

**Malaria Entangled: Ribeirinhos, Plants, Mosquitoes, and Public Health
Interventions in the Brazilian Amazon**

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For Érico and Henrique

[One way] of understand[ing] our evolutionary relationship with microbes [like Plasmodium parasites] comes, of all places, from a classic children's story. It's called the 'Red Queen hypothesis', and it goes like this: as we evolve, so do pathogens; as pathogens evolve, so do we. Medicines like antibiotics and poisons like chlorine give us a temporary protection from these predators. But eventually a microbe evolves that can overcome these measures. Its descendants then put the pressure back on us. Round and round we go. Like the Red Queen Alice meets in Lewis Carroll's *Through the Looking-Glass*, we're running as fast as we can just to stay in one place. (Barnard, 2005, p. 45)

Abstract

This ethnographic study was conducted among the riverine people, also known as Ribeirinhos, in the state of Amazonas, Brazil, during four months of field research. The study focused on learning from Ribeirinhos' experiences and practices of malaria. In this thesis, I argue that paying attention to Ribeirinhos' experiences and diagnostic, treatment, and control practices of malaria can provide useful insights into blind spots in the current interventions to control the disease in Brazil. As this is a thesis by publications, the findings are presented in three manuscripts. The first manuscript focuses on how malaria is experienced by Ribeirinhos. It explores the embodiment of malaria, empirical strategies to distinguish it from other febrile sicknesses, misalignment between bodies and current biomedical diagnosis methods, "becomings" of bodies and experiences, and the vicissitudes of having the disease. The second manuscript examines experiences and treatment practices for vivax malaria highlighting the uses of pharmaceuticals, side effects of antimalarial drugs, and traditional treatments for malaria. The third manuscript describes Ribeirinhos' perceptions of malaria-carrying mosquitoes, their everyday practices to manage these beings, and their experiences with control interventions, such as time monitoring recommendations (TMR), indoor residual spraying (IRS), and insecticide-treated nets (ITN). The three manuscripts clearly show that Ribeirinhos' lives are thoroughly entangled with Amazonian rivers and forests; malaria also takes part in these entanglements. Learning from their experiences and practices of malaria has provided information about the nuances, improvisations, and continuous negotiations required to coexist with the parasite and disease vectors.

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Acronyms

BMPCP - Brazilian Malaria Prevention and Control Program

CECM: Campanha de Erradicação e Controle da Malária

CDC: Centers for Disease Control and Prevention

CEM: Campanha de Erradicação da Malária

CHA: Community Health Agent

DDT: Dichlorodiphenyltrichloroethane

DNERu: Departamento Nacional de Endemias Rurais

EDCA: Endemic Disease Control Agent

FMT: Fundação de Medicina Tropical Dr. Heitor Vieira Dourado

FVS: Fundação de Vigilância em Saúde

FSESP: Fundação Serviço Especial de Saúde Pública

FUNASA: Fundação Nacional de Saúde

FVS: Fundação de Vigilância em Saúde do Estado do Amazonas

GMEP: Global Malaria Eradication Program

INCRA: Instituto Nacional de Colonização e Reforma Agrária

IBGE: Instituto Brasileiro de Geografia e Estatística

IRS: Indoor residual spraying

ITN: Insecticide-treated nets

PAHO: Pan American Health Organization

RBM: Roll Back Malaria

SESP: Serviço Especial de Saúde Pública

SUCAM: Superintendência de Campanhas de Saúde Pública

SUFRAMA: Superintendência da Zona Franca de Manaus

US: United States

WHO: World Health Organization

WWII: World War II

List of words in Portuguese expressed by Ribeirinhos

Agente: endemic disease control agents

Baratinhas: cockroaches

Bicho de sete cabeças: big deal

Bolsa família: conditional cash transfer program provided by the Brazilian government to families living in poverty.

Brechas: gaps

Carapanã: mosquito

Casa da malária: malaria facility

Cartelonas: large plastic blisters

Comidas reimosas: harmful food

Empolado: skin rashes

Exame da malária: malaria diagnosis

Fel: bile

Homem: man

Igarapé: small rivers

Invasão: popular term used to designate illegal occupation lots of land

Lâmina: glass slide used to collect blood and, further to perform microscopic analysis of the blood specimen

Leseira: dizziness

Malária encasquetou com ela: malaria stuck on her

Malária fraca: mild malaria

Malária forte: strong malaria

Mosquiteiros: mosquito nets

Na beira do igarapé: on bank of a river

Novatos: newcomers

O povo: people

Pesquisa: research

Pilora: feel unwell after taking malaria pills with an empty stomach

Pinicada or espinhada: itching

Pinicar muito: itching a lot

Piulas: pills or tablets of medications

Profissionais da saúde: health workers

Provoquei: vomited

Remédio: medicine

Retorno: cure verification slide testing; the act of being tested for malaria right after pharmaceutical treatment ends.

Ribeirinho: people who live on floating houses or in dwellings near to rivers

Roçado: vegetable garden

Tratamento complementar: complementary treatments

Uma doença: an illness, sickness

Uma agonização: agony

Uma injeção: a vaccine

Veneno: insecticide

Virose: viral infections with symptoms similar to a cold or influenza

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Introduction

Despite centuries of malarial occurrences, how those affected live, feel, and interact with the disease in Brazil has received little attention in scientific literature. To address to this gap in knowledge, in this thesis I examine how individuals living in malarious areas of Manaus and Careiro in the state of Amazonas, Brazil relate to malaria in their daily lives. My interest in this area emerged when I was working as a manager in the Health Education and Social Mobilization Department in a public health foundation in Manaus. The position gave me the opportunity to propose health education strategies and policies to control vector-borne diseases, including, malaria, dengue, leishmaniasis, Chagas disease, and other diseases. Among my other duties, I also introduced interventions to encourage people to change their risk behaviours regarding these maladies, and was subsequently told that my expertise in education was a valuable asset to “teach” populations how to prevent diseases. Initially, I did not know how much we could learn from people who live with the illness, and once I realized the potential, I undertook this thesis to take advantage of their valuable knowledge.

My work in the rural Brazilian Amazon began in 2004, and I was immediately surprised by the different ways people learned about and dealt with malaria. My own knowledge of the disease was based on reading biomedical books, and the rural people demonstrated other methods to understand and treat the sickness. Their knowledge was based on lived experiences of dealing with malaria within their homes and communities. In 2009, I made a decision that promoted the research in this thesis; that is, to learn from Ribeirinhos’ experiences and practices of malaria, and shed light on many blind spots in

the current interventions. The thesis focuses on how malaria is part of life for riverine populations in a peri-urban area of Manaus and a rural area of Careiro, namely the Ribeirinhos, a non-indigenous people of Amazonia.

Anthropological literature defines non-indigenous people living in the Brazilian Amazon through two main terms: Caboclo and Ribeirinho. Lima (1999) noted that the term Caboclo was first used by European colonizers to define indigenous populations as *índios* (Indians). Caboclo, as a social category, designates miscigenate race descendants of *índios* and Europeans (Ibid) and, “to a lesser extent, [it denominates] the miscegenation of African slaves from Northeast Brazil who migrated to work in the debt-peonage, patron-client Amazonian rubber economy (*aviamento*) at the turn of the twentieth century” (Minzenberg & Wallace, 2014, p. 99). Revière (1972, p. 29) argued that the term Caboclo, “is highly derogatory and the term carries a definite pejorative sense”. Furthermore, Pace (2006, p. 86; my translation)¹ stated that the Amazonian people do not call themselves Caboclos because to them the term refers to, “a person without social value, who knows nothing, [is] uninformed, [a] descendant of a weakened race...Indian and illiterate”. During the fieldwork, my research participants rarely called themselves Caboclos; rather, they introduced themselves to me as Brazilians, Ribeirinhos, peasants, or “pure” Amazonian individuals born in the state of Amazonas. The latter designation denies any identification of race/ethnicity with Amazonian indigenous populations. Therefore, to move out of the pejorative interpretation of the social category Caboclo, I consider my research participants to be Ribeirinhos.

¹ I translated all references published in Portuguese and quoted herein.

² Communication by email.

³ The Joshua project is a research initiative and evangelical mission that works with ethnic groups around the world, including Ribeirinhos from the Brazilian Amazon.

⁴ *Quilombola* is a complex social category and refers descendants of African slaves who were brought to

In the literature the term Ribeirinho is used to characterize the geographic localization of people who live near to or on the margins of the rivers, *igarapés* (small rivers), lakes and streams that comprise the Brazilian Amazon basin. Furthermore, Ribeirinhos are also defined as *camponeses* (peasants) to refer to their farming activity (Fraxe, 2000), *guardiões da floresta* (forest keepers) to emphasize their cautious use of forest resources (Scherer, 2004), amphibian men (Fraxe, 2000) and water people (Furtado, Leitão, & Mello, 1993), all to describe their intimate relationships with water and land during the periodic overflow or ebb of rivers.

Accounted for in the Brazilian government census as rural populations, and underrepresented in scientific studies (Silva, 2006), Ribeirinhos or Caboclos are defined by Nugent (1993) as an invisible population. The Instituto Brasileiro de Geografia e Estatística do Brasil (IBGE) (Brazilian Institute of Geography and Statistics) told me that so far, the IBGE has not included Ribeirinhos as a distinct population in previous censuses, though, there is a possibility of considering them on the next nationwide census in 2017². The Joshua Project³ estimates that approximately seven million Ribeirinhos live in the Brazilian Amazon (Joshua Project, 2016). Ribeirinhos' socio-political invisibility is reflected in the Brazilian government policies for the Amazon region, which ignore the human groups who inhabit the region. In 2007, the Brazilian government granted Ribeirinhos traditional population status, which gave them the same status as indigenous and *quilombola* populations⁴ (Brasil, 2007).

² Communication by email.

³ The Joshua project is a research initiative and evangelical mission that works with ethnic groups around the world, including Ribeirinhos from the Brazilian Amazon.

⁴ *Quilombola* is a complex social category and refers descendants of African slaves who were brought to Brazil during the colonial period. Antunes et al (2011) observed that in addition to their African ancestry,

The rights of traditional peoples were established on 02/07/2007 by Decree 6.040 (Ibid). The decree established the country's policy for sustainable development of people and traditional communities. In this regard, Bolaños (2014, p. 53) noted that:

This Decree made the existence of traditional communities within the protected areas legal, while the traditional populations, in return, commit to make sustainable use of natural resources. The Decree also provides a definition of traditional people as those groups who recognize themselves as culturally distinct, maintain their own forms of social organizations, and occupy and use territories and natural resources for their cultural, social, religious, and economic reproduction.

In practice, the decree defines Ribeirinhos as traditional people living in protected environmental areas, now called sustainable development areas, who are protected from being displaced and prohibited to sustain themselves with forest resources. A number of studies have reported that the Ribeirinhos' way of life is intertwined with the cycles of nature (Bolaños, 2014; Fraxe, 2000; Furtado et al., 1993; Minzenberg & Wallace, 2014; Scherer, 2004). For example, Scherer (2004, p. 2) noted that, "the phenomenon of flood and receding of rivers broadly regulates everyday life of Ribeirinhos in such a way that working activities like agriculture, fishing, hunting, and vegetal extractivism are aligned to this seasonal cycle". The continuance of the Ribeirinhos' way of life is ensured by oral tradition; that is, the knowledge of how to use

the term also encompasses to the history of African people who rebelled against slavery in Brazil, and those who still fight for their land rights.

natural resources including medicinal plants, religious practices, techniques of building houses, and legends, among other traditions that are passed down to newer generations orally (Fraxe, 2004). In analyzing the oral transmission of knowledge among Ribeirinhos, Lima and Andrade (2010, p. 62) stated that their, “knowledge is mainly built in practice. From a very young age, Ribeirinho men and women emesh their lives, from dawn to dusk, with routines of local activities in which children, youth and adults come together to hunt, fish, plant, harvest, care for their pets [...]”. Ribeirinhos’ lives are thoroughly entangled with Amazonian rivers and forests, and I argue that this is one of many reasons malaria, a disease “typical” of forest areas and rivers, is a part of their lives.

Scherer (2004) observed that Ribeirinhos’ communities are spatially organized in 20 to 30 wooden houses, and I found this in the Panelão community, one of my study locations. My other study location, the Brasileirinho community, is a peri-urban area of Manaus and, where the spatial organization is a mixture of rural and urban surroundings. I selected these two communities as study locations due to their historical incidence of malaria, and the numerous public health interventions that have been conducted there, which I will discuss further.

Everyday life in the Brazilian Amazon, particularly in the Brasileirinho and Panelão communities, includes Ribeirinhos rising as early as 4:30 – 5:00 am to go fishing, garden, gather tropical fruits, hunt, and feed and prepare their children for school. There is consensus in riverine communities that work activities should begin before the heat becomes unbearable. At sunset, generally around 5:00 pm, many Ribeirinhos gather outside their dwellings on verandahs or in backyards to chat with relatives, friends, and acquaintances who come by to visit. In this context, malaria, a disease defined by

biomedical studies foreign to the area, yet known through daily experiences, is a frequent topic of discussions.

Indeed, Ribeirinhos get information about malaria from numerous sources, including their own experiences of malarial infections and those of their friends, relatives, and neighbours with whom they have shared their stories, as well as endemic disease control agents (EDCA) and community health agents (CHA), who routinely visit to check if anyone is ill, and public health educators who occasionally lecture on the topic in their communities. While Ribeirinhos learn clinical and scientific explanations of malaria from EDCA and CHA, they also know malaria intimately as part of their lives. Hence, they have developed their own ways of dealing with its daily manifestations.

I begin this thesis by discussing my notes of participant observation from fieldwork between January and April 2015. My aim here is to establish that Ribeirinhos are knowledgeable people, whose lived experiences of malaria and public health interventions provide a deep understanding of the disease transmission in Brazil. In my study of malaria, I propose a shift from the public health approaches toward people's experiences of malaria, to dig into entanglements among bodies, mosquitoes, pathogens, health technologies, and government disciplinary actions; namely malaria interventions. Proposing to focus on the experiences and practices of malaria is not an assumption that Ribeirinhos' knowledge is better or worse than that of Western biomedicine's experts. That is, I do not intend to provide, "romantic evaluations of one [kind of knowledge] and demonizations of the other" (Harding, 2008, p. 6). My understanding is that multiple ways of knowing about malaria will add to the overall knowledge of its transmission, diagnosis, treatment, and control. Ribeirinhos'

experiential knowledge, for example, provides how malaria is experienced in the lived body (Merleau-Ponty, 2014) based on cohabitation with the disease vector and parasites (thus knowing from inside, as Ingold (2013) argued), while biomedical knowledge addresses malaria from a physiological view-point of the disease (outside perspective).

Recent studies done by the anthropologist Ingold (2000) and the epidemiologist Krieger (2004) explored the interwoven relationships between bodies and their environments. Ingold (Ibid) asserted that humans dwell in the environment in such a way that they reciprocally and dynamically shape one another. In a similar vein, Krieger (Ibid) stated that all aspects of human biology can only be understood in relation to history, such as the colonial roots of malaria and affected people, living conditions, and interactions with their environment and other species. These ideas proposed by the two scholars challenge some of the biomedical assumptions that underlie public health programs, such as malaria control strategies that address the disease from biological and behavioural perspectives.

The ideology of malaria control and elimination programs frames its incidence as a biotechnological problem, rather than a complex issue associated with the living conditions of afflicted populations, which allow precarious interactions among humans, malaria pathogens, and disease vectors (Hausmann-Muela & Eckl, 2015). Though the World Health Organization (WHO) recently placed the patient at the center of malaria interventions, in practice malaria control programs are still tied to vertical health policies aimed at malaria pathogens (in the human host) and malaria-carrying mosquitoes.

Studies examining people's lived experiences of malaria are scarce. Indeed, the majority of qualitative research investigating how populations deal with malaria is done

in African countries, with *Plasmodium falciparum*, the predominant plasmodium species causing malarial infections in that continent, as their prime focus of study (see Agyepong, 1992; Langwick, 2001; Launiala, 2010). Studies analyzing how populations relate to malaria, particularly in Brazil, tend to explore individuals' risk behaviours associated with the disease transmission, and discrepancies between individuals' and public health knowledge through knowledge, attitude, and practice surveys (KAP) (Cardozo-Trujillo, Schall, Martinez-Espinosa, Coura, & Suárez-Mutis, 2012; Reiners, Azevedo, Ricci, & Souza, 2010; Saraiva, 2007; Suarez-Mutis, Coura, Massara, & Schall, 2011). KAP-oriented studies are often used to provide a baseline for the implementation of malaria interventions. Furthermore, some research explores malaria from an anthropological viewpoint; how indigenous populations of Brazilian Amazon perceive and act on malaria (Laplante, 2004), and how the sickness is represented among non-indigenous riverine populations (Nogueira, 2010). There is also a growing body of research regarding the history of malaria interventions in Brazil (see Arruda, 2015; Benchimol & da Silva, 2008; Camargo, 2003; Hochman, 2010; Schweickardt, 2011). Overall, these studies do not provide a thick ethnographic description of Ribeirinhos' lived experiences and practices of malaria.

As many scholars suggest, there is a need for research that goes beyond malaria as a disease that unfolds in the biological body, and examines the other side of malaria interventions, namely afflicted individuals (Hausmann-Muela & Eckl, 2015; Muela Ribera, Hausmann-Muela, Gryseels, & Peeters Grietens, 2016). My thesis addresses this by asking:

How can paying attention to Ribeirinhos' experiences and diagnostic, treatment,

and control practices of malaria provide insight into blind spots of the current interventions to control the disease in Brazil?

The key goal of my dissertation is to investigate how Ribeirinhos living in a peri-urban community of Manaus and a rural community of Careiro, in the state of Amazonas, negotiate universalistic public health interventions and their own experiential knowledge of malaria, and make decisions about interventions/practices they will or will not incorporate into their everyday routines. The specific objectives of my study are:

I. To gain an understanding of how malaria manifests before and after it is diagnosed by health services. Specifically, I intend to learn about Ribeirinhos' diagnostic/discerning practices, including local strategies to differentiate symptoms of malaria from other febrile sicknesses occurring in the Brazilian Amazon, as well as to comprehend dynamics within family and social contexts that emerge when someone becomes ill due to malaria.

II. To examine experiences and treatment practices used to address malarial infections, including both homemade medicines and pharmaceuticals provided by public health services.

III. To investigate strategies used to avoid or control malarial infections when possible, or strategies to live with malaria when it is not.

The organization of this dissertation follows the thesis-by-paper format. In Chapter 1, I present a literature review, which describes clinical, epidemiological, and historical aspects of malaria, paradigms informing malaria programs worldwide and in Brazil, and studies relevant to understanding malaria in the Brazilian Amazon. Chapter 2 discusses the theoretical orientations of the study, from phenomenology to the related

concepts of embodiment, dwelling, and entanglement as methods of taking experiential knowledge into consideration. Chapter 3 defines the methodology applied in my ethnographic fieldwork, and Chapter 4 describes Ribeirinhos' experiential knowledge of malaria. Chapter 5 explores Ribeirinhos' experiences and treatment practices for vivax malaria, and Chapter 6 discusses Ribeirinhos' experiences with *Anopheles* mosquitoes and vector control interventions. The final section of the thesis brings the entanglements addressed in the three papers together, to determine how malaria affects people living with it in the Amazon. I show how paying attention to lived experiences of malaria and its external interventions provides more meaningful and grounded understanding of the disease in this context. The final sections are the bibliography that is referred to throughout the thesis, and the appendices.

