effectiveness in preventing mosquito bites and malaria.

Participants expressed a lack of acceptability for Olyset® bed nets due to unfavourable characteristics (namely its large mesh size that is perceived to allow small mosquitoes to fly through and its tendency to wrinkle and shorten making it difficult to keep tucked securely under sleeping Most mats). participants reported both DuraNet® and PermaNet® to be acceptable.

Both PermaNet® and DuraNet® were deemed acceptable by participants because of their perceived effectiveness. DuraNet® was mostly favored over PermaNet® due to its durability and increased ventilation.

#### Appendix B

## Semi structure interview for the key informant interviews and the focus group discussions.

- 1. What do you know about malaria transmission?
- 2. What do you know about any environmental factors that contributes to malaria transmission including increased risks in the rainy season?
- 3. What do you use to control the malaria vector?
- 4. What are the symptoms of malaria?
- 5. Who can get malaria?
- 6. What did you do when you get malaria?
- 7. What any other factors that contribute to malaria (e.g social-economic factors)?
- 8. What do you know about national malaria control programs?
- 9. Did you involve in any health programs on malaria? What type of activity were there?
- 10. What can you do to prevent malaria in your community?
- 11. Any other comments that would like to add?

#### Appendix C

#### Information sheet for individual interview

## **Participant Information Sheet**



#### **Date Information Sheet Produced:**

11th of March 2012

#### **Project Title**

Community perceptions and practices in relation to malaria control in Timor Leste.

#### **An Invitation**

My name is Maria Lurdes Gama Soares and I am a Master's student of Public Health. I am currently studying at Auckland University of Technology, Auckland, New Zealand. I am undertaking research on community health looking at the perceptions and the practices of community members about malaria and what they do to control malaria in their community. I would like to invite you to take part in this research. Your participant is entirely voluntary and you can choose to withdraw at any time during the interview up to when the data will be analyzed.

#### What is the purpose of this research?

The purpose of this study is to explore the community's perceptions and practices in Timor Leste in relation to malaria control. This will also provide some basis for considering ways of increasing community involvement in malaria control in Timor Leste. This research on community health will help prepare me for my Master's thesis. The findings of this study will be presented in professional forums, conferences and written as a journal article.

#### How was I identified and why am I being invited to participate in this research?

You have been invited as a potential participant because you are living in a rural area and you are at risk of contracting malaria because you live close to the areas where mosquitoes might transmit malaria.

#### What will happen in this research?

If you choose to participate you are invited to take part in an interview. The interview will be conducted in your home if it is convenient for you or you could provide a place is comfortable for you to do this interview. We prefer to do this interview in the morning. However, you could inform me when the best time for me to interview you. There will be 12 questions exploring your knowledge about malaria and your practices on prevention and controlling malaria in your community. Once the information has been collected it will be analyzed by looking in detail at topics that are mentioned by participants. You can choose to withdraw at any time during this interview taken place.

#### What are the discomforts and risks?

There are no anticipated risks of taking part in this research.

#### How will these discomforts and risks be alleviated?

There is none, the content of the semi-structured interviews contain no topics that are sensitive or embarrassing. However, you will be free to withdraw from the study at any time, without giving a reason. Whilst it may be possible that you may become upset if some of your family members have died from malaria, there are no counselling services available in Timor Leste to which you could be referred. Therefore, you can withdraw from the study, and time will be given for you to compose yourself if you wish to continue.

#### What are the benefits?

The result of the study will be used to increase community involvement in malaria control programs in Timor Leste.

Your perceptions and practices in controlling malaria may help to clarify the needs of increasing community involvement in malaria control programs in Timor Leste and this can help the Ministry of Health and other relevant non-government organizations to provide some specific training for the community to involve them actively in malaria control programs in their community.

#### How will my privacy be protected?

This interview will be audiotaped but your participation will still remain confidential in this study as your name and address will not be recorded in this study. I also would like you to know that your confidentiality will be limited as others, such as a health volunteer or local leader (head of the village or hamlet) may know you because of the small population of your area.