The next chapter highlights literature on clinical, epidemiological, historical, social, anthropological, and policy aspects of malaria that are relevant to understanding my study of the disease in the Brazilian Amazon.

Chapter 1

Literature review

Over the past two decades, there has been a marked increase in the number of studies analyzing the biomedical, ecological, historical, anthropological, sociological, and economic aspects of malaria. While the bibliography on malaria is vast, in the Americas little attention has been paid to individuals' experiences and diagnostic, treatment, and preventive practices of the sickness. In this review, I provide a brief description of i) the clinical, epidemiological, and historical aspects of malaria, ii) deadly outbreaks and public health interventions to contain the disease in Brazil, iii) contemporary malaria health care and vector control policies in Brazil, and iv) populations' practices of malaria in African and Latin American countries.

Malaria from a biomedical perspective

Malaria is defined in the biomedical literature as an acute febrile infectious disease whose etiologic agents, namely plasmodium, are transmitted by certain species of Anopheles mosquitoes (Brasil 2010). The most common clinical characterizations of malaria in medical texts include fever, severe anemia, respiratory distress, poor pregnancy outcomes, potential coma, and death (Ibid). The transmission of malaria involves two hosts: humans and female Anopheles mosquitoes (CDC, 2016b). There are more than 400 Anopheles species globally (Cunningham, 2009), and 54 are found in Brazil (Brasil, 2014). Of these, 33 are present in the Brazilian Amazon, with

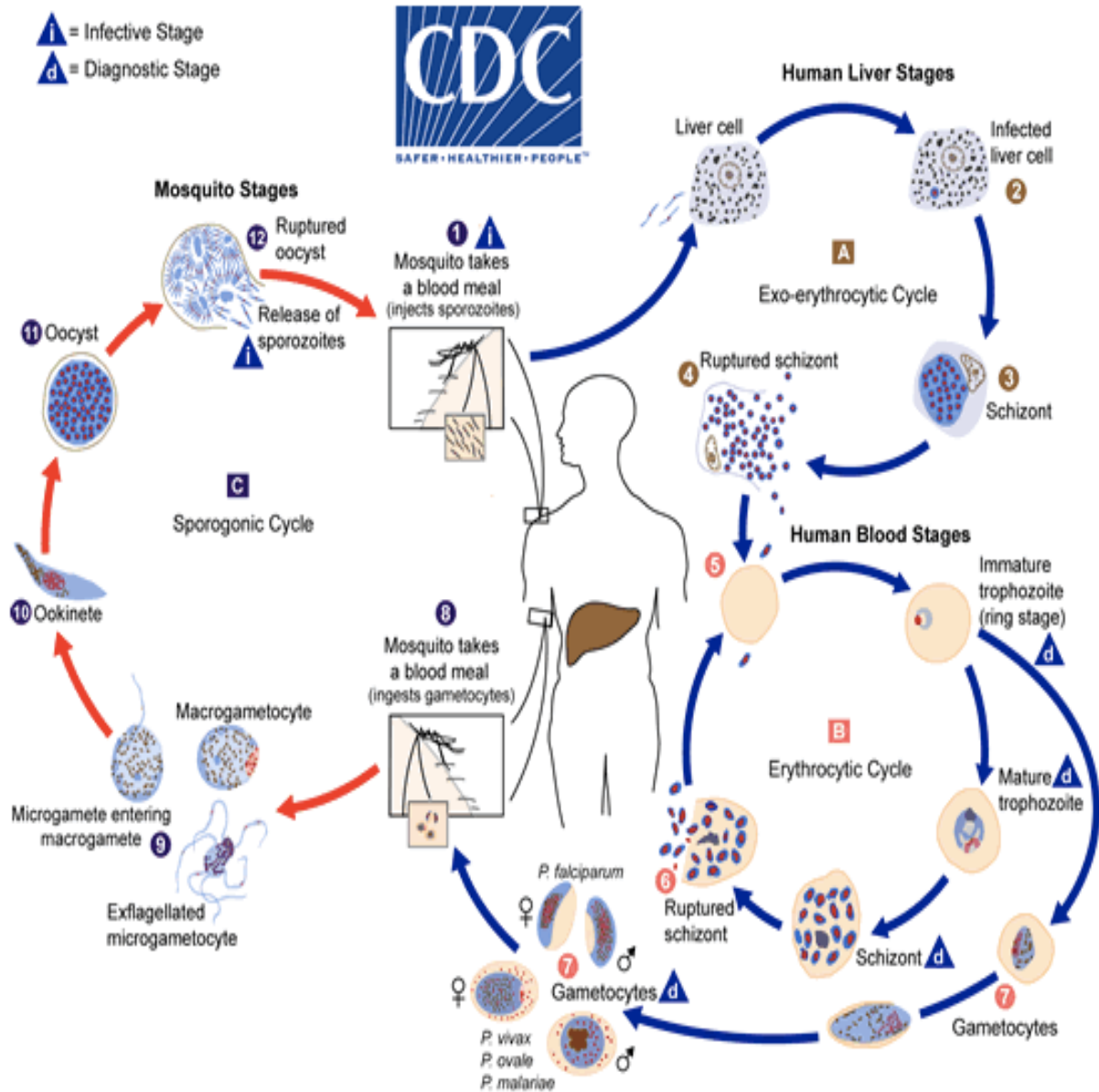


Figure 1.1: Life cycle of plasmodium parasites.

the *Anopheles darlingi* being the main malaria vector there (Tadei & Thatcher, 2000).

Only the female *Anopheles* mosquitoes carry the disease, and the plasmodium that causes it is, “a microscopic parasite that uses the insect to hatch its eggs and inject its offspring into animals [including humans]” (Cunningham, 2009, p. 16). A diagram of the life cycle

of plasmodium parasites, provided by CDC (2016b), is shown in the **Figure 1.1**.

The CDC illustration shows that the cycle of malaria begins when a disease-carrying mosquito feeds on human blood (1). Once in the body, parasite forms known as sporozoites migrate to the liver (2). Once there, they develop into schizonts (3), which eventually rupture and release merozoite (2, 3, 4). This initial replication is called exo-erythrocytic schizogony (A). The next step in the parasite's life, the erythrocytic cycle (B), takes place in the blood. In this cycle, the microorganisms replicate in the erythrocytes. Merozoites, a different form of the parasite, infect red blood cells (5). There, the parasites evolve into trophozoites and mature into schizonts, which rupture and release merozoites (6). Some parasites develop into sexual forms known as gametocytes; which present male (microgametocytes) and female (macrogametocytes) forms (7). Mosquito vectors are infected by gametocytes when they ingest human blood (8). Once in the mosquito the parasites begin another life cycle known as the sporogonic cycle (C), and migrate to the mosquito's stomach, where they match and generate zygotes (9). The zygotes evolve into ookinete forms (10), which invade the stomach wall of the mosquito and develop into oocysts (11). The oocysts then mature, rupture, and release sporozoites, which make their way to the mosquito's saliva glands. The plasmodium life cycle starts with the infective inoculation of malaria vectors, such as when they penetrate a human being (1).

A total of 125 plasmodium species have been reported globally (Hay, Guerra, Tatem, Noor, & Snow, 2004). Five of these can cause malaria in humans: *Plasmodium falciparum*, *Plasmodium vivax*, *Plasmodium malariae*, *Plasmodium ovale*, and *Plasmodium knowlesi* (Brasil, 2014; Singh et al., 2004). Cunningham (2009, p. 16) noted

that to, “grow, these Plasmodia require our liver cells; to feed they need our red blood cells. While humans don’t need the parasites, the parasites need us”. Worldwide, *Plasmodium falciparum* and *Plasmodium vivax* are responsible for most malaria cases. Scholars report that the intensity of malarial symptoms experienced by an individual is determined by the species of plasmodium causing the malarial infection (Val, Monteiro, & Lacerda, 2013).

Official estimates provided by the WHO in December, 2015 reported a global total of 214 million cases of malaria and 438,000 deaths in that year (WHO, 2016b). Though most cases and fatalities were reported in sub-Saharan Africa, the disease also occurs in Asian, Latin American, and Middle Eastern countries (Ibid) (see **Figure1.2**). Epidemiological analysis shows a 35% decrease in malaria cases and a 60% reduction in fatalities worldwide between 2000 and 2015, which means nearly 6.2 million malaria deaths were avoided over that period (Ibid). Malaria transmission is found in 21 countries of the Americas, and according to the latest epidemiological information released by the WHO, there were 390,000 cases of malaria and 79 fatalities in the region in 2014, with an estimated 37% of these cases reported in Brazil. Between 2000 and 2014 malaria incidence in Brazil decreased by more than 75%, though the country accounted for approximately 50% of deaths in the American region (Ibid).

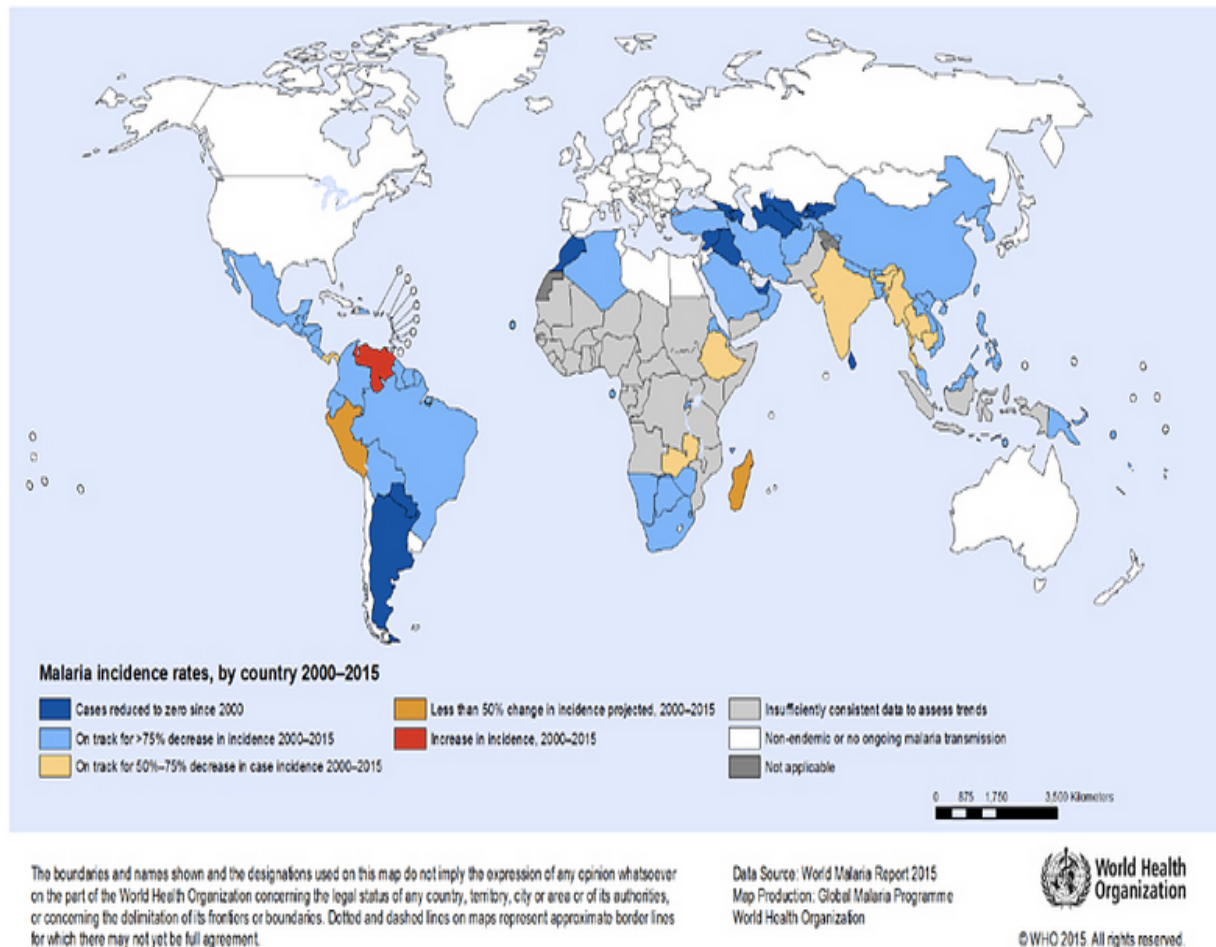


Figure 1.2: Projected changes in malaria incidence rate by country from 2000 to 2015.

In Brazil, 84% of malarial infections are caused by *Plasmodium vivax* and 16% by *Plasmodium falciparum* (Ministério da Saúde, 2015). The legal Amazon region is composed of nine Brazilian states (Acre, Amazonas, Amapá, Pará, Matogrosso, Maranhão, Rondônia, Roraima, and Tocantins) as shown in **Figure 1.3**, and accounts for 99.5% of the overall malaria caseload in the country (Ibid). The CDC (2016a) map of malaria transmission in Brazil shows that eight states of the Brazilian Amazon have consistent malaria transmission, and one, Tocantins, has some affected areas.



Figure 1.3: Areas of malaria transmission in Brazil.

The state of Amazonas, where my fieldwork was conducted, accounted for approximately 57% of the malaria cases of Brazil in 2015 (FVS, 2016). Circa five decades ago, malaria incidence was reported in most Brazilian states. This decrease was due to many influences, including, public health campaigns supported by eradication frameworks, migratory movements, environmental factors, contemporary diagnostic methods, treatments, vector control strategies, and improved living conditions (Hochman, 2009; Marques, 1987; Sampaio et al., 2015).

A brief historical account of malaria

The word malaria (mal'aria) literally means “bad air” in Italian (Rowton, 2009). In the mid-sixteen century, Italians used the word to describe the role of noxious vapor or miasma in so-called marsh fevers (Institute of Medicine, 1991). Lobo (2012) stated that the word “mal'aria” became “malaria” in English approximately 200 years later. Studies have found that malaria is not indigenous to the Americas, and different historical accounts report that falciparum malaria was probably introduced in the western hemisphere through slave trading during the 16th century (Kiple & Ornelas, 1996). Despite the efforts of historians, anthropologists, archaeologists, biologists, and epidemiologists, the emergence of malaria in the New World is still under debate. Based on evidence that American indigenous peoples treated *ague* or periodic fevers (White, 2008) with a potion made of cinchona bark, a number of scholars claim that the disease was already present in the New World (Litsios, 2001).

In 1630, cinchona bark used by Peruvian indigenous populations was associated with curing of a feverous member of the Spanish royal family (Honigsbaum, 2001). In 1632, Spanish missionaries took the plant to Europe, where its commercialization began.

Cinchona became known as Jesuits' bark or *Cinchona officinalis* (Bruce-Chwatt, 1981), and in the 17th century, it was the first compound to treat malaria (Camargo, 2003). The introduction of Jesuits' bark in Europe provided diagnostic differentiation between true marsh fever, cured by the new drug, and other fevers (Bruce-Chwatt, 1981). In 1820, European chemists created quinine, a synthetic form of the plant (Meshnick & Dobson, 2001). Historical accounts highlight that quinine played a key role in imperialist expansion to “pestilential” tropical countries (Greene, Basilico, Kim, & Farmer, 2013).

In the 19th century, the need to, “render the tropical world fit for the white habitation and white investment” (Farley, 2003, p. 4) promoted the professionalization of colonial medicine as a means to protect settlers and, in some cases, ensure the health of local people who worked in plantations and mines under colonial power. Colonial medicine practitioners provided the first epidemiological accounts which, “compared bodies (settlers and local people) and diseases across all continents, and led to widespread use of the term tropical medicine” (Greene et al., 2013, p. 38). Greene et al. remarked that these findings supported assumptions that local individuals were reservoirs of diseases, and reinforced the premise that black bodies were better adapted to living and working in tropical conditions. The slave trade was rationalized by these ideas and subsequently expanded across continents. This meant ships not only carried slaves and riches from the colonies to other countries, but many pathogens as well.

Until the latter half of the 19th century, the miasma theory was widely adopted to explain that the origin of malaria was associated with stagnant marsh waters (Poser & Bruyn, 1999). In 1880, Charles L. A. Laveran, a French physician based in Algeria, proposed that malaria was caused by a protozoan he called *Oscillatoria malariae* (Bruce-

Chwatt, 1981; Councilman & Abbott, 1885), and Laveran also suggested that the transmission of the disease to humans was linked to a vector (Poser & Bruyn, 1999). In 1885, the Italian pathologist Ettore Marchiafava changed the name of Laveran's parasite to plasmodium (Ledermann, 2008). The British physician Patrick Manson, inspired by Laveran's work and his own research on filariasis in China, formulated the hypothesis that malaria was a vector-borne disease transmitted by mosquitoes (Cook, 2007). Manson's malaria-mosquito hypothesis was described in a paper entitled *On the Nature and Significance of the Crescentic and Flagellated Bodies in Malarial Blood*, which was published in the British Medical Journal in 1894 (Rowton, 2009). In the paper, Manson argued that mosquitoes were involved in malaria transmission because parasites developed inside them. However, he was unable to clarify how the parasite and host were implicated in the disease transmission (Ibid).

In 1892, British doctor Ronald Ross, influenced by Laveran and Manson's works, attempted to clarify the pathways by which malaria parasites caused human malaria (Poser & Bruyn, 1999). In 1897, during dissection of a mosquito he had fed with malarial patients' blood, Ross found a form of a malaria parasite in its stomach. At the time, the species of mosquito was unknown (Ibid). Ross' discovery is a milestone in the understanding of malaria transmission, as it, "provided malariologists with a new weapon against this ancient disease" (Cox, 2010, p. 6). The implication of mosquitoes as malaria vectors inspired mosquito avoidance methods, including screens on dwellings to prevent contact, the use of oils, larvivorous fish, and drainage of marshes to exterminate mosquito larvae (Bruce-Chwatt, 1988). One year after Ross' discovery (1893), Italian scientists

Grassi, Bignami, and Bastianelli identified the malaria carrying-mosquito as an *Anopheles* and two plasmodium species (*falciparum* and *vivax*) (Cox, 2010).

Toward the end of the 19th century, Sir Patrick Manson and other physicians created a sub-field of medicine related to diseases of specific latitudes and regions, known as tropical medicine. The goals of the new discipline were to advance knowledge of tropical pathogens and vectors, and diseases such as yellow fever, filariasis, and malaria, to ensure that imperialist expansion would not be hindered by these maladies (Farley, 2003; Löwy, 2006). In 1899, the first school of tropical medicine was founded at the Albert Dock Hospital in London, England (Cook, 2007).

Later, the concept of tropical diseases was questioned by many scholars, including its founding father, Manson (Löwy, 2006). The main issue was that tropical diseases were not restricted to countries with tropical climates; malaria, for example, was also endemic in some European and North American countries (Worboys, 1996). This challenged the belief that tropical diseases were only found in tropical regions. A hypothesis proposed that populations exposed to malaria were, “often bounded more by socioeconomic status than by latitude” (Farmer, 1996, pp. 260–1), and that, “[p]oor countries predominate in the same regions as malaria” (Gallup & Sachs, 2001, p. 85). Furthermore, the term tropical was broadly associated with European racial and cultural prejudice towards populations and regions that had been colonized (Stepan, 1997). All these factors supported the new understanding of malaria as a disease whose transmission is tied to sociological-political-economic and ecological forces, rather than just locations (Farmer, 1996; Malaney, Sielman, & Sachs, 2004; Sachs & Malaney, 2002).

The sociopolitical component of tropical medicine was prevalent until after the 1970's. In recent years, international organizations such as the Liverpool and London Schools of Tropical Medicine, and the Rockefeller Foundation, have played key roles in the definition of high-priority health problems and implementation of vertical and authoritarian health policies to control or eradicate diseases in developing countries (Farley, 2003; Hochman, 2009; Löwy, 2006). While the emergence of tropical medicine is associated with imperialist expansion and its negative impacts related to slavery, imposed acculturation, and economic exploitation, it has also made remarkable contributions to the technical and scientific knowledge of infectious diseases and their control strategies (Farley, 2003; Löwy, 2006). In 1978, imperial medicine policies were finally succeeded by the primary health care approach proposed by the WHO at a conference on primary health care in Alma-Ata (now called Almaty), Kazakhstan (Farley, 2003).

The worldwide implementation of primary health care approach as the main model of attention to health, does not imply that the imperial medicine roots were totally eliminated. Colonial repressive ideology is still ingrained in current public health strategies as some people continue to be considered reservoir of diseases, and individuals are disciplined to incorporate biomedical strategies into their private lives and homes. Continued practices of imperial medicine, as described by Farley (2003), Greene et al (2013), and Löwy (2006), and other scholars, as well as WHO interventions, reflect the history of Brazilian malaria outbreaks, and the national strategies to eradicate and control the disease over the years.

Malaria in Brazil: Deadly outbreaks and public health campaigns to contain the disease

Historical accounts suggest that malaria was brought to Brazil on ships carrying Portuguese colonizers to the country (Freitas, 1988). Jesuits letters dating back to the end of the 16th century refer to occurrences of tertian and quartan fevers⁵ in the new colonies (Barretto, 1967), and in the mid-18th century, fevers regularly affected, and in some cases decimated, entire indigenous villages and Portuguese settlements (Buchillet, 1995). The fevers usually motivated indigenous people, who were turned into slaves by the Portuguese settlers, to escape from the colonies (Ibid). All of Brazil was affected by malaria until the 1960's, with the exception of the southern region⁶ (Camargo, 2003). However, from the late in 1900's to the first half of 20th century, two of the four most deadly malaria outbreaks in the country occurred in the Brazilian Amazon. The two epidemics were linked to commercial enterprises based in the rainforest, including construction of the Madeira-Mamoré railroad to link Guajará-Mirim in the state of Amazonas in the Brazil-Bolivia frontier to Porto Velho, in the Brazilian state of Rondônia, as well as the international commercialization of latex, known as the rubber boom. Both initiatives resulted in significantly increased human migration to previously untapped Amazonian regions in the states of Amazonas, Pará, Acre, and Rondônia (Camargo, 2003).

Brazilian historians Benchimol and da Silva (2008) noted that first attempts to build the Madeira-Mamoré railroad were made in 1872, 1873-4, and 1877. The

⁵ The term 'tertian' is used to describe malaria symptoms that manifested every second day due to infections caused by *P. falciparum*, *P. vivax*, and *P. ovale*, while 'quartan' refers to symptoms that manifest every third day as a result of infections caused by *P. malariae* (CDC, 2015).

⁶This region is not receptive to malaria due to ecological reasons such as low temperatures.

construction was interrupted a number of times due to poor health conditions that lead to sickness and death of construction workers. In 1910, Brazilian physicians Oswaldo Cruz and Belizário Pena were hired by the Madeira-Mamoré Railway Company to evaluate the sanitary conditions in the railway construction plant, and to propose strategies to prevent the spread of the disease among the workers. They left Rio de Janeiro in June, 1910 and reached the construction site in Porto Velho, on July 9 (Carl Lovelace cited in Ferreira (2005, p.233)). They remained in the area for approximately 28 days (Benchimol & da Silva, 2008).

Cruz and Pena found that *falciparum* malaria was involved in many of the various hardships faced by railroad workers, including nutritional diseases, tuberculosis, pneumonia, work accidents, and violence, and, “was the main culprit behind the unhealthy conditions on the Madeira-Mamoré” (Benchimol & da Silva, 2008, p. 745). Cruz (1913) noticed that railroad workers were often hesitant to take quinine due to its bitter taste and side-effects, which included ringing in the ears, tremors, and nausea. To address this, he proposed implementing supervised ‘quininization’⁷ of workers, mandatory use of protective measures such as using mosquito nets and blood tests three times a week, among other measures. Cruz also observed that quinine was becoming less effective against malaria parasites (Ibid), as did Brazilian physician Arthur Neiva in 1907 in Xerém, Rio de Janeiro⁸ (Benchimol & da Silva, 2008). Cruz surmised that the malaria epidemics during the railroad construction were due to emeshed relations among “humans, pathogens and [insect] vectors characteristic of the local flora and fauna”

⁷ Administration of quinine.

⁸ Stepan’s (2003) historical analysis of campaigns against malaria in Brazil points out that Brazilian doctors may be the first scholars to find that *falciparum* parasites were becoming resistant to quinine.

(Cruz, 1913, p. 571). Despite serious health problems afflicting the workers, the railroad was finally completed in five years (from 1907 to 1912). It is estimated that of the 21,817 employees hired by the Madeira-Mamoré Railway Company from 1878 to 1912, roughly 6,208 (~28%) died during its construction (Ferreira, 2005). The high worker mortality rate during the railway construction earned it the nickname “devil’s railway” (Benchimol & da Silva, 2008; Ferreira, 2005).

Similarly, during the first rubber boom (from 1894 to 1912), approximately 300,000 immigrants fleeing severe drought in the Brazilian Northeast region were drawn to the Amazon forest to work in the rubber fields (Garcia, 2005). Economic losses associated with the high number of rubber tappers afflicted with malaria in the Brazilian Amazon raised the concerns of political authorities. Thus, in 1912, the federal government asked the Superintendência de Defesa da Borracha (Superintendent of Rubber Defense) for a plan to contain both mortality of rubber tappers and maintain the rubber extraction industry (Cruz, Chagas, & Peixoto, 1972). Thereby, in 1912 a scientific expedition was conducted to evaluate the medical and sanitary conditions in the Amazon Valley (Ibid). The initiative was coordinated by Brazilian physician Carlos Chagas, and took five months to complete (Ibid). Chagas and a team of physicians visited communities and rubber fields located in the inner areas of the Brazilian Amazon. Lima and Botelho (2013) noted that the physicians cared for patients, conducted microscopic examinations, dispensed medicines, and performed autopsies, among other activities. Moved by the hazardous living conditions of the migrants who came to work in rubber fields, Chagas reported that:

Men who come to the Amazon forest from the healthy northeast Brazilian states bring the vitality of a strong race, and great ambition to achieve economic success through Homeric struggle. However, they very soon regret their ignorance of malaria with the annihilation of their vitality. There is a giant migratory wave of people from the state of Ceará, known as the Cearenses. Though they are a brave people who exemplify the national tenacity, they are quickly decimated by malaria. Those who do not perish, or whose fate has been less cruel, leave the rubber fields with the permanent organic lesions that accompany the disease. (Chagas, 1913, p. 450)⁹

The actual number of fatalities during the first rubber boom is unavailable, because most workers died in the fields and their deaths were not officially recorded (Chagas, 1913). The expedition Chagas coordinated provided the first sanitation map of the Amazon region (Stepan, 2003). In their report, Cruz and Chagas stated that malaria was the major cause of morbidity and mortality in the Brazilian Amazon, and that the disease was associated with low economic development of the region (Cruz, 1913). They also associated the control of malaria with the need to alleviate the poor living and working conditions of Amazonian inhabitants. Cruz and his team proposed interventions to curb malaria, just as the golden age of rubber production in Brazil fell into decline in 1913. Thus, Brazilian rubber plantations were closed, and many rubber tappers, who had been discharged migrated to Manaus and other municipalities. Malaria interventions were

⁹Chagas commented on “the strong race of *Cearenses*”. His commentary depicts the prejudice against indigenous people who were considered unfit to work in rubber fields. I reference him here to illustrate working conditions and struggles newcomers faced when they arrived in the Brazilian Amazon. I do not share his views throughout this work, though it was Chagas who documented the hardships and diseases commonly found at rubber fields and riverine communities in the state of Amazonas, between October 1912 and March 1913.

overshadowed by the economic crisis Brazil faced due to the loss of the international rubber market (Stepan, 2003).

From the end of the 19th century, malaria emerged as pathology of political and public health interest in the state of Amazonas (Albuquerque & Suárez Mutis, 1998). Up to 1913, yellow fever was considered the important infectious disease in the state of Amazonas and other Brazilian regions, because it mostly affected foreign individuals (Dias, 1999). Malaria, however, afflicted the poor populations in the outskirts of Manaus and other regions of the state (Batista, 1946). At the beginning of the 20th century, the theories of miasma and mosquito vectors were the paradigms informing public health interventions in the state of Amazonas. While advocates of the miasma theory recommended boiling drinking water, washing fruits, and vegetables with hot water, and cooking food well (Arruda, 2015), followers of the theory of mosquito vector focused public health interventions on the elimination of mosquitoes (Schweickardt, 2011). In 1903, Brazilian physician Alfredo da Matta, who was the Chief of Sanitary Services in the state of Amazonas, acknowledged that malaria was caused by a mosquito vector as proposed by Ronald Ross, even though he still believed that the disease could also be transmitted by water (Ibid).

At the beginning of 20th century, Batista (1946) noted that there were few health care institutions in the state of Amazonas, and that charitable institutions and the army provided most of health care for sick individuals. Batista also observed that treatment for patients infected with malaria, or *empaludados* as he referred to those with the disease, consisted of hospital care and home visits in Manaus only, and that quinine (oral or intravenous) was the prescribed treatment. Schweickardt's (2011) historical account of

sanitary campaigns in Manaus reported that the state government created the Campanha de Profilaxia Rural (Specific Prophylaxis Campaign) in 1906, to control yellow fever and malaria in the capital of the state of Amazonas. Schweickardt noted that health authorities believed that it was possible to simultaneously extinguish *Stegomyia* and *Anopheles*, the mosquito vectors of these two diseases. These campaigns were based on draining stagnant water and applying kerosene on water surfaces to kill mosquito larvae; in addition, local residents were told to burn home-made pyrethrum cones to repel mosquitoes. In hospitals, those with yellow fever or malaria were usually protected/isolated under mosquito nets to prevent spreading the diseases. Patients with a malarial infection that was confirmed by microscopic analysis were prescribed quinine, as were individuals who shared a dwelling with a malarial patient. Thus, quinine was used to both prevent (prophylaxis) and treat malaria.

In 1918, the Serviço de Quinina Oficial (Official Quinine Service) was launched to provide free medication to afflicted populations, and since then medications to treat malaria in Brazil have been free (Brasil, 1918). In 1921, the Serviço de Profilaxia Rural (Service of Rural Prophylaxis) was established to control malaria exclusively in Manaus and other municipalities of the state of Amazonas (Schweickardt, 2011). Since then, this service has treated rural populations living in malarious areas. The occurrences of malaria epidemics in the Brazilian Amazon fostered the emergence of malaria services in endemic areas.

In the beginning of the 20th century, cases of malaria were registered nationwide (Camargo, 2003). In 1938, an incident caught the attention of national and international malaria experts: an epidemic in two states of the Brazilian Northeast region caused by

Anopheles gambiae. As previously mentioned, *Anopheles darlingi* is the main malaria vector species in Brazil (Deane, 1989), and *Anopheles gambiae* was introduced to the country by ships that periodically travelled from Dakar, Africa to Natal, state of Rio Grande do Norte, Brazil. *Anopheles gambiae* eventually spread from the state of Rio Grande do Norte to the neighbouring state of Ceara, and during the subsequent outbreak the two states faced 100,000 cases of malaria, and registered 14,000 to 20,000 deaths (Manwell, 1968). Deane (1989) noted that when the outbreak began, the United States (US) was preparing to join World War II, and American health authorities were concerned that *Anopheles gambiae* could spread from Brazil to the Panama Canal. Thus, the US government, through the Rockefeller Foundation, established an agreement with the Brazilian government to support the creation of the Serviço de Malária do Nordeste (Northeastern Malaria Service) in 1939 (Marques, 1998a), and provided financial and technical support to Brazilian malariologists (Tauil, Deane, Sabroza, & Ribeiro, 1985). Interventions to exterminate the *Anopheles gambiae* included application of paris green (an arsenic-based larvicide) and indoor spraying of pyrethrum insecticide (Marques, 1998a). Those with malarial infections were treated with quinine and, in some cases, Atebrin (Silveira & Rezende, 2001). In the 1940's, the *Anopheles gambiae* was eradicated from Brazil (Camargo 2003), and the campaign against it provided Brazilian malariologists with the technical expertise to help control malaria epidemics across the country (Ibid). The Serviço de Malária do Nordeste remained in place until 1941 (Fundação Nacional de Saúde, 2016).

During the 1940's, public health authorities' attention was focused on the Brazilian Amazon once again. At the time, malaria epidemics in the region were related

to World War II (WWII), due to the Japanese army taking over rubber fields in Malaysia and Java (Brown, 2005). The invasion compelled the United States (US) to seek latex in other countries in order to supply war and industrial demands, and to support efforts to develop new drugs to treat malaria (Meshnick & Dobson, 2001). The US also wanted latex from Brazil, and to respond to this need the Brazilian federal government dispatched approximately 55,000 Brazilian men to extract latex in the Amazon states from 1941 to 1945 (Martinello, 2004). As these workers were recruited during WWII, they were called *soldados da borracha* (rubber soldiers), and their work was referred to as the *batalha da borracha* (rubber battle) (Ibid). Moraes (1988) observed that roughly 31,000 rubber soldiers died in the Brazilian Amazon, with most fatalities due to malaria, yellow fever, hepatitis, and jaguar attacks (Morales, 2002).

The Serviço Nacional da Malária (National Malaria Service) was established in 1941 (Marques, 1998a), inspired by the success of the *Anopheles gambiae* eradication campaign implemented in the two states in the Brazilian Northeast region. In 1942, an international collaboration between Brazil and the US Institute of Inter-American Affairs resulted in the creation of the Serviço Especial de Saúde Pública (SESP)¹⁰ (Public Health Special Service) (Fundação Nacional de Saúde, 2016). SESP was established to support health interventions and prophylaxis of malaria, focusing primarily on rubber tappers living in the Brazilian Amazon who were hired during WWII (Ibid). At the time the service was launched, malaria impacted six to eight million cases nationwide¹¹; that is,

¹⁰ SESP was a bilateral agency created on July 17, 1942, in the context of World War II. It was subordinate to the Ministry of Education and Health and aimed to implement actions to combat malaria and other endemic diseases in the areas of rubber extraction in the Brazilian Amazon, as well mineral extraction areas (Casa Oswaldo Cruz, n.d.).

¹¹ There is disagreement about the number of cases registered in the 1940s. Hochman (2009), for instance, refers eight million cases of malaria, meaning that roughly 1/7 of Brazilian population was afflicted by

20% of the Brazilian population was affected by the disease annually (Barros-Barreto, 1940). The need for innovative approaches to ‘fight the disease’ led the country to introduce new medicines and insecticides into their control interventions.

Medicines and DDT as technological arsenal to fight malaria

As mentioned, the Japanese invasion prevented the US government from accessing cinchona plantations in Malaysia and Java (Brown, 2005), and this motivated research to develop new medications against the disease. At the end of the 1940’s, the synthetic drug Chloroquine became the main medication used to treat malarial infections. Other synthetic compounds were also developed during WWII, including primaquine, mefloquine, and tafenoquine¹² (Meshnick & Dobson, 2001). In addition to pharmaceutical advancements, WWII also fostered development in the chemical industry, particularly pesticides; most notably dichlorodiphenyltrichloroethane (DDT) (Torres et al., 2009). The effectiveness of DDT against mosquitoes during WWII led the WHO and many malaria experts to predict total eradication of the disease. The WHO defines eradication as, “the permanent reduction to zero of the worldwide incidence of malaria infection caused by human malaria parasites” (WHO, 2016d, para. 1). Debates about the need for socio-economic investment to fight malaria were rendered moot by the perceived possibility to eradicate the disease vector with DDT (Camargo, 2003).

In 1945, the Serviço Nacional da Malária used DDT for the first time in the state of Pará, and other states of the Brazilian Amazon, and two years later it became the

malarial infections in the 1940s. However, the Brazilian Ministry of Health argues that 6 million cases were registered in that decade.

¹² Currently, clinical trials are being conducted to establish the effectiveness of tafenoquine associated with primaquine in the radical cure of vivax malaria relapses (Llanos-Cuentas et al., 2014).

main tool to control malaria in other endemic regions of the country (Hochman, 2009). After five years of intensive DDT use, malaria incidence had fallen by 95% to 97% in most of Brazil's malarious regions, with the exception of the Amazon basin where disease transmission was not reduced (Ibid). In other words, the territorial extension of the Brazilian Amazon, the geographic isolation of its inhabitants (Ribeirinhos and indigenous populations), and poor living conditions, such as dwellings without walls challenged the efficiency of DDT (Ibid).

During this period, it became evident that the standardized vector control interventions recommended by the WHO and other international institutions such as the Rockefeller Foundation, were not compatible with the ecological and population characteristics of the Brazilian Amazon. Thus, in the early 1950's Brazilian scholars proposed a prophylactic approach called Pinotti's method that used chloroquinized salt to control malaria in regions unsuitable for DDT indoor spraying (Hochman, 2010). In short term, it was expected that, daily consumption of medicated salt would eliminate sources of plasmodium infection in human hosts, after which malaria transmission would be interrupted without the need to eliminate its mosquito vector (Ibid). The distribution of the chloroquinized salt began in 1959 in the Brazilian state of Pará, and was implemented in the state of Amazonas the following year (Marques, 1998b). The initial plan was to scale up the medicated salt to prevent malaria in other Brazilian states (Ibid).

Concurrent with the challenges to control malaria in the Brazilian Amazon and the emergence of the chloroquine salt to control the disease in hard-to-reach regions, in the early 1950's the WHO announced that the first cases of DDT resistance in the malaria vectors had been reported in other countries (Tauil, 2003). Thus, in 1955 the WHO

created the Global Malaria Eradication Program (GMEP) (Nájera, González-Silva, & Alonso, 2011). The eradication programs were intended to interrupt transmission of the disease by primarily exterminating malaria vectors through the use of DDT and other insecticides (Meshnick & Dobson, 2001). However, public health authorities, politicians, and donors overestimated the effectiveness of DDT, and the, “destruction of mosquito breeding marshes, prevention of mosquito bites, and other measures traditionally used in malaria control were abandoned, depicted not only as unnecessary but as antagonistic to the higher goal of eradication” (Nájera et al., 2011, p. 3). Moreover, metaphoric terms inspired in army operations began to define malaria interventions, such as referring to DDT as the weapon to fight the enemy of malaria (Brown, 2005).