#### What are the costs of participating in this research?

The interview will take approximately 30 to 60 minutes of your time.

#### What opportunity do I have to consider this invitation?

You will have a week to decide whether you would like to participate or not. I would like you to inform me when you are available to be interviewed.

How do I agree to participate in this research?

After you read this information sheet, or having the contents explained to you verbally, then you can let

me know if you wish to participate in this study. Before you begin the interview, I will also give you a

consent form to sign or you can provide me your thumb print on this consent form.

Will I receive feedback on the results of this research?

A final result of this study will be presented back to the community who takes part in this study through a

PowerPoint presentation.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project

Supervisor, Penny Neave: penny.neave@aut.ac.nz

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Dr

Rosemary Godbold, rosemary.godbold@aut.ac.nz, 921 9999 ext 6902.

Whom do I contact for further information about this research?

**Researcher Contact Details:** 

Researcher Contact Details:

Maria Lurdes Gama Soares: lurdezinha05@yahoo.com

**Project Supervisor Contact Details:** 

Penny Neave: penny.neave@aut.ac.nz, 9219999 ext 7407

Approved by the Auckland University of Technology Ethics Committee on the 30th of March 2012

Application number 12/64.

**Project Supervisor Contact Details:** 

Community Health Development Department, School of Public Health and Psychosocial Studies.

AUT University, Private Bag 1142, New Zealand.

Tel: 09921 9999 X7407

Approved by the Auckland University of Technology Ethics Committee on the 26th of April 2012, **AUTEC Reference number 12/64.** 

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#### Appendix D

#### Information sheet for focus group discussion

## **Participant Information Sheet**



#### **Date Information Sheet Produced:**

11<sup>th</sup> of March 2012

#### **Project Title**

Community perceptions and practices in relation to malaria control in Timor Leste.

#### An Invitation

My name is Maria Lurdes Gama Soares and I am a Master's student of Public Health. I am currently studying at Auckland University of Technology, Auckland, New Zealand. I am undertaking research on community health looking at the perceptions and the practices of community members about malaria and what they do to control malaria in their community. I would like to invite you to take part in this research. Your participant is entirely voluntary and you can choose to withdraw at any time during the interview up to when the data will be analyzed.

#### What is the purpose of this research?

The purpose of this study is to explore the community's perceptions and practices in Timor Leste in relation to malaria control. This will also provide some basis for considering ways of increasing community involvement in malaria control in Timor Leste. This research on community health will help prepare me for my Master's thesis. The findings of this study will be presented in professional forums, conferences and written as a journal article.

#### How was I identified and why am I being invited to participate in this research?

You have been invited as a potential participant because you are living in a rural area and you are at risk of contracting malaria because you live close to the areas where mosquitoes might transmit malaria.

#### What will happen in this research?

If you choose to participate you are invited to attend a Focus Group Discussion. This Focus Group Discussion will be conducted at the Community Centre. There are few topics of discussion which will be asked during this discussion. The topics will be around your knowledge and practices in preventing and controlling malaria. Once the information has been collected it will be analyzed, looking in detail at

topics that are mentioned by participants. You can choose to withdraw at any time during this interview taken place.

Once the information has been collected it will be analyzed using thematic analysis. You can choose to withdraw at any time during this discussion taken place.

#### What are the discomforts and risks?

There are no anticipated risks of taking part in this Focus Group Discussion.

#### How will these discomforts and risks be alleviated?

There are no risks for you to participate in this Focus Group Discussion. However, if there is any question asked in the focus group discussion you that you personally do not wish to discuss, you are free to tell the researcher this.

#### What are the benefits?

The result of the study will be used to increase community involvement in malaria control programs in Timor Leste. Your perceptions and practices in controlling malaria may help to clarify the needs of increasing community involvement in malaria control programs in Timor Leste and this can help the Ministry of Health and other relevant non-government organizations to provide some specific training for the community to involve them actively in malaria control programs in their community.