Hochman (2009) noted that when the WHO launched its initiative to globally eradicate malaria the disease was no longer considered a health threat in Brazil, thus Brazilian malariologists saw no epidemiological need to convert their national strategy to reflect the global eradication program. In 1956, 70% of Brazilians lived in rural areas where they were vulnerable to tuberculosis, leprosy, Chagas disease, cholera, yaws, trachoma, schistosomiasis, goiters, and other ailments. These diseases were considered threats to the socioeconomic development of the country, because ill individuals could not enter the job market. In 1956, the Departamento Nacional de Endemias Rurais (DNERu) (National Department for Rural Endemic Diseases) was established to combat these diseases, and it replaced the previous National Malaria Service. Hochman also remarked that this new organization of health services in Brazil, which brought malaria and other rural endemic diseases together under a single department, was not in line with the WHO recommendations that required malarious countries to establish specific

agencies and foundations to eradicate malaria.

In 1957, the economic crisis and difficulties finding international financing for development projects in Brazil, forced the government to align its recently launched health program to the international health agenda (Hochman, 2009). At that time, the US health cooperation policy was restricted to providing financial aid to countries willing to convert malaria control programs into eradication campaigns (Cueto, 2008). In 1958, Brazil created the Campanha de Erradicação e Controle da Malária (CECM) (Malaria eradication and control campaign) in liaison with the National Department for Rural Endemic Diseases (Marques, 1998a). The initial task of the eradication campaign was to create a technical work group to plan the Brazilian eradication strategies. Rather than reacting to epidemiological emergencies, the national economic crisis motivated Brazil to bring malaria eradication to the top of its political agenda (Hochman, 2009), and the need to address the disease became the prime healthcare mission. Also in 1958, the Brazilian government signed an agreement with the Pan American Sanitary bureau (now known as the Pan American Health Organization (PAHO)) which committed the organization to provide Brazil with technical assistance, training, and antimalarial medications (Marques, 1998a). The malaria eradication and control campaign was launched in Brazil in 1959 (Hochman, 2010). It was intended to function for five to seven years, based on the scale-up of available tools, such as DDT, medicines, and chloroquinized salt (Hochman, 2010; Taail et al., 1985). Similar eradication programs were also implemented in Colombia, Tanzania, Malaysia, and Indonesia (Spielman, 2006).

In 1960, the US cancelled their financial support for SESP (Griffing, Taail, Udhayakumar, & Silva-Flannery, 2015), and as a result SESP became the Fundação

Serviço Especial de Saúde Pública (FSESP) (Public Health Special Service Foundation), which was integrated with the newly created ministry of health (Fundação Nacional de Saúde, 2016). In 1961, the chloroquinized salt was phased out in Brazil due to the emergence of chloroquine resistance *falciparum* parasites (Marques, 1998a). In addition, the salt was very unpopular in local people due its taste, as well as the high humidity of Brazilian Amazon regions compromised its storage, pregnant women and children could not take it, and among other factors (Hochman, 2010). Hochman (Ibid, see pages 177-8) remarked that while the medicated salt was a Brazilian innovation to counteract a health issue in the country, the intervention had similar characteristics to the ‘magic-bullet’, namely DDT; that is, it was a solution imposed on people that was not tailored to their reality. Furthermore, some scholars argued that chloroquine resistant *falciparum* parasites originated in South America, Africa, and Asia due to overuse of chloroquinized salt (Spielman, 2006; Zalis, 2000).

The outcomes of the eradication campaign were celebrated in Brazil in 1961, when malaria incidence in the country decreased dramatically to 36,900 cases (Tauil, 2003). In 1965, the Brazilian government embraced the global eradication campaign introduced by the WHO, and replaced the CECM with the Campanha de Erradicação da Malaria (CEM) (Malaria Eradication Campaign) (Marques, 1998a). CEM was dissociated from the National Department for Rural Endemic Diseases, and became an autonomous organization in charge of exterminating malaria vectors and treating the sick (Griffing et al., 2015). During the 1960’s, another epidemiological change was taking shape: malaria was clustering in the states of the Brazilian Amazon, where it remains entrenched to the present day.

Malaria epidemics: A collateral effect of government policies to foster economic growth of the states of the Brazilian Amazon

In the mid 1960's, the Brazilian government implemented policies to develop the Brazilian Amazon region, starting with agricultural settlement programs intended to foster economic growth in the region. The programs subsidized the distribution of parcels of land to families. In addition, the government sponsored many construction projects, including the Trans-Amazonian Highway, hydro-power plants, and mining companies. These initiatives attracted thousands from south, southeast, and northeast Brazil to the untapped lands of the rainforest (Smith, 1982). The Instituto Nacional de Colonização e Reforma Agrária (INCRA), a government agency responsible for distributing land to migrant families, was unable to accommodate the huge uncontrolled influx of settlers and job seekers who arrived daily in the newly-created agricultural settlements. Smith (Ibid) noted that settlers were housed in wooden huts and large tents at various locations along the highways, where they lived for months in conditions that exposed them to malaria and other diseases. The huts and tents did not have walls, thus DDT was not used in these areas.

In 1967, the Zona Franca de Manaus (Manaus Free Trade Zone) and its accompanying industrial district were established in Manaus (ZFM, 2016), and they attracted several international electronic and motorcycle manufacturers. Marques and Pinheiro (1998, see pages 249-51) noted that this initiative created 40,000 jobs, and the majority of workers were recruited in Manaus and other municipalities of the state of Amazonas. Thus, there was a rural to urban shift, which increased the population of Manaus by 63% due to the new jobs in the industrial district during the 1980's; that is,

the population grew from 312,000 inhabitants to 634,000.

The newcomers who settled in Manaus did not received housing benefits from the Brazilian government, so they used the forest areas located in the suburbs of Manaus to build their dwellings. This is when the process of peripheralization¹³ of Manaus intensified, as the destruction of forest areas fostered by ineffective government housing policies led to outbreaks of malaria in Manaus. Indeed, government enterprises in Brazil caused increased incidence of malaria in the country overall, from 52,000 in 1970 to 578,000 in 1989 (Marques & Gutierrez, 1994). The massive influx of people into the Brazilian Amazon, a lack of housing policies, and environmental degradation are some of the many factors that drove the increase of malaria transmission into the area. Malaria outbreaks in Manaus, with similar socio-economic and ecological root causes, continue today.

Post-eradication era: Eradication mindset versus the need of innovative interventions on malaria

In 1969, the failure of the eradication campaigns to prevent the spread of malaria epidemics supported the argument that the disease could not be eradicated with ‘magic-bullets’, namely insecticides and antimalarial drugs. A number of scholars criticized the reductionist approach underlying the global eradication campaigns. American microbiologist Dubos (1964, p. 377), for example, noted that:

Malaria is not a single disease, but a huge congeries of diseases, occupying a

¹³ I use this term to draw attention to the emergence of poor neighbourhoods in Manaus. Kühn (2015) debated the concept of peripheralization through a sociological lens, and determined that the meaning of the term goes beyond geographic location and includes unequal power relations.

large number of ecological provinces each with its particular conditions. The multiplicity of problems comprised under the single word malaria makes it therefore hazardous to conclude that a given procedure that has been effective in a particular area will necessarily prove effective in another where the climate, the topography, the plant and animal populations are different, to say nothing of the habits of the human populations [...]. In all cases also the problems posed by the biological and epidemiological peculiarities of each type of infection are still further complicated by financial, administrative, and political uncertainties.

Dubos (Ibid) observed that the main errors of the global eradication campaign was disregarding the critical role of the ecological, political, financial, and bureaucratic factors associating with implementing universal health policies across countries, states, and municipalities. These challenges led the WHO to cancel its efforts to eradicate malaria in the short term, and instead, it recommended a policy based on both continuous surveillance and control of the disease (Cueto, 2013). National malaria programs worldwide were reframed to control the disease, and though entomological interventions continued to be the main strategy of the programs, the mosquito vector remained the main target and eradication as the ultimate goal to be achieved (Nájera et al., 2011).

In 1970, Marques (1998a) reported that the Brazilian malaria eradication campaign was reviewed and, based on geographic, epidemiological, and socioeconomic factors, states outside the Amazon area were classified as short-term eradication areas, while the states of the Amazon region were considered long-term eradication regions.

The Superintendência de Campanhas de Saúde Pública¹⁴ (SUCAM) (Superintendence of Public Health Campaigns) was established in 1970, and served as the umbrella organization from the Brazilian Malaria Eradication Campaign, the Smallpox Eradication Campaign, and the National Department for Rural Endemic Diseases (Ibid).

From 1970 to 1989, public health authorities have proposed several malaria interventions in Brazil, and three of these received the most attention in the literature: Estratificação Epidemiológica (Epidemiological Stratification Program), Operação Impacto (Impact Intervention), and Projeto de Controle da Malária na Bacia Amazônica (the Amazon Basin Malaria Control Project). Loiola, Silva, and Tauil (2002) noted that, though the Epidemiological Stratification Program began in 1980, it was financially and technically unable to support the geographic dispersion of malarial afflicted people. Thus, in 1986 SUCAM launched the Impact Intervention, which had the same strategy as the previous program, but also complemented traditional antimalarial interventions with collective treatment¹⁵ of Amazon residents with chloroquine, primaquine, pyrimethamine (Daraprim®), sulphadoxine, and mefloquine (Ibid). However, this intervention did not meet its objectives, and was strongly criticized due to overuse of mefloquine. Cueto (2013) reported that during in the 1980's, mefloquine was a new synthetic drug analogue of quinine, developed to counteract chloroquine-resistant falciparum plasmodium.

Epidemiological stratification program and impact intervention were ultimately

¹⁴ SUCAM was created to supervise, coordinate, and conduct endemic disease eradication and control campaigns throughout the Brazilian territory. It was also responsible for epidemiological investigations, technical support for federal, state, and municipal institutions, public health agreements, sanitation works related to endemic disease control, professional training, information health systems, and other duties (Marques, 1998a).

¹⁵ Loiola, Silva, and Tauil (2002) explained that collective treatment was performed to reduce malaria transmission in high incidence zones where vector control actions had failed. It was implemented in three phases: 1) febrile and non-febrile individuals living in the same house were treated for malaria, 2) only febrile persons received malaria medications, and 3) only individuals with malarial infections confirmed by microscopic analysis of thick blood smears received treatment.

replaced by the Amazon Basin malaria control project (from 1989 to 1993), which was co-funded by the World Bank and the Brazilian government (Akavan, 1997). It was claimed that this intervention had prevented 1.9 million new cases of malaria and 236,000 deaths, as well as averted 8.8 million disability adjusted life years lost (DALYs) due to malaria (The World Bank Group, 1997). Even with these positive outcomes, however, the Amazon Basin malaria control project was still inspired by the eradication framework (Loiola et al., 2002), and was primarily used to prevent the disease through the indoor-spraying of insecticides¹⁶. Until then, the Brazilian malaria control strategy has established itself as a health service separate from the national health care system.

Cueto (2013) noted that until the middle of 1990's low priority was given to malaria programs worldwide, and this decreased research on new drugs in Western countries. Though treatment for falciparum malaria was challenged by chloroquine and mefloquine resistant parasites at the time, Cueto also reported that new hope had emerged with the introduction of artemisinin-based therapy, a new drug developed by the Chinese pharmaceutical chemist Youyou Tu and her research team¹⁷ (Tu, 2011). In 2001, the WHO endorsed the use of artemisinin as a first line medication to treat non-complicated falciparum malaria (WHO, 2006), but a few years later, it proved to be ineffective as single-drug therapy due to parasite resistance. Since 2006, falciparum malaria has been treated with artemisinin combination therapies (White, 2008). However, artemisinin-resistant parasites have been reported in five countries since 2015: Cambodia, the Lao People's Democratic Republic, Myanmar, Thailand and Vietnam (WHO, 2015a).

Artemisinin combination therapies are still the recommended treatment regimen for

¹⁶ DDT, for instance, was phased out in Brazil in 1997 only (Torres et al., 2009).

¹⁷ Youyou Tu's role in the isolation of the artemisinin molecule from the plant *qinghaosu* (*Artemisia annua*) in 1972 earned her the Nobel Prize in Medicine in 2015 (Su & Miller, 2015).

falciparum malaria (WHO, 2016a).

Contemporary malaria control policies and the Brazilian malaria prevention and control program

Changes in the paradigm of malaria control programs and their vertical organization were instituted after the 1992 Amsterdam meeting of the WHO, where for the first time, the organization stated that malaria is a multilayered issue, and reversed its priorities from vector control strategies to early diagnosis and adequate treatment of the sick, also known as patient-centered approach (WHO, 1993). In addition, it emphasized the importance of decentralizing the coordination of national malaria control programs down to the states, and the municipalities in malarious regions. It considered inter-sectorial actions and community participation essential components of malaria control programs. In Brazil, this intervention was called Programa Integrado de Controle da Malária (Integrate Malaria Control Program) (Loiola et al., 2002).

When the WHO proposed the patient-centered approach as the foundational paradigm of malaria programs, in Brazil malaria control programs were already being redefined at the federal, state, and municipal levels, due to the Sistema Único de Saúde (Universal Health Care Policy) which was implemented in the country in 1988 (Faleiros, Silva, Vasconcellos, & Silveira, 2006). In 1991, the Fundação Nacional de Saúde (FUNASA) (National Health Foundation) was created to implement the new structure of health services. The CEM and FSESP were integrated with FUNASA, which had public health governance similar to SUCAM (Fundação Nacional de Saúde, 2016). As well, the diagnosis and treatment of malarial infections were integrated in the Programa Saúde da Família (Family Health Program) which was the primary health care strategy in Brazil

(Tauil, 2003), and remains so to the present day. In the years following the WHO call to malarious countries to restructure their malaria control programs to a patient-centered approach, Brazil accounted for the 40% of malaria cases in the Americas in 1999 and the incidence was increasing (Ibid). Loiola et al (2002) pointed out that in the same year, the PAHO and the Roll Back Malaria Partnership (RBM)¹⁸ of the WHO organized a meeting in Lima, Peru to discuss the situation of malaria in the Americas, and all the countries in the Amazon region participated. It was there that the Brazilian government launched the Programa de Intensificação das Ações de Controle da Malária (Program for the Intensification of Malaria Control), which aimed to reduce malaria cases to half of those reported in 1999 by 2001, and half the fatality rate by 2002. The program targeted the nine states of the Brazilian Amazon, and Loiola et al (Ibid) reported that the incidence of malaria reduced from the 630,985 cases in 1999 to 383,654 in 2001; a 39% of caseload reduction. Loiola et al, however, did not report the fatality rate reduction associated with the implementation of the Program for the Intensification of Malaria Control.

Following the changes in the health care structure of the country, in 2003 the Brazilian Malaria Prevention and Control Program (BMPCP) was created. Prior to this, malaria interventions had been conducted through sporadic public health campaigns and planos emergenciais (contingency plans), under the coordination of FUNASA, state and municipal health secretariats (Brasil, 2002). The main goals of BMPCP are to: i) reduce the mortality and severity of malaria cases, ii) decrease the disease incidence, iii) eliminate its transmission in urban areas, and iv) maintain the absence of the disease in

¹⁸ RBM, “is the global platform for coordinated action against malaria [...]. The Partnership is comprised of more than 500 partners, including malaria endemic countries, their bilateral and multilateral development partners, the private sector, nongovernmental and community-based organizations, foundations, and research and academic institutions” (RBM, 2016, para. 1).

areas where transmission had been interrupted (Brasil, 2003). The BMPCP is aligned with the WHO policies, which recommend three key interventions to control this disease: early diagnosis and treatment with effective drugs, distribution of insecticide-treated nets (ITN), and indoor residual spraying (IRS) (Ibid).

The BMPCP also concentrates efforts to raise awareness of the importance of early diagnosis, treatment, and adherence to control strategies to those individuals living in malarious areas (Brasil, 2003). As mentioned in the introduction of this thesis, health education interventions were my field of expertise, and I participated in BMPCP implementation in the state of Amazonas. Based on my personal experience, I believe a key weakness in health education programs is assuming that people have no knowledge of diseases. Furthermore, health education interventions are still tied to an education strategy with health educators teaching targeted population how they must control malaria in their homes and communities by seeking diagnosis, adhering to IRS and ITN, and avoiding exposure to malaria-carrying mosquitoes. Nading (2014) described similar health education campaigns in Nicaragua, where the community health agents who conducted dengue interventions instructed the local people to both govern their individual lives and manage their dwellings to control the disease. Indeed, with educational campaigns aimed at malaria and dengue, it is assumed that providing proper information will translate into the healthy behaviours.

From 2003 to 2005 the incidence of malaria in the Brazilian Amazon increased again, due to socio-economic and environmental factors that were not previously addressed, including migratory movement, new agricultural settlements, unofficial settlements (land invasions), and deforestation from logging (Oliveira-Ferreira et al.,

2010). To counteract the spread of malaria outbreaks, the Brazilian Minister of Health broadened inter-institutional partnerships, and with multi-sector mobilization the incidence of malaria began to decline in 2006 (Ibid). In 2007, the Bill and Melinda Gates Foundation repeated the call for complete eradication of malaria worldwide, which raised debate about the feasibility and impact of malaria eradication today (Das Pam, 2010; Liu, Modrek, Gosling, & Feachem, 2013). The abandonment of control measures and reductions in financial and scientific resources for malaria programs during the global eradication campaign, are clearly remembered by scholars and policy makers who have witnessed and predicted the failure of this program. The WHO endorsed the eradication effort, stating that while malaria elimination, which the WHO defines as, “the interruption of local mosquito-borne malaria transmission” (WHO, 2016d, para. 1) is the primary objective, malaria eradication is the ultimate goal. Currently, global malaria programs are moving toward the elimination agenda, focusing on the progressive interruption of malaria transmission in endemic areas (Feachem et al., 2010).

In 2010, BMPCP received support from the Global Fund to fight AIDS, tuberculosis, and malaria¹⁹. In Brazil, this funding lasted from 2010 to 2012, and supplemented the national financial resources allotted to malaria interventions (Sampaio et al., 2015). The Global Fund investments supported and broadened number of programs, including training local professionals in the diagnosis and treatment of malaria and epidemiology, massive distribution of ITN, the diagnosis and treatment of sick individuals, and biomedical research (Ibid). In other words, identification of ill

¹⁹ The Global Fund was established in 2002. It is a partnership among governments, civil society, private sectors and people affected by Aids, tuberculosis, and malaria; it invests roughly US\$4 billion a year to health programs in countries where these diseases are a health issue (Global Fund, 2016). It is through partnerships like RBM and Global Fund that global health policies to control malaria reach countries and remotes areas where the disease is endemic.

individuals, treatment, epidemiological surveillance, and vector control strategies all benefited from this partnership. From 2010 to 2014, the incidence of malaria in Brazil fell approximately 60%; that is, 333.528 malaria cases were reported in 2010, compared to 139.289 in 2014 (Ministério da Saúde, 2015). In November 2015, BMPCP announced the Plan for the Elimination of Malaria in Brazil, which primarily focuses on the reduction of infections caused by *Plasmodium falciparum* in the country (Roll Back Malaria Initiative, 2015).

Vaccine development

The development of vaccines to prevent malaria has long been a top priority of research investment, particularly after the renewed appeal to eradicate malaria. However, developing a vaccine to protect humans from infections caused by parasites is far more complex than that required for virus and bacteria (Hoffman, Vekemans, Richie, & Duffy, 2015). This complexity is associated with the life cycles that parasites, such as those that cause malaria, go through. Though, five plasmodium species that cause human malaria have been identified (CDC, 2016b), most vaccine development has concentrated on infections caused by *Plasmodium falciparum*, which target liver stage development of this parasites in the human host. Hence, vaccines currently under trial are classified as pre-erythrocytic and erythrocytic vaccines, and transmission blocking vaccines (i.e. those aimed to prevent infection of malaria vectors) (Moreno & Joyner, 2015). According to the latest WHO report on vaccine development, “more than 20 vaccine constructs are currently being evaluated in clinical trials or are in advanced preclinical development” (WHO, 2016c, para. 1). In 2015, there were only two *Plasmodium vivax* vaccine candidates in advanced stages of clinical trails, and the results of these studies are not yet

available (Hoffman et al., 2015). However, after thirty years of research, one *Plasmodium falciparum* vaccine was licensed in 2015: RTS,S/AS01, commercially known as *Mosquirix* (Plebanski & Flanagan, 2017). Its performance has been evaluated and, current recommendations suggest that the vaccine could potentially be used in combination with other malaria control strategies, such as diagnosis, treatment, and vector control interventions (WHO, 2016c).

Populations' practices of malaria in African and Latin American countries

In this section I examine studies about peoples' experiences and practices of malaria, though, the majority of research in this area has concentrated on traditional care practices in African countries. Some of these studies considered the occurrences of *asra* (Agyepong, 1992), *degedege* (Langwick, 2001), and *sumaya* (Dugas, Dube, & Bibeau, 2009). Each one of these terms implies different systems of caring for sick individuals that is based on traditional medicine practices, rather than the Western approaches.

Early in 20th century, the Brazilian government hired physicians to provide health care to individuals working in development enterprises, which provided the first descriptions of how people typically managed fever. Cruz, Chagas, and Peixoto (1972) noted that from 1910 to 1912 in Manaus and rural regions of the state of Amazonas, people treated malarial infections with oral or other solutions made with a low concentrations of quinine, or no quinine at all. These medications were sold by peddlers, who travelled to the remote regions of the Amazon forest (Ibid). Coffee, brandy (cachaça), purgatives, suppositories, and other home treatments, were also used by the local people to relieve malarial malaise (Caser & Sá, 2011; Schweickardt, 2011; Schweickardt & Lima, 2010; Vital & Hochman, 2013).

Fraxe (2004) documented the Caboclo-Ribeirinho culture in one municipality in the State of Amazonas. Fraxe argued that the presence of a community health agent in the community provoked paradigm changes in the understanding of malaria etiology and treatment. Consequently, local beliefs that malaria is transmitted by water, and traditional treatments that can be used to recover from the sickness, were gradually replaced by biomedical knowledge and interventions. Nogueira (2010) reported similar findings highlighting Ribeirinhos' preference for malaria medications provided by BMPCP, and their perception of not being fully recovered when conventional treatment ended. The Fraxe and Nogueira's studies point out that people's understandings and practices of malaria were mostly displaced by biomedical interventions. However, I do not characterize Ribeirinhos' experiences and practices of malaria in the same way as these two scholars. Rather, I argue that Ribeirinhos rely on multiple resources to treat malaria, and in the Brazilian Amazon, public health interventions coexist with alternative practices of care.

Buchillet (1995) showed that the Desana ethnic group, who lives in the Brazilian Amazon, associated malaria transmission with shamanistic practices, poisoning or envy. According to the author, the Desanas have incorporated public health interventions into their communities, combining them with spells, songs, and rituals to heal malaria. Desanas' understanding of diseases incorporates elements of society and the cosmic world; consequently, diseases are explained through myths and usually attributed to superhuman origins (Ibid). As a result, biomedical knowledge is considered only one way of knowing about diseases.

I also examined two studies that were conducted in other Latin American

countries. Lipowsky, Kroeger, and Vasquez (1992) investigated the sociomedical aspects of malaria in Colombia, and their findings indicated that people believed malaria causes an inflammation of the spleen. This led to the systematization of care practices, including food restrictions based on the hot/cold paradigm, and prayer performed by spleen-prayers (*rezaderas del baço*). The other study was conducted by Muela Ribera et al. (2016), and investigated how social and cultural aspects influence Peruvian populations' adherence to malaria treatment. These scholars found that malaria symptoms and the adverse reactions to antimalarial drugs are explained by the hot/cold paradigm, also known as humoral theory. Based on this paradigm local individuals developed their own practices to restore body balance, and in some cases, these led to treatment interruption. The studies by Lipowsky, Kroeger, and Vasquez and Muela Ribera et al. provide evidence of plural ways people understand and treat malaria in the Amazon region.

Based on the research reviewed here, I believe that the experiences and practices of malaria by people in the Brazilian Amazon are still open to further investigation.

Conclusion:

In this literature review, I provided a genealogy of malaria and its foremost interventions. The examination of several studies that evaluated the clinical, epidemiological, historical, ecological, and policy aspects of malaria, demonstrated that technological tools, such as medicines, insecticides, and ITN have been the building blocks of malaria programs in Brazil for over a century. And yet, people remain passive recipients of these interventions. Equally important, the resistance of malaria-carrying mosquitoes and disease pathogens to malaria interventions indicate that while the social and environmental conditions that sustain disease transmission were not addressed,

outbreaks of malaria remain a risk. I also analyzed studies that examined people's practices of malaria and showed, for example, that some scholars considered that in the Brazilian Amazon traditional health care practices employed for the treatment of malaria were gradually replaced by biomedical interventions. In the next section I discuss the theoretical approach that guided my study of malaria.

Chapter 2

Theoretical orientations

As discussed in the previous chapter, prevalent knowledge of malaria is grounded in a biomedical framework defined through its pathological agents, vectors, and physiological manifestations in the body. In fact, primacy is given to its causes and somatic effects, rather than to entanglements among pathogens, the disease vector, humans, environment, and public health interventions to control the disease. I suggest that this biomedical framework is in line with the naturalist ontology, which dates back to the 16th century. The reasoning underlying such ontology rests upon the dichotomy between nature (in this case, bodies, parasites, mosquitoes, and environment) and culture (knowledge, attitudes, and practices). Specifically, the naturalist ontology “preserve[s] a space for ‘really natural’ nature which is unaffected by the diverse constructions that the human mind might place upon it” (Ingold, 2000, p. 107).

To bring this into perspective, Descola (2013), for instance, differentiates naturalism within animism, totemism, and analogism. Without entering into this debate in depth, it is relevant to mention that the nature-culture ontological divide is not shared by all people, nor is it pertinent when dealing with life experiences. Further, in the Amazonian context, for example, life is not lived according to the naturalist separation between nature and culture. In fact, there is greater prevalence of animism (Ibid) or what some prefer to call perspectivism in Amazonia (see Viveiros De Castro, 1998). Descola, for instance, describes that animism as based on an understanding that human and nonhuman beings have the same interiority (soul and subjective), but different

physicalities. Specifically, for Amazonian indigenous peoples, plants and animals are ‘humanized’ and therefore, they have a ‘soul’ like that of humans (see Descola, 2013, pp. 129–138).

Recently, Kohn (2007; 2013) demonstrated that certain Amazonian populations embrace trans-species relationships in which humans and nonhumans share human subjectivities. These perspectives of living in and relating to the world show that, “the world is not to be seen as the exclusive playground of humans but as a vast array of meaningful differences between qualities and beings that can be systematically organized, not in spite of, but because of these differences” (Descola, 2013, p. 268). Throughout this theoretical framework, I build on the following approaches to study Ribeirinhos’ experiences and practices of malaria: existential phenomenology introduced by Merleau-Ponty, Csordas, and Krieger’s propositions of the concept of embodiment, critical medical anthropology; the dwelling perspective; and the notion of entanglement, among other approaches. I open this theoretical debate with authors who present a critical analysis of reductionist approaches of the body in which public health programs are grounded, namely naturalistic philosophy proposed by Descartes in the 17th century, and experimental medicine introduced by Claude Bernard in the second half of the 20th century.

Cartesian approach to the body

At the time Descartes proposed his dualistic philosophy, body and soul were in the domain of the Orthodox Christian church. To respect religious precepts, Descartes (2003, p. 55) claimed that the, “human soul does not perish with the human body”. In doing so, he maintained the Christian belief that the soul continues to exist in a sacred

realm, and he equated the human body with an object of physical sciences; hence, subjected to mechanical laws. In relation to the mind-body dissociation, Descartes (2003, p. 119) stated:

[T]here is a great difference between the mind and the body, inasmuch as the body is by its very nature always divisible, and the mind is entirely indivisible. For, as a matter of fact, when I consider the mind, that is to say, myself inasmuch as I am only a thinking thing, I cannot distinguish in myself any parts, but apprehend myself; to be one and entire; and although the whole mind seems to be united to the whole body, yet if a foot or an arm, or some other part, is separated from my body, I am aware that nothing has being taken from my mind.

While Descartes opened an opportunity for the study of human anatomy and physiology, French physiologist Claude Bernard, in 1865, introduced a method of research to study vital phenomena, known as experimental medicine. Bernard, inspired by Cartesian philosophy and his own interest in clarifying universal laws of vital processes, created a framework for experimental medicine based on laboratory experiments with animals. The experiential method is described in his seminal work, *Introduction to the Study of Experimental Medicine*. Bernard (1949, p. 10) relied on the assumption that, “physiological and pathological states are ruled by the same forces; they differ only because of the special conditions under which the vital laws manifest themselves”. The experimental method as applied to medicine led to the broad use of

scientific methods in life sciences (see also Normandin, 2007).

In fact, contemporary medical science is imbued with Cartesian philosophy and Bernardian experimental medicine principles. Capra, for instance, suggested that the current biomedical interventions have reduced the complex phenomena of life to biological mechanisms in such a way that disease becomes a biological issue “analyzed by proceeding to smaller and smaller fragments, from organs and tissues to cells, and finally, to the molecular level” (1982, p. 83). Capra (Ibid) remarked that diseases are generally defined upon a specific etiology; that is, one disease, one cause. By implication, there is a scientific quest for developing a technological fix that may eliminate or eradicate diseases.

By the same token, the rationale underlying BMPCP is to clear away the causal genesis of this disease, namely plasmodium. In doing so, an individual with malarial infection is treated for and prevented from transmitting the disease to other individuals at once (Brasil, 2003). The biological body, composed of cells, tissues, and biochemistry as Brenner (2000) defines it, is the object handled in malaria diagnosis and treatment. At the core of these biomedical practices rests the Cartesian assumption that the patient’s body is similar to a machine, where components and mechanisms are well known by biomedical professionals, but still out of population’s understanding.

Accordingly, public health policy makers consider vector control strategies as important tools in the control of the disease. However, a main issue of mosquito-killing interventions is their ability to mask root causes of malaria, namely environmental exploitation, which creates ideal conditions for malaria-carrying mosquitoes to proliferate, and social inequalities that expose people to the disease vector. Moreover, for

Hochman (2009, p. 322) these technological vector strategies are tied to the “magic-bullet conception which assumes that it is possible to fight the malaria vector without changing the mosquito biology and the environment we share with it”.

In fact, as stated earlier, public health policy makers prioritize the use of technologies to treat malarial infected bodies and control the disease vector, while individuals’ experiences of the sickness and its interventions are neglected. The primacy of scientific knowledge over the individuals’ ways of knowing and handling of sicknesses can be understood through the political ploy of the natural sciences unveiled by Latour (2000, p. 118):

Primary qualities define the real stuff out of which nature is made, particles, strings, atoms, genes, depending on the discipline, while secondary qualities defines the way that people subjectively represent this same universe [...]. The common world (of what the universe is really made up) is known by the scientists, but invisible to the eyes of the common people. While what is visible, lived, felt, is, to be sure, subjectively essential but utterly inessential, since it is not how the universe is made up.

Through this political ploy, Latour calls attention to the nature-culture divide prevalent in the natural and life sciences, as well as the secondary role of experiential knowledge. As an ethnographer who examines how peri-urban and rural Amazonian people related to malaria, I aim to reiterate the validity of experiential ways of knowing and dealing with sicknesses. Specifically, I aim to broaden our understanding of how

malaria is experienced outside clinical settings. By doing so, I build on phenomenological and critical medical anthropology approaches to situate malaria as an experiential phenomenon, which cannot be understood through its somatic manifestation only, but as an event in an individual's life.

The existential phenomenology proposed by Merleau-Ponty

In this study, I take inspiration from the phenomenological approach introduced by Merleau-Ponty to move away from the ontological perspective that sees the body as an assemblage of organs dissociated from the environment. Rather, I understand the body as Merleau-Ponty (2014, p. 84) describes it, that is, as “the vehicle of being in the world, and for a living being have a body means be united with a definite milieu, merging with certain projects and being perpetually engaged therein”. Merleau-Ponty definition of the body differs from Descartes', focusing rather on the lived body to contend a subject whose life is entangled with the world in everyday perception and movement. For Merleau-Ponty (2014, p. 11), perception is a way individuals embody the world, and the “background against which all acts stand out”.

The body is central in Merleau-Ponty's phenomenology; through it we inhabit and experience the world (Ibid). For Sadala and Adorno (2002, p. 286), Merleau-Ponty's understanding of the body goes, “beyond the materialist concept of a body, which deems it an object, and the spiritual approach, which does not take the body into account as something opposite to the soul, Merleau-Ponty takes the body as the ‘self’ - ‘I do not have a body, but I'm my body’ ”. At the heart of Merleau-Ponty's phenomenological approach lies the existential understanding of world, a consciousness of objects, beings, and environment that we continuously build before any reflective thought or scientific

knowledge objectification (Merleau-Ponty, 2014). In this sense, the world and knowledge we have about it is given in experience, rather than passed on to an individual through social schemas, mental models, cognitive sciences among other mechanisms (Merleau-Ponty, 2014). Merleau-Ponty's existential phenomenology is inspired by Husserl's phenomenology²⁰. Merleau-Ponty (1956, p. 59) explained that phenomenology is,

the study of essences and accordingly its treatment of every problem is an attempt to define an essence, the essence of perception, or the essence of consciousness, for example. But phenomenology is also a philosophy which replaces essences in existence, and does not believe that man and the world can be understood save on the basis of fact. It is a transcendental philosophy which suspends our spontaneous natural affirmation in order to understand them, but it is also a philosophy for which the world is always “really there” as an inalienable presence which precedes reflection. The whole effort of phenomenology is to recover this naive contact with the world and to give it at least a philosophical status. It is a philosophy intent upon being an “exact science”, but is also an account of space, time, and the world “as lived”.

Merleau-Ponty makes visible his antagonism to rationalism and its assumptions that knowledge stems exclusively from facts and experiments, which is the solely approach for understanding phenomena within natural and life sciences. In this regard, Merleau-Ponty (2014, p. 8) observed that, “[t]he entire universe of science is constructed

²⁰ At the end of the 19th century, Husserl proposed an alternative approach to attend to social scientists' frustration with natural sciences methods, which were not able to grasp the sense of life and human experiences (Merleau-Ponty, 1956).

upon the lived world, and if we wish to think science rigorously, to appreciate precisely its sense and its scope, we must first to awaken that experience of the world of which science is the second-order expression". Merleau-Ponty's phenomenological approach proposes a return to the essence of things as part of our lived and experienced world. However, he noted that, "seeking the essence of the world is not to seek what is an idea, after having reduced it to a theme of discourse; rather, it is to seek what it in fact is for us, prior to every thematization" (2014, p. xxix).

To avoid the reductionism imposed by current biomedical approaches that view malaria solely as a physiological alteration in the body, I take inspiration from Merleau-Ponty's existential phenomenology to understand malaria as an experiential phenomenon. As previously suggested, the clinical gaze pervading malaria control interventions disregards the lived experiences of people that coevolve with malaria pathogens in the everyday. In contrast, a phenomenological lens takes into consideration that malaria is not enclosed in the biological body, yet it is expressed outwardly. Moreover, phenomenology differs from other approaches by placing its focus on actual experience of phenomenon while other perspectives, such as those of cognitive sciences, seek causal explanations of an event (Geertz, 1974). Specifically, phenomenology foregrounds events that happen, including sicknesses, as these are promptly experienced by individuals as conscious human beings (Merleau-Ponty, 2014, see page xxix). By following this approach, lived experiences of malaria afflicted individuals reveal the very essence of this illness, that is, what it feels like to live through diverse situations due to malarial infections. In this regard, Finlay (2012, p. 6) noted that,

accounts of lived experience of health and wellbeing, illness, disability, pain, emotional trauma, and so forth, are often poignant and powerful. Such accounts offer us a way to get ‘up close and personal’ with specific experiences, to better understand and empathize with what others may be going through. They challenge our blind spots and taken-for-granted assumptions. Reminding us of our fragile existence, they can resonate and touch us in unpredictable ways.

To describe Ribeirinhos’ lived experiences and practices of malaria, I do not draw on phenomenology as research method primarily based on *époché* (bracketing) and phenomenological reduction (Sadala & Adorno, 2002). Rather, I engage with Merleau-Ponty’s existential phenomenology as a philosophical approach to understand experiences and practices of malaria as pre-objective categories; that is, as these present themselves to my research participants before being objectified/thematized in scientific terms. In this approach, scientific knowledge of malaria is bracketed, and the researcher follows how the illness unfolds and is experienced within ongoing life-making processes in everyday living (See Katz & Csordas, 2003; Laplante, 2015).

Embodiment as lived experience

Analyzing the dimension and findings of phenomenological approaches in anthropology, Desjarlais and Throop (2011) noted that phenomenological approaches have been used in tandem with a variety of theoretical approaches to account for political and economic forces, as well as cultural and psychological facets in individuals’ lives. In this dissertation, I also follow other approaches to address Ribeirinhos’ experiences and practices of malaria since these are not dissociated from the social-cultural and

environmental milieu in which they unfold.

In this sense, I draw on Csordas' work to understand the ongoing constitution of Ribeirinhos' experiences and practices of malaria. Csordas threads both Merleau-Ponty's notion of perception and Bourdieu's concept of habitus to introduce the paradigm of embodiment to, "understand the nature of human experience in culture"²¹ (Csordas, 2002, p. 2). By taking inspiration from Merleau-Ponty, Csordas reasserts that objects do not hold any meaning *a priori* since they are products of our perceptions (1990, 2002). And based on Bourdieu, Csordas argues that the ways we attend to our bodily experiences, such as illnesses and other endogenous processes, are bound up with our social reality (Ibid). In this light, the contribution of the paradigm of embodiment to the analysis of malaria as an experiential phenomenon is two-fold. First, it implies to transcend the category malaria as it is objectified in Western medicine. Biomedical sciences, as I described in the literature review, provide a clinical account of malaria, enclosing it in a complex set of fixed etiological, anatomical, physiological, and environmental definitions (Law, 2004)²². While these definitions guide diagnosis and disease interventions, they are unable to grasp the experiential meaning of falling ill. Indeed, definitions and classifications, "displace what they stand for in our experience of them so that, rather than concepts point us to reality; realities are relegated to be mere explanations of concepts" (Crotty, 1998, p. 80).

Second, it involves rethinking the conflicting relation between culture and biology (Csordas, 1990). A number of studies have relied upon approaches of classical

²¹ Csordas (2002, p. 4) understands "culture not only in terms of symbols, schemas, traits, rules, customs, text or communication, but equally in terms of sense, movement, intersubjectivity, spatiality, passion, desire, habit, evocation, and intuition".

²² Law provides an analysis of how disease is conceptualized within biomedical knowledge. I applied his understand to malaria, though he does not examine this disease.

science that associate culture with ways people think about and relate to malaria (Dunn, Le Mare, & Makungu, 2011; Essé et al., 2008; Panter-Brick, Clarke, Lomas, Pinder, & Lindsay, 2006; Pell, Straus, Andrew, Meñaca, & Pool, 2011). In these studies, local understanding and practices of malaria are often linked to risk behaviours, rather than to a form of embodied experience (Farquhar, 1994). Furthermore, such studies often tend to explore divergences between cultural beliefs and public health knowledge. By doing so, these studies fail to connect with multiple ways the body is experienced; that is, as the locus of phenomenological experiences of suffering and pleasure, as a social metaphor that captures dynamic interactions between nature and social worlds, and as an object/subject of government regulation (Scheper-Hughes & Lock, 1987). Csordas (1990, 2002), by contrast, endorsed that cultural meaning is intrinsic to bodily experiences. In doing so, he defines embodiment as, “an experiential understanding of our worldly existence and biology as a form of objectified knowledge about our bodily beings” (2002, p. 8). Particularly, social and cultural factors permeate ways an individual experiences an illness from its etiology, onset, and bodily effects, to an elaboration of strategies to cope with ill effects (Csordas, 1990, 2002). Therefore, understanding malaria in terms of embodiment begins with the premise that, “the body is not an object to be studied in relation to culture, but is to be considered the subject of culture, or in other words, the existential ground of culture” (Csordas, 1990, p. 5).

My understanding of embodiment goes beyond the anthropological notion proposed by Csordas. I also comprehend embodiment as the social epidemiologist Krieger (2004, p. 351) conceptualized it; that is, as “an idea [that] refers to how we, like any living organism, literally incorporate, biologically, the world in which we live,

including our societal and ecological circumstances”. While Krieger draws on embodiment to call attention of biomedical professionals about the crucial role of context in health, I take inspiration from this concept to highlight that our bodies tell stories about conditions of our existence. In some instances, these stories reveal pathways by which people, pathogens, and disease vectors meet (or not) and produce diseases (or not). Likewise, Ribeirinhos’ experiences and practices of malaria also attest to their struggles to make a living within a fractured social and economic context.

Even though Csordas (1990, 2002) and Krieger’s (2004) approaches look at distinct issues, they indicate that the body cannot be understood in relation to different cultures, but rather in relation to multiple cultures (and religion, as Csordas suggests) and contexts (as Krieger proposes). In addition, Descola (2013), Kohn (2007, 2013), and Viveiros De Castro (1998) also proposed ways of understanding and relating to the world that move beyond the nature-culture divide. All these authors pave the way for scholars to critically rethink the conflicting relation between culture and nature, which underlies approaches to the body. In short, they show that culture and biology, or the social and natural realms, equally shape things we do with our bodies (Csordas, 2002), our experiences, and ways we dwell in the world.

Dwelling perspective

The ways in which people engage in the environment have been at the heart of Ingold’s concerns. Drawing inspiration from Heidegger and Merleau-Ponty’s phenomenological approaches, and later from Deleuze and Guattari’s (2014) radical rhizoming phenomenology, Ingold (Ingold, 2000, p. 155) criticized studies that assert that, “earth is presented to humanity as a surface to be occupied rather than a world to be

inhabited”. Ingold calls this stance building perspective, which he contrasts to his proposed dwelling perspective, an expression borrowed from Heidegger, and which he later replaces by the perspective of the inhabitant. According to Ingold, the building perspective is based on the Cartesian stance that places humans and nature in divergent positions.

In contrast, in the dwelling perspective, Ingold (2000, p. 186) supplanted human disengagement with the environment by giving a sense that the ways humans relate to nature “arise within the current of their involved activity, in the specific relational context of their practical engagement with their surroundings”. Given that not only do dwelling activities contribute to the creation of conditions under which human and nonhuman lives flourish, but they also form each other into a continuous movement of becoming (Ibid). As Ingold further states, “[h]uman beings do not, in their movements, inscribe their life histories upon the surface of nature as do writers upon the page, rather these histories are woven, along with the life-cycles of plants and animals into the texture of surface itself” (2000, p. 198). In the dwelling perspective, the environment is considered a zone of entanglement in which organisms are continuously being constituted within a relational field, known as meshwork (Ingold, 2008, p. 1809). According to Ingold, “every organism - indeed, every thing - is itself an entanglement, a tissue of knots whose constituent strands, as they become tied up with other strands, in other bundles, make up the meshwork” (Ibid). Ingold’s dwelling perspective and conceptualization of the environment as a zone of entanglement provide insight to an understanding of how malaria is tied to a wider set of fluid relations among humans, non-humans, and ecological-sociological-political and economic factors in which Ribeirinhos are

dynamically woven together.

Entanglement

The notion of entanglement has been used in many disciplines to emphasize, among other things, “a world, and also processes of world-making” (Fitzgerald & Callard, 2014, para. 4). Anthropologist Kath Weston, for instance, draws on the concept of entanglement as referred to in quantum physics. In this discipline, entanglement refers to, “a link between particles whereby a change in one particle is accompanied by a corresponding change in the state of the other, even when the two particles are nowhere near one another in any sense that could be explained by the principles of classical mechanics” (Weston & Helmreich, 2006, p. 108). Weston’s understanding of entanglement demonstrates a relational aspect between things and events. I mention this concept herein to call attention to malaria transmission as an outcome of events that connect global and local contexts; bodies and microbes, as well as government policies and individual wills.

The concept of entanglement as used in archaeology is described by Hodder (2011, p. 162) to characterize the, “dependence of humans on things, things on things, and things on humans”. Hodder emphasized that, “[i]t is not the materials themselves that cause entanglement, but the interlacing of materials with the whole suite of ways in which humans and things depend on each other”(Ibid. p. 164). Hodder’s understanding of entanglement invites us to think about a myriad of processes by which Ribeirinhos’ lives are connected to malarious areas, including employment, housing, and food needs.

In anthropology of life, Hustak and Myers (2012, p. 96) introduced the notion of entanglement as a form of interspecies relationality or attachment in which, “organisms

reach toward one another and involve themselves in one another's lives". Comprehending malaria as a form of attachment requires thinking about enmeshments and intimacies that bring human, pathogens, and malaria-carrying mosquitoes together. In short, the notions of entanglement that I take inspiration from do not enclose malaria to either the patient's body or the disease vector, as malaria control interventions usually do; rather, these notions shed light on pathways by which relationalities and materialities play out in the occurrence of malaria among Ribeirinhos from the Brazilian Amazon.

Conclusion:

This chapter set out the theoretical ground to understand malaria beyond clinical and biomedical frameworks, specifically through Merleau-Ponty's existentialist phenomenology, which describes illness experiences as a different form of existence, rather than a disease confined in the human body. Csordas' notion of embodiment is used to highlight the role of social context in experiencing and managing sicknesses. Krieger's work is used to emphasize the material dimension of embodiment; that is, how social inequalities play out in the 'becomings' of bodies and malaria. Furthermore, I took inspiration from Ingold's concept of dwelling and perspective of entanglement to draw attention to forms of attachment among humans, malaria-carrying mosquitoes, and malaria pathogens. In conclusion, this chapter presented theoretical perspectives and key concepts I employed in the fieldwork and in the analysis of Ribeirinhos' experiences and practices of malaria. The next chapter presents the methodology that allowed me to learn from Ribeirinhos about their understandings, experiences, and practices of malaria and its public health interventions.

Chapter 3

Methodology

In this chapter, I delineate the methods used to conduct my research study²³. I drew on ethnographic methodology to learn from Ribeirinhos' lived experiences of malaria and public health interventions to control the disease. Tedlock (2003, p. 26) defined ethnography as, "an ongoing attempt to place particular encounters, events, and understanding in a fuller, more meaningful context". The author (Ibid) also emphasized that far from being a recording of past experiences, ethnography is an ongoing process of fieldwork aimed to grasp those meanings research participants attach to facts and experiences. Ingold (2014) introduced a different perspective on ethnography, as he prefers to call it "doing anthropology", namely participant observation understood as attuned attention, or an education of attention to learn from people's experiences. The latter is the method I followed.

I spent over four months with my research participants, endemic disease control agents, and other health workers. During fieldwork, I used data collection methods traditionally employed in anthropology, including participant observation, semi-structured interviews, and photographs. Though I am not trained as an anthropologist, I conducted my research study within the School of Sociological and Anthropological Studies, under the supervision of an anthropologist. Coming from a public health and education backgrounds, it is precisely doing this kind of research that led me to choose a disciplinary supervisor from this field. From the onset of my research study, I felt such

²³ This research study was approved by the Research Ethics Boards of the University of Ottawa and the Fundação de Medicina Tropical Dr. Heitor Vieira Dourado (FMT). REB certificates may be found in the Appendix A of the dissertation.

in-depth research with people affected by malaria was lacking to ground the implementation of context-driven public health interventions in Brazil. As my first ethnographic fieldwork experience, it was an intense experience characterized by initial anxiety, shyness (my own and those of my research participants), empathy, exchange of experiences, trust, concerns with my son's health, who was nearby staying with my parents-in-law (yet our home is in Canada), re-elaboration of my knowledge that was primarily based on public health paradigms, and learning from the perspective of those who experience the illness.

This chapter is organized into sections presenting the context I learned from my experiences getting into the field, personal experiences in fieldwork, dynamics of establishing rapports and reflexivities in the field, description of data collection methods, and procedures employed in data analysis. I begin with the characterization of the study locations.

Study locations

My study was carried out with Ribeirinhos who live in the Brasileirinho community in Manaus and in the Panelão community in Careiro (**Figure 3.1**). I selected the Brasileirinho community as a study location because of its epidemiological relevance; that is, it is the community in which the majority of malaria cases are reported in Manaus. According to malaria epidemiological reports provided by public health officials from the Fundação de Vigilância em Saúde (FVS) (Health Surveillance Foundation), in 2015, the Brasileirinho community reported 1,511 malaria cases against to 1,084 cases in 2014. The Panelão community has also been a place where malaria epidemics occurred for at least one decade. Nowadays, as I further explain, malaria incidence decreased. The two

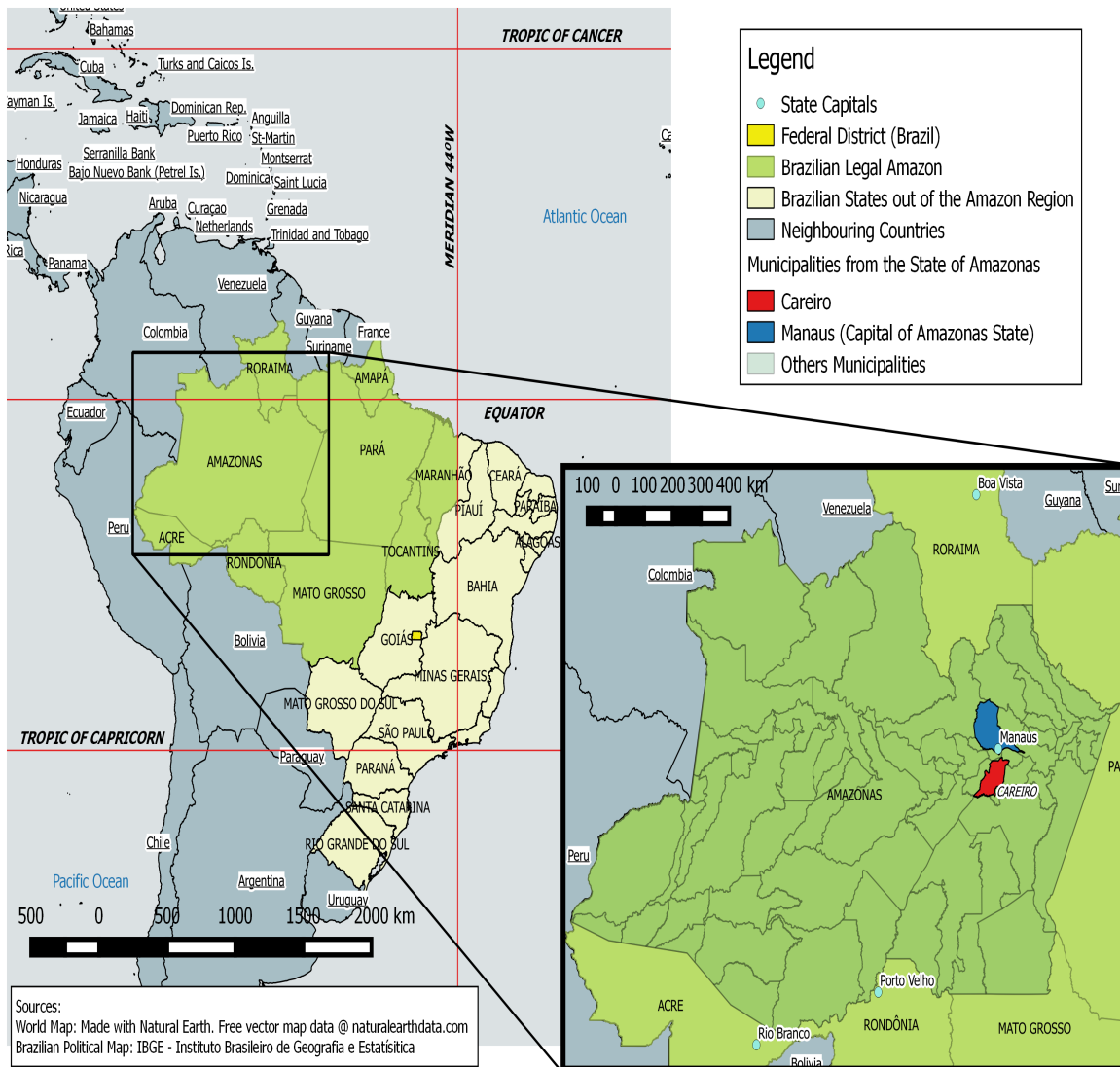


Figure 3.1: Map showing municipalities where the study locations are situated.

study settings provided ideal contexts to learn from people's experiences and practices of malaria since the disease is a common occurrence, and people have developed numerous strategies to contain its spread.

Brasileirinho community

“Here is a forgotten community and we live on the margins of the Brazilian society. I am not ashamed to say this. Indeed, I feel I am Brazilian in double because I was born in Brazil, and live in the Brasileirinho [community]” (João Mauro, 64 years old). The above quote provides a characterization of the Brasileirinho community, from a conversation I had with a Ribeirinho who lived in this community for approximately 14 years. His words define his experience of living in a community where people face financial and social hardships on a daily basis. The Brasileirinho community is on the outskirts of Manaus, 45-minute driving distance from the downtown area of the capital, and is situated on the edge of both the east urban area of Manaus and forest areas under federal government management. The origin of the community is tied to the urban development of Manaus, fostered by the creation of the *Zona Franca de Manaus* (Manaus Free Trade Zone) in 1967 (ZFM, 2016). Zona Franca de Manaus is under the management of the Superintendência da Zona Franca de Manaus (SUFRAMA). SUFRAMA’s mission is to foster economic development of the state of Amazonas through the implementation of industries, especially in Manaus. SUFRAMA owns land lots designated for the construction of industry plants in the capital or in the metropolitan region. During the end of 1970’s and beginning of 1980’s, people illegally occupied land lots of this institution, which were intended for the expansion of Manaus industrial plant called Distrito Industrial 2 (Industrial District 2) (Personal communication with a SUFRAMA official). These land lot occupants removed primary forest areas and began a horticultural plantation in the east area of Manaus, including Brasileirinho community. In the 1990’s, after a litigation process between SUFRAMA and land lot occupants, the area

was gradually transformed into rural land lots. In 1998, SUFRAMA transferred land ownership of invaded areas to the state government of Amazonas. The government decided to support the development of a horticultural pole in that area and granted the land claimants a concession agreement; that is, they were allowed to use the land for agriculture purposes, but do not own it.

Brasileirinho community is an area of urban development pressure, which is sought by wealthy developers envisioning future development projects and by the poor people seeking a place to build dwellings. Consequently, land tenure conflicts between business corporations and peasants/Ribeirinhos often occur. Land invasions are also common in this area. I visited two areas where people recently occupied and built homes. They told me stories of suffering and lack of opportunities for better lives. Most people who reside in the *invasão*²⁴ (invaded areas) live in dwellings made of plastic, cardboard, wood, and bricks. They are deprived of electricity, water and sewage services, public transportation, social assistance, and police services. As noted in local newspapers, *invasões* constitute illegal appropriation, selling of land, and environmental crimes (Correio da Amazônia, 2015; Rede Amazônia, 2015). In contrast, for land occupants, *invasão* means hope, protection, and family reunion. In other words, it is a re-start of a new life without concerns about insufficient money for rental housing. As noted by a public health worker, malaria outbreaks often happen during the construction of *invasões* (unlicensed neighbourhoods) in Manaus. As a result, malaria services are intensified in these areas to reduce the disease transmission. Though, for land invasion residents,

²⁴ *Invasão* is the popular term used to both designate illegal occupation of land lots belonging to governmental institutions, corporations, or individuals, and defined unlicensed neighbourhoods.

malaria is not perceived as a serious problem, satisfying their basic housing needs is a crucial issue.

The socio-economic organization of the Brasileirinho community mirrors the Brazilian pervasive social inequalities; that is, poor Ribeirinhos reside in precarious dwellings and work in farms and vegetable gardens (they are underpaid and sometimes have no income at all), and middle class individuals who own places to spend weekends and holidays in the community. The spatial organization of the community blends characteristics of urban and rural surroundings, including two industrial cattle slaughterhouses, small companies that produce concrete and aluminum products, an electric power station that supplies power demand of Manaus, farm lodges, good standard and precarious dwellings, water parks composed of rivers and *igarapés* where people bathe, night clubs, a dozen churches, small commercial stores, a school, and a malaria facility, among other places.

In a conversation with the manager of the malaria facility from Brasileirinho community, I was told that the community is a malarious risk area that raises concerns for malaria workers due to intense flux of people who spend nights, weekends, and holidays there. From an epidemiological standpoint, the Brasileirinho community is a malaria receptive area, as it has a high density of Anopheline mosquitoes and humans, as well as ecological factors that maintain the disease transmission. It is important to note that the urban areas of Manaus are not receptive to malaria because urbanization and high temperatures are not compatible with environmental conditions in which malaria-carrying mosquitos develop.

Panelão Community

The Panelão community is located in the rural area of the municipality of Careiro, situated 112 km from the state capital. Access from Manaus to Careiro is made via ferryboat that operates daily. The ferryboat departs from Porto da Ceasa (Ceasa harbor) in Manaus and crosses the Rio Negro (Black river) and Rio Solimões (Solimões river) and then arrives in the municipality of Careiro da Várzea. Manaus-Careiro trip takes over a total of two hours: 45 minutes to one hour by ferryboat, followed by an approximately 100-km drive.

The Panelão community is an agricultural settlement, which is situated five-to-seven-minute drive distance from the Careiro municipality. The access road to the rural community is paved. Roads inside the community are unpaved and, in some areas, have huge potholes. Similarly to the Brasileirinho community, during rainy days precarious conditions of roads in the community make the traffic very dangerous for pedestrians and drivers. As I witnessed, school transportation is cancelled on these days, and Ribeirinhos cannot go to the city through the road. Therefore, some use boats to travel to Careiro.

The agricultural settlement of Panelão was founded on December 17, 1998 by the Instituto Nacional de Colonização e Reforma Agrária (INCRA). A total of 260 families can be settled in this settlement, and is a total of 3.663 hectares. Approximately 857 people live in the community. In a conversation with the community leader of the Panelão, I was told that 236 families live in the community; 45 of these families moved out of the community before completing one year of residence. She also explained that the majority of dwellings are made of wood (n=207), wood and masonry (n=25), or masonry only (n=4). I noted that the community has one school, churches (n=5), one

primary health care facility that was under construction, fish farms, and one cooperative of rural workers that produces manioc flour and other regional products.

During the time I conducted fieldwork, few families were granted land ownership certificates. Rather, the majority were granted a concession agreement, which states they can live and grow crops in the Panelão community. Usually, new settlers receive financial support from INCRA to build houses. This benefit ranges from BRL \$1 to BRL \$5.000 (Brazilian real) (from CAD\$ 0.37 to CAD\$ 1830 CAD). Ribeirinhos who live in the community depend on subsistence agriculture, government pension benefits, and *bolsa família* program²⁵ (family benefit). They plant manioc, banana, beans, cowpea, lettuce, tomatoes, and peppers, among other vegetables. They fish, hunt, gather tropical fruit in the forest, and raise chickens and ducks. The surplus produce is sold in Careiro and Manaus. To do so, Ribeirinhos resort to the *atravessadores de produtos* (produce brokers), who sell their produce in the cities and charge a brokering fee.

During fieldwork, there was no malaria facility in the community. An endemic disease control agent was in charge of monitoring individuals with symptoms suggestive of malaria during weekdays only. The community has two community health agents. These health professionals are from the family health program and are in charge of monitoring the health conditions of local residents of a specific community zone. Though community health agents work in partnership with endemic disease control agents, as they perform the thick blood smear slide (blood collection), and deliver it in the Careiro hospital or *gerência de endemias* (district of endemic diseases), they are not able to

²⁵ The Brazilian government to support poor families with children created the *Bolsa família* benefit. The families usually receive an average of R\$70.00 (about US\$35) in direct transfers. In return, these families keep their children in school and take them for regular health checks (vaccination and growth monitoring). As a result, the *Bolsa Família* benefit is helping both to reduce poverty and foster families to invest in education of their children. (The World Bank Group, 2016).

perform malaria diagnosis by themselves because it requires appropriate procedures, equipment, and training. Even in cases when rapid diagnosis tests (RDT) are used, test results are validated by microscopic analysis. Treatment is dispensed by the municipal district of endemic diseases or by the municipal hospital. Community health agents and endemic disease control agents usually deliver the antimalarial medications in the patients' home.

Malaria epidemics occurred in the Panelão community during the inception of the agricultural settlement. Lack of government support to settlers, who were attracted to this development enterprise, played a part in the emergence of these outbreaks. Deforestation, migratory movements, and precarious living conditions brought individuals, malaria mosquitoes, and the disease pathogens into contact with each other. In a visit to the district of endemic diseases of Careiro, a technician responsible for the malaria epidemiological system (SIVEP)²⁶ told me that malaria cases from the Panelão community were first reported in the SIVEP in 2003. Before 2003, malaria cases were registered in other information system known as SISMAL²⁷. The technician explained that in 2003, epidemiological reports presented cases registered in one community area, namely PA Panelão Vicinal Principal. In that year, 760 cases of malaria were reported in the community of only 255 inhabitants. In 2004, incidence of malaria increased to 1,047 cases. Though my dissertation is not aimed to explore epidemiological aspects of malaria, I mention these numbers to call attention to malaria prevalence in the initial phase of creation of the Panelão community, and to contrast it to the present situation.

²⁶ SIVEP is the malaria epidemiological system implemented by BMPCP, which remains in present day.

²⁷ Information system for malaria.

Though malaria incidence in the community has reduced, the decline is not perceived by local residents as an exclusive achievement of malaria services. Rather, in a conversation with the director of the local school, who was raised and lives in the community, I was told that when the agricultural settlement of the Panelão was founded, people lived in precarious dwellings like tents. They had no electricity, toilets; domestic use of water, including for drinking, was fetched from rivers, where people also bathed. He noted that currently, there are people who continue to live in poor conditions, but the majority of local residents live in good standard houses (with complete walls), have electricity, indoor toilets, have well-water, including some with air conditioning.

In 2014, 105 cases of malaria were reported in the Panelão community. In 2015, malaria incidence decreased dramatically to 47 cases. I selected this community as a study setting because of its emergence as an agricultural settlement in which people came to live in forest areas, and were exposed to the disease due to inadequate government support. In present day, improvements in housing, reduction of influx of people, and organization of malaria services at municipal level corroborated with decrease of malaria incidence the Panelão Community. Lived experiences of people who live in the Panelão community reflect those of several families and individuals who seek a place to live and work in rural settings of the Brazilian Amazon.

Entering the field

I arrived in Manaus in the beginning of December 2014. Initially, I settled down in my parents-in-law's apartment, downtown Manaus. My first contact with Ribeirinhos and endemic disease control agents took place in January 2015 after the holidays celebrated in December. This was not my choice, but a request from the Brazilian

research ethics committee. In 2014, I received the Globalink research grant from Mitacs. As part of requirements of this grant, I was assigned a host supervisor in Brazil, a medical doctor from the Fundação de Medicina Tropical (FMT) (Medicine Tropical Foundation), who assisted me with the selection of study locations, research field activities, and provided me with an institutional identification to allow my entrance in the FMT to observe the patient triage ward and malaria diagnosis laboratory.

At our first meeting, the host supervisor noted the dramatic reduction of malaria incidence in the state of Amazonas, which he attributed to investment in professional training, increased distribution of insecticide-treated nets, and expansion of diagnosis and treatment facilities across the Brazilian Amazon²⁸. The supervisor told me that nowadays hospital wards are crowded with patients in treatment for cancer and other infectious diseases. In contrast, malaria is clustered in rural areas of the state. He also explained that if malaria incidence continues to decrease, in the future it might be possible to implement in the state a strategy known as mass drug administration²⁹. Reducing malaria incidence, he remarked, is essential to move towards the elimination of the disease in Brazil.

I spent December arranging fieldwork logistic and contacting public health professionals in Manaus. In a visit to FVS, I spoke with the director of the Foundation. We discussed about the situation of malaria in the state of Amazonas. The director observed that malaria incidence in the state of Amazonas has reduced in 2014, and that keeping it low is always a challenge because Manaus is still the locus of systematic

²⁸Improvements in malaria services and structure were partially financed by the Global Fund to Fight AIDS, Tuberculosis, and Malaria from 2010 to 2012 (Sampaio et al., 2015).

²⁹ The Centers for Disease Control and Prevention defines mass drug administration (MDA) as the “treatment of the entire population in a geographic area with a curative dose of an antimalarial drug without first testing for infection and regardless of the presence of symptoms” (CDC, 2015, para. 2).

disorganized land occupations (*invasões*). He concluded by saying that, “the area [Brasileirinho community] that you will do your research study, there are areas like this”. To support my fieldwork, he provided me with a vehicle and a driver, put me in contact with the nurse who was responsible for the malaria control program in Careiro, and advised me to talk to the manager and endemic disease control agents (EDCA) of the malaria facility from the Brasileirinho community because they know the area and would be able to introduce me to Ribeirinhos.

As my research fieldwork comprised two separate locations, I created a weekly schedule to visit each community. Thus, I spent one week in the Brasileirinho community (Manaus) and, on the following week, I was in the Panelão community (Careiro). To do fieldwork in the Brasileirinho community, I continued to live in my in-law’s home. My daily routine in Manaus was to wake up as early as 6:00 am. The driver picked me at 7:00 am. We arrived in the Brasileirinho community as early as 7:45 am.

In the beginning of fieldwork, I first visited the malaria facility in order to follow an endemic disease control agent to a Ribeirinho’s home. As part of malaria services, each endemic disease control agent is responsible for Ribeirinhos who live in a specific zone of the community. Thus, during my fieldwork, I visited Brasileirinho community with five endemic disease control agents. They introduced me to Ribeirinhos, and then left to do their work in other dwellings. I had plenty of time to speak with Ribeirinhos. I followed them while they weeded their backyards, sewed clothes, prepared meals, planted vegetables, took care of their (grand) children, welcomed their neighbours in their homes, or went to grocery stores. I assisted in their daily chores, such as caring for children, weeding backyards, and gathering fruit in the orchard. I spent the day in the

community, leaving around 4:00 pm. At night, I wrote up fieldnotes, replied to emails (when I was in Manaus only), and planned field activities for the next day.

My fieldwork in the Panelão community began early morning as well. I stayed in a hotel located in the rural area of Careiro because it was a five-minute drive distance from the Panelão community. The driver, who was assigned to me by the director of the Fundação de Vigilância em Saúde, stayed in the hotel as well. In the beginning, an endemic disease control agent introduced me to Ribeirinhos in the Panelão community. I usually spent the day in the community, and at sunset I returned to the hotel and I worked on my fieldnotes. The hotel had no Internet access. I got used to limited access to the Internet and used it when I was in Manaus. I had a cellphone to communicate with my family, but the cellphone service was inconsistent. I learned from hotel workers that I needed to walk around the hotel to get a signal. In the evenings, I used to walk around the hotel backyard until I was able to talk to my family. On these occasions, I was bitten by mosquitoes several times. I took some precautions to avoid exposure to malaria-carrying mosquitoes, such as wearing long-sleeve shirts and trousers. I mentioned this situation here to highlight that local communication through cellphones remains difficult in rural areas of the Brazilian Amazon. Thus, people are used to put red cloths in front their homes as a signal that someone in that house may be sick from malaria. They also ask other people to tell endemic disease control agents or community health agents that they present malarial symptoms; hence, they need to be screened for the disease (see Figure 3.2).



Figure 3.2: Red cloth placed by a Ribeirinho in a road to show that someone is sick from malaria in that area

In both study communities, I visited homes and community schools. In the beginning, most conversations were about malaria, but after establishing rapport with residents, I was welcomed into conversations on politics, religion, everyday hardships, violence, as well as gossip. These conversations introduced me to the experienced social

and political context in which the risk of contracting malaria is not perceived as a threat to Ribeirinhos. I conducted fieldwork during the rainy season, also known as Amazonic winter. Thus, on a few occasions, I had to cancel visits to the study communities. My research participants knew that in the case of torrential rain, I would not reach their communities due to precarious roads.

The field research also involved personal life changes experienced not only by me, but my family as well. My husband and three-year-old son came with me to Manaus. By the end of January my husband returned to Canada. I preferred to have my son living with his grandparents in Manaus. He was born in Canada, this was his second trip to Brazil, and seemed to be a great moment to experience his grandparents' affection. I enrolled him in a local school; he became friends with many children, and learned Portuguese and capoeira, as well as local songs and Amazonia literature. The warm and humid weather was a novelty to him, but, unfortunately, he became sick many times, and was hospitalized on one occasion. I was in Manaus on that day. I cancelled a visit to the Brasileirinho Community. My son had diarrhea, vomiting, and fever. In the morning when these symptoms manifested, my mother-in-law and I treated him at home. In the afternoon, he fainted, and we rushed him to a public children hospital. We waited about 20 minutes to be seen by a doctor. He was diagnosed with a viral infection and mild dehydration. The doctor required his prompt hospitalization. My son and I shared the children's ward with about 17 children and their caregivers, sometimes their mothers, fathers, or other relatives. Throughout the night, nurses and hospital workers placed more beds on the ward hall to accommodate other children who were hospitalized. I had barely eaten during that day. At dawn, when a laboratory technician came to collect my son's

blood, I fainted. When I recovered consciousness, the mother of another child was taking care of me. She asked if I ate. I said I did not. She gave me crackers she brought to feed her child and herself. I ate and felt better. I thanked her for her help. She said ‘we’ (the mothers of hospitalized children) should support each other. She asked me to take care of her daughter while she went to the washroom. I gratefully thanked her for her support again and took care of her daughter. My son was discharged from the hospital the following morning. She stayed in the hospital with her daughter, and I did not see her anymore. I share my personal experience of coping with hospitalization of my son because in my fieldwork I met mothers and grandmothers who had their children and grandchildren hospitalized due to malaria. As they did, I felt alone, displaced, and sad in seeing my son and other children sick.

On another occasion when I was in Careiro, my mother-in-law called to say that my son was in the hospital again. I learned it after 9:00 pm, so I was not able to drive to Manaus because the ferryboat did not operate at late hours. I wished to take care of my son and support my family in that moment but the distance and lack of transportation services in Careiro prevented me from doing this. On that day, I experienced what geographic isolation and difficulty of access means. This time, my son had a throat infection, and was discharged from the hospital soon after seeing a doctor. During fieldwork, my son experienced many respiratory issues. I did not panic because of this. Rather, I accepted it as a process of him opening onto the world. I also remembered that I had similar illness experiences during my childhood.

When I lived in Manaus from 2004 to 2010, I did not have children and was a public health worker whose experiences of illness were my own, and health care

assistance was provided by private health services. The experiences of having my son sick provided me with a different perspective about people's struggles with illnesses and brought me close to the experiences of my own research participants. Therefore, from a former public health worker and a PhD student, I became a person who was dealing with illnesses in my family and fieldwork routines. These experiences enabled me to have more empathy for what people were experiencing.

Establishing rapports and reflexivity in the field

As Pink (2001, p. 20) noted, "it is not solely the subjectivity of the researcher that may 'shade' his or her understanding of 'reality', but the relationship between the subjectivities of researcher and informants that produces a negotiated version of reality". Thus, in ethnographic research, researchers should clarify about the position they take in the field, how research participants perceive the researcher's presence in their homes and daily lives, and how these aspects may interfere with the experiences that research participants share with the researcher (Bernard, 2000; Lichterman, 2015).

On my first visit to the malaria facility of Brasileirinho community and Careiro I was in a different position from that of a public health professional. I was not there to say what endemic disease control agents should do or to lecture Ribeirinhos about malaria. Rather, I was there to cordially ask their collaboration in my research study. Thus, I introduced myself as a PhD student who was there to learn with Ribeirinhos about their experiences and practices of malaria. I explained to endemic disease control agents that I needed their help in my research study because they knew these communities intimately. Hence, they were best to guide me to Ribeirinhos' homes, and introduce me to them. The endemic disease control agents granted their support to my research study because they

found it interesting and different from other studies that they provided support, namely clinical and entomological research. Their support to my fieldwork was essential, as they are the agents by which public health policies infiltrate Ribeirinhos' private spaces and lives. Endemic disease control agents introduced me to Ribeirinhos, but they did not stay during the time I talked to or interviewed my research participants. I appreciated their support in the recruiting process, but predicted that their presence would affect Ribeirinhos' willingness to talk to me spontaneously. In one instance, an endemic disease control agent remained in the Ribeirinho's home with me. I noted that my research participant became very quiet and distant from me. Conversely, when I visited him alone, we talked about issues beyond experiences and practices of malaria. Later on, I was told that often endemic disease control agents visit the homes of Ribeirinhos unannounced and uninvited; other times, these do not come when Ribeirinhos need their assistance. I then understood that animosities, distrust, and resentment occur regularly as privacy is disrupted, and adequate care is not provided.

When first contacting Ribeirinhos, I introduced myself as a PhD student from a Canadian university and who was also a visiting student in the Tropical Medicine Foundation. I explained that I am a Brazilian citizen, who lived in Manaus for many years, and who was living in Canada to conclude my studies. After having said that, I was afraid of being perceived as a highly educated woman, who was in their communities to only take their knowledge and time. Therefore, I shared with them my familial origins. I told them my parents were raised in low-income families from the Brazilian state of Rio Grande do Sul, both of whom were born into large families like Ribeirinhos' families. My parents have three to five years of education. My mother was prevented from

attending school because she needed to help her mother with household chores and rearing her six siblings. Similarly, my father had to work in the vegetable garden of his family; he had neither shoes nor clothes to attend school. Sharing my humble origin with Ribeirinhos brought us closer because they knew that I was familiar with the socio-economic hardships and daily struggles most of them experience on a daily basis.

I told Ribeirinhos that I was there to do a research study to learn from their experiences and practices of malaria. To my surprise, Ribeirinhos were very familiar with the word *pesquisa* (research). They told me stories of many students and researchers who came to their homes examine their bodies or to collect their blood, as well as to *pescar mosquitos com uma rede*³⁰ (to ‘fish’ mosquitoes with a net), to help professors from Manaus, who are looking for a cure for malaria. On one occasion, a Ribeirinho told me that a student called Clara (or Clarinha as he referred to her) brought him a *pupunheira* seed (*Bactris gasipaes*) from a delicious *pupunha* she ate. He laughed and said that, “the problem *vizinha* (neighbour) is that she didn’t even know that the seed died after the *pupunha* was cooked!” From such stories of visiting researchers, it became apparent that their attitudes and scientific practices become the subject of jokes among.

When I told Ribeirinhos that I had not ever had malaria, some looked puzzled, perhaps trying to figure out why a student/individual who never had malaria would want to learn from their malarial experiences. As I asked questions to Ribeirinhos and endemic disease control agents, I was also questioned about my personal life. They wanted to know if I was married, if I had children and what Canada was like. I told them I was married and had a three-year-old son. I explained that I preferred to leave my son with his

³⁰ In this case, Ribeirinhos referred to entomological procedures employed in studies investigating biting behaviour of malaria vectors.

grandparents to focus on my study. They understood my decision because this reality is also lived by many women in their communities, and Ribeirinhos often take care of their grandchildren as well. I told them of my experiences in Canada.

As Ribeirinhos' homes are usually far apart, I visited them by truck. As the vehicle belonged to the state government, I was asked if I worked for the government. I emphasized that I did not work for the government, and that truck was temporarily loaned to me to support fieldwork. Having a truck also brought me close to Ribeirinhos because some took a ride with me to downtown and other places. When someone asked me for a ride to a malaria facility, I waited for about 45 minutes to an 1 hour to bring them back to their homes. In some cases, I took care of babies and played with children while mothers waited for the results of malaria test. When people rode with me, we talked about work, the time living in the community, the poor quality of roads, health issues, and malaria, of course.

As the time went by, I was known in the study communities as the *pesquisadora do Canadá* (researcher from Canada). On one occasion, a research participant told me a Ribeirinho would like to talk to me because he needed my help. I went to his home, and he introduced me to his children. He asked for my help to book a doctor appointment for one of his children because he needed a doctor's statement about the child's mental health to request *aposentadoria por invalidez* (government disability benefit) for her. I explained to him I did not work with doctors in Careiro and was not in a position to do so. When I left his home, I headed to the community health agent's home and appealed to her to schedule a doctor appointment for his child. She took note of the child's father's name, and told me she would visit the family soon.

Gradually, I was accepted in the Ribeirinhos' homes. I was offered food, tropical fruits, coffee, sweet treats, *garrafas de chás* (tea bottles), and medicinal herbs. Initially, I did not feel comfortable in accepting their food; I thought they should save it for themselves, but I decided to accept it. In exchange for their generosity, I gave crackers, bread, juice, candy, and balloons. In both study locations, I received comments from my research participants and endemic disease control agents that I was the first person who intended to learn with Ribeirinhos.

I was warmly welcomed in research participants' homes. Usually, I shook hands with men and was hugged by women and children. As I spent some months in their communities on many occasions we met on roads, in the community school, and in their neighbours' homes. While my role as a 3-year-old boy's mother, and daughter of low-income parents allowed me to build rapport with Ribeirinhos, my experience of taking care of a sick child prepared me to empathize with Ribeirinhos' experiences of malaria.

Research methods to learn about Ribeirinhos' experiences and practices of malaria

I drew on participant observation, semi-structured interviews, and photographs to understand Ribeirinhos' meanings, experiences, and practices of malaria. DeWalt and DeWalt (2002, p. 1) noted that participant observation is, "a method in which the researcher takes part in the daily activities, rituals, interactions, and events of a group of people as one of the means of learning the explicit and tacit aspects of their routines and their culture". Participant observation, DeWalt and DeWalt highlight, is both a data collection method which improves the quality of data gathered in the field, and an analytical tool that strengthens the interpretation of data. That being said, my participant observations consisted of conversations with Ribeirinhos, endemic disease control agents

who guided me to Ribeirinhos' homes, and those I met in my research participants' homes when doing malaria active case detection, blood collecting, medication delivering, and insecticide spraying in dwellings (only in the Brasileirinho community). I visited the school of the Brasileirinho and Panelão community, and spoke with Ribeirinhos who worked there. As diagnosis and treatment approaches were often mentioned by my research participants, I felt a need to understand how these interventions were carried out. Hence, I also observed how patients with malarial symptoms were screened, how blood was prepared and analyzed microscopically, and how medications were dispensed to patients. These observations were conducted in the Brasileirinho community, Careiro, and in the Tropical Medicine Foundation in Manaus. I also visited technicians responsible for epidemiological reports to learn about incidence of malaria as this information is not publicly available.

Ribeirinhos told plenty of stories of malaria. We talked about the frequency they came down from malaria; family struggles with the illness; intensity of each malarial bout; followed and interrupted treatments; persons who had several malarial bouts in the community – the *campeões de malária* (champions of malaria) in their words; homemade treatments; water, wind, microbes, and mosquitoes that transmit malaria; insecticides spraying; alternative practices of avoiding the illness. We also spoke of how their communities were founded, issues such as precarious roads and lack of quality public transportation, violence, and deficits on malaria services, among other issues. Stories, objects, structures, human and non-human beings, technologies, and government policies enumerated by Ribeirinhos constitute examples of what I call entanglements; that is,

things, beings, and relations that connect malaria pathogens, mosquito-vectors, affected bodies, and public health technologies.

The research participants of my study were selected through snowball sampling (Ritchie, Elam, Tennant, & Rahim, 2006). To do so, I established as inclusion criteria that research participants were at least 18 years old, lived in one of the two study communities for at least one year, had had malaria at least once in the last two years, and agreed to participate in the research activities. Ribeirinhos and endemic diseases control agents referred those they judged as having relevant experiences and practices of malaria to share. Hennick, Hutter, and Bailey (2001) noted that, snowball sampling is the ideal strategy to select hard to reach populations because subjects refer other individuals they know to have profiles that interest the researcher. However, this recruitment strategy can result in a composition of sampling in which research participants share the same socio-cultural characteristics; consequently, the sampling may be subject to bias. To ensure the variability of practices and experiences of malaria, I identified different geographic points within the study communities to recruit my research participants. I visited all subjects who were referred to me, and made a list of potential research participants I thought would be interesting to follow on a regular basis, and carry out interviews.

To broaden my understanding of malaria I selected 30 Ribeirinhos (15 Ribeirinhos in each study community), and visited them regularly (See appendix B for detailed information on socio-demographic characteristics of my research participants). Twenty-one women and nine men participated in this study (See appendix C for detailed information on research participants). The significantly larger number of women may be related to the fact that fieldwork activities were carried out during the day, and at that

time, there were more women at home. The ages of my research participants ranged from 18 to 91 years. I observed daily routines within these thirty research participants' homes, and interviewed them. I selected semi-structured interviews as proposed by Minayo (2007), as this interview style allows research participants freedom to express, in their own terms, perspectives about the phenomenon under study. I also benefited from this type of interview in that I identified topics that would be included in or excluded from the interview guide. During the interviews, I followed a pre-elaborated guide (Appendix D), but I remained open to follow new directions on the questions to attend to new subjects introduced by the research participants.

I scheduled the interviews with Ribeirinhos who agreed to participate in my ethnographic study, and emphasized that their experiences would be kept confidential; therefore, they could talk about malaria and malaria services without fear that their opinions would be exposed. Respect and trust were fundamental aspects of our meetings. Upon my request, my research participants allowed me to record interviews with a digital voice recorder, and to take pictures. One of my research participants was illiterate. In this case, I got his fingerprint on the informed consent form (Appendix E).

During the interviews, I noted that my questions were not reaching out enough to Ribeirinhos; so, I rephrased them until the meaning was understandable. For example, this issue happened when I asked research participants, "how do you get malaria?" Some interlocutors replied, "what did you mean by that?" I asked again, "how did you get sick from malaria?" Most research participants understood the question in this way. However, one Ribeirinho did not. So, after figuring out a better way to re-phrase the question again I asked her, "how did malaria get inside of her body?" She promptly shared her

experience of getting caught by malaria when she and her kids bathed on the *igarapé* located a three-minute walk distance from her home. Another issue of the interviews was that some Ribeirinhos replied to questions with information that endemic disease control agents disseminate in their communities. For example, when I asked, “how did you get sick from malaria?”, Ribeirinhos answered me, “well, according to the man (endemic disease control agents), I got malaria from a mosquito”. Using humor, I asked if what they told me was what they themselves thought about it or if it was what the endemic diseases control agent told them. Ribeirinhos laughed when I asked this, and later told me that was what the endemic disease control agent told them, but they had a different opinion. In a different situation, one research participant surprised me when she asked if she could speak the truth during the interviews. I ensured that she could share her experiences because I was not there to judge or expose her opinions.

Interviews were conducted in the Ribeirinhos’ homes, under trees, or on verandahs. All interviews were carried out in Portuguese, and lasted for 1 to 1.5 hours (Appendix E). Interviews were audio-recorded, transcribed into Portuguese, and translated into English. At night, I listened to the interviews, and, when necessary, I clarified with my interviewees parts of the conversation that were not clear. I used a word-processing program to create a file with all transcribed interviews. I created pseudonyms to ensure anonymity of my research participants. As my focus was on Ribeirinhos’ lived experiences of malaria, I did not plan to interview endemic diseases control agents, or other health professionals who work in the malaria prevention and control program from the state of Amazonas. I acknowledge, however, that their perspectives about malaria would have made the discussions stronger. In contrast, it is

important to note that Ribeirinhos also work as endemic disease control agents. Two of my research participants currently work or worked as endemic disease control agents.

I also resorted to photographs to register visual aspects of Ribeirinhos' daily routines, and their experiences of malaria. Pink (2007, p. 28) noted that, "photography can inspire people to represent and then articulate embodied and material experiences that they do not usually recall in verbal interviewing. More generally, visual explorations produce useful data for understanding how people experience their social and material environment". The photographs were used to record Ribeirinhos' realities, and further to support conversations about malaria transmission sites and plants used in homemade treatments. My research participants were familiar with photographs and did not feel intimidated by the tablet and camera I used to capture the images. After I took pictures, I showed the images to them. Then, together we looked at the images and discussed how they were related to malaria. I took notes of our conversations about the photographs. The use of photographs provided my research participants with a different perspective of the reality they were immersed in. For example, a research participant told me she stays inside home at dusk to prevent malaria-carrying mosquitoes from transmitting the disease to her. When she looked at an image of her home, she noticed gaps in walls and ceiling of her dwelling. She then said that even staying at home is not an effective way to avoid the sickness, because mosquitoes can enter through gaps in the house structure. In all instances where I used photographs, notes of conversations about the images were taken.

Pink (2007) observed that though photographs record visible characteristics/elements of a reality, they may be intrusive in that the researcher registers research participants' routines and homes. My research participants granted me the use of

their images, and were with me at the moment their images were recorded. To attend to these ethical issues, I initially planned to register places, medicines, and routines of malaria control interventions performed in Ribeirinhos' homes, but my research participants wanted to appear in the images holding, for instance, their plants, teas, and mosquito nets.

To make sense of what I learned through my numerous methods, I used multiple sources of data collection to allow for data triangulation (Denzin, 2009). The following data were used in the triangulation: notes of participant observation obtained from conversations with my research participants; health professionals I met in Ribeirinhos' homes; transcripts of interviews; and field notes about the interpretation of photographs. In the interpretation of the data, I also resorted to textbooks about malaria, databases about medicinal plants, reports about malaria interventions, guidelines of malaria treatment, and vector control interventions.

Thematic analysis (Braun & Clarke, 2006) was employed to analyze the collected data. I chose thematic analysis because this method, "provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data" (Braun & Clarke, 2006, p. 5). To do so, I transcribed the interviews and organized notes of participant observation obtained through informal conversations and discussion about the photographs. I read and re-read transcriptions and field notes to become familiar with the data. Prior to interpreting the data, I elaborated a list of questions about meanings associated with malaria; how it is called and felt by Ribeirinhos; local explanation about the sickness causation; diagnostic, treatments, and preventive practices, among other questions. These questions guided initial interpretation

of data and based on this, I generated initial codes. Braun and Clarke (2006) observed that codes describe interesting features of the data. Thus, based on these features, I highlighted excerpts of transcribed data and field notes, and collated them in their respective codes. I elaborated descriptive codes, such as experiences of falling sick from malaria, and interpretive codes like fear of having malaria again. After the elaboration of codes, I organized them into potential themes. I then went back to the transcription of interviews and field notes to select extracts of data to support each theme. I named the themes, and then I read the transcripts and field notes again to check for new codes and themes. Data analysis was carried out without use of software.

The themes guided the elaboration of the three manuscripts presenting the findings of the study. In the first manuscript, “Riberinhos’ experiential knowledge, suffering and vicissitudes of having malaria in the Brazilian Amazon”, seven themes were elaborated: Symptomatology and common ways malaria is experienced through the body; Nosology: Classification of malaria according to experiential knowledge; Etiology: Encounters between humans and malaria vectors; Health care-seeking practices: The place of experience in discerning malarial bouts from other sicknesses at home; Misalignment of body and biomedical diagnosis of malaria: From technologies to (mis)information; Malarial infections and the becomings of bodies and experiences; and Vicissitudes of having malaria.

In the second manuscript, “Entangled pharmacopeias: Ribeirinhos’ lived experiences and treatment practices for *Plasmodium vivax* in the Brazilian Amazon”, five themes were elaborated: Malaria pills: Essential but unpleasant; Perceived effects of antimalarial medications; Malaria pills: Suffering to be endured; Healing from inside out:

Invigorating the sick individual; and Malaria and homemade treatments as relations.

Finally, in the third manuscript, “Porous malaria vector control interventions:

Ethnographic tale of clever malaria mosquitoes and tenacious Ribeirinhos from the Brazilian Amazon”, four themes were developed: Cohabiting with mosquitoes; Everyday practices of chasing mosquitoes away; Public health strategies to fight malaria-carrying mosquitoes (TMR, IRS, ITN); and Malaria: treatable, but not preventable.

Conclusion:

In this chapter, I described how I entered the field and the methodological trajectory that allowed me to learn from Ribeirinhos with regards to ways malaria is lived in the Brazilian Amazon. In the next chapter, I present three manuscripts that examine, through Ribeirinhos’ perspectives, the three main strategies used to control malaria in the Brazilian Amazon, including diagnosis, treatment, and vector control interventions. The conclusion of the thesis is presented after these manuscripts. This brings all strategies and Ribeirinhos’ experiences together as part of the same entanglement. In addition, I discuss contributions of the study, and how its findings provide insight into blind spots of current malaria control interventions in Brazil. Finally, I offer some potential routes for further research on the topic.

Chapter 4

Manuscript title:

Ribeirinhos' experiential knowledge, suffering, and vicissitudes of having malaria in the Brazilian Amazon

Abstract

This paper focuses on the multiple ways, in which Ribeirinhos experience malaria in their homes and communities. It describes the local understanding of malaria, strategies to distinguish the illness from other febrile sicknesses, how it is socially lived, challenges for detecting the disease through biomedical diagnosis methods, and vicissitudes of having malaria in the Brazilian Amazon. It draws on cases of Ribeirinhos from a peri-urban community of Manaus and a rural community from Careiro, state of Amazonas, Brazil. Although malaria is biomedically characterized by the pathogens causing the disease, Ribeirinhos have developed other standards to define malaria including the intensity of symptoms, the interval between the infections, and the types of medications dispensed to them. In the riverine communities I studied, the etiology of malaria includes mosquitoes, microbes, water, wind, sun, and person-to-person transmission. Malaria is bodily and socially experienced as a sickness that depletes vitality and damages the liver and blood. Symptoms of malaria were found to overlap with other febrile sicknesses. Hence, they developed skills to monitor how a malaise unfolds in their bodies. Experiential knowledge of malaria plays a key role in the early detection of the sickness. Individuals who have no previous experience with malaria were found to spend more time seeking health care than those who had multiple malarial bouts. Equally important, Ribeirinhos perceive that malaria is part of the landscape they inhabit.

Keywords: Medical Anthropology; Malaria; Ribeirinhos; Experiential knowledge, Local understandings, Biomedical diagnosis; Brazilian Amazon

Background:

Malaria is a parasitic disease transmitted to humans by female *Anopheles* mosquitoes infected with a pathogen known as *plasmodium*. Its occurrence in Brazil dates back to the colonial period (from the 14th to 19th centuries), where malaria cases were reported in almost all areas of the country (Benchimol & da Silva, 2008; Camargo, 2003; Hochman, 2009). Currently, malaria transmission occurs in the states of the Brazilian Amazon basin (Brasil, 2003). The state of Amazonas, where I did my fieldwork, has the largest territorial extension of Brazil (1,559.161 km²), 98% of which is covered by pristine forests; it also has one of the largest freshwater springs in the world (Governo do Estado do Amazonas, 2016). It is estimated that 4 million people live in the state of Amazonas, that is, 2% of the total population of Brazil (IBGE, 2016). It is the second most populous state of the Amazon region (Ibid). Approximately 20% of the population lives in a rural setting, 30.78 % live in poverty, 16.43% live in extreme poverty, and 24% of children live in extreme poverty (Programa das Nações Unidas para o Desenvolvimento, 2014). Malaria stands out as the main infectious disease in the state. Within the populations of the state of Amazonas, riverine people, commonly called *Ribeirinhos*, are among the individuals frequently affected by the sickness.

Within the medical anthropology literature, three terms distinguish different conceptual systems related to disease, illness, and sickness. Despite the fact of these terms are colloquially and interchangeably used, they refer to distinct ontological realities. Eisenberg (1977, p. 11) noted that, “patients suffer 'illnesses'; physicians diagnose and treat 'diseases'. [...] [I]llnesses are *experiences* of disvalued changes in states of being and in social function; diseases, [...] are *abnormalities* in the *structure* and

function of body organs and systems”. Eisenberg draws on the concept of disease to highlight body pathologies that an individual is affected by, whereas he refers to illness to underline individuals’ psychosocial experiences because of a disease. Young (1982) observed that despite concepts of disease and illness taking the individual as their point of reference to provide explanatory models, both concepts fall short because they desocialize the sufferer’s experiences. Attending to this conceptual flaw, Young (1982, p. 270) referred to sickness as a “process of socializing disease and illness”. Young (Ibid) also stated that,

[e]very culture has rules for translating signs into symptoms, for linking symptomatology to etiologies and interventions, and for using the evidence provided by interventions to confirm translations and legitimize outcomes. The path a person follows from translation to socially significant outcome constitutes his sickness.

By nuancing these concepts, I clarify that in this paper, I am interested in all three aspects of malaria intertwined; that is, as a disease-entity that is experienced bodily (illness) and lived socially (sickness). In addition, the disease-entity is a socially constructed category pertaining to biomedical thought; a category that is lived and felt in multiple ways. Accordingly, I take inspiration from Merleau-Ponty’s phenomenological approach to describe Ribeirinhos’ experiences of malaria, and to understand the illness as a form of existence, rather than a pathological event enclosed in the body. Furthermore, I draw on critical studies in medicine, science, and cultural phenomenology (Csordas,

1994) to understand how Ribeirinhos articulate malaria and its biomedical interventions into their everyday lives.

In what follows, I focus on Ribeirinhos' experiential knowledge of malaria in the Brazilian Amazon. In this study, experiential knowledge is understood to be a form of knowledge that is built upon individuals' own experiences of health, sickness, and well-being. Experiential knowledge, scholars argue, includes the embodiment of biomedical knowledge to which people have access to through health education campaigns, and conversations with health professionals, among other media (Caron-Flinterman, Broerse, & Bunders, 2005). That being said, in this paper, I ask how Ribeirinhos experience and deal with malaria outside of a clinical setting. My intent is to show the local strategies used to discern malaria from the other febrile sicknesses Ribeirinhos commonly experience, as well as clarify the dynamics that emerge when someone falls sick. Although I describe local experiences of malaria, I do not compare them against scientific knowledge of the disease; rather, my argument offers an illustration of multiple ways of knowing about and intervening in malaria beyond a clinical setting.

In Brazil, malaria services rely on two main diagnostic methods for detecting malaria in humans: microscopic diagnosis using stained thick blood smears, and rapid diagnosis tests (Brasil, 2009b). Particularly in the state of Amazonas, health education campaigns highlight that access to diagnosis and treatment is the main care approach to "fight" malaria in the "human host". Efforts to reduce the incidence of or eliminate malaria require close attention to ways afflicted people deal with malaria in their dwellings and communities. Populations have, after all, always played an active role in public health interventions aimed to control malaria. The reduction of 76.8% of malaria

incidence in Brazil between 2000 and 2014 