#### How will my privacy be protected?

This interview will be audiotaped but your participation will still remain confidential in this study as your name and address will not be recorded in this study. I also would like you to know that your confidentiality will be limited as others, such as a health volunteer or local leader (head of the village or hamlet) may know you because of the small population of your area.

#### What are the costs of participating in this research?

The Focus Group Discussion will take approximately 45 to 90 minutes.

#### What opportunity do I have to consider this invitation?

You will have a week to decide whether you would like to participate or not. I would like you to inform me when you are available to attend this Focus Group Discussion.

#### How do I agree to participate in this research?

After you read this information sheet, or having the contents explained to you verbally, then you can let me know if you wish to participate in this study. Before you begin the interview, I will also give you a consent form to sign or you can provide me your thumb print on this consent form.

#### Will I receive feedback on the results of this research?

A final result of this study will be presented back to the community who takes part in this study through a PowerPoint presentation.

#### What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Penny Neave: penny.neave@aut.ac.nz

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Dr Rosemary Godbold, *rosemary.godbold@aut.ac.nz*, 921 9999 ext 6902.

#### Whom do I contact for further information about this research?

**Researcher Contact Details:** 

Researcher Contact Details:

Maria Lurdes Gama Soares: lurdezinha05@yahoo.com

Project Supervisor Contact Details:

Penny Neave: penny.neave@aut.ac.nz, 9219999 ext 7407

Approved by the Auckland University of Technology Ethics Committee on 30<sup>th</sup> of March 2012 Application number 12/64.

#### **Project Supervisor Contact Details:**

Community Health Development Department, School of Public Health and Psychosocial Studies.

AUT University, Private Bag 1142, New Zealand.

Tel: 09921 9999 X7407

Approved by the Auckland University of Technology Ethics Committee on the 26th of April 2012, AUTEC Reference number 12/64.

#### Consent form for individual interviews

## Consent form Individual interview



Project title: Community perceptions and practices in relation to malaria control in Timor Leste Project Supervisor: Penny Neave Researcher: Maria Lurdes Gama Soares 0 I have read and understood the information provided about this research project in the Information Sheet dated 11<sup>th</sup> of March 2012. 0 I have had an opportunity to ask questions and to have them answered. 0 I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed. 0 I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way. 0 If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed. 0 I agree to take part in this research. 0 I wish to receive a copy of the report from the research (please tick one): Yes (No ( Participant's signature: Participant's name: Participant's Contact Details (if appropriate): .....

Note: The Participant should retain a copy of this form.

AUTEC Reference number 12/64.

Approved by the Auckland University of Technology Ethics Committee on the 26th of April 201,

#### Consent form for focus group discussion

#### **Consent Form**

#### **Focus Groups Discussion**



Project title: Community perceptions and practices in relation to malaria control in Timor Leste Project Supervisor: Penny Neave Researcher: Maria Lurdes Gama Soares 0 I have read and understood the information provided about this research project in the Information Sheet dated 11<sup>th</sup> of March 2012. 0 I have had an opportunity to ask questions and to have them answered. 0 I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential. I understand that notes will be taken during the focus group and that it will also be audio-taped 0 and transcribed. 0 I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way. 0 If I withdraw, I understand that while it may not be possible to destroy all records of the focus group discussion of which I was part, the relevant information about myself including tapes and transcripts, or parts thereof, will not be used. 0 I agree to take part in this research. 0 I wish to receive a copy of the report from the research (please tick one): Yes (No ( Participant's signature: Participant's name: Participant's Contact Details (if appropriate): .....

Approved by the Auckland University of Technology Ethics Committee on the 26th of April 201, AUTEC Reference number 12/64.

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Note: The Participant should retain a copy of this form.

Date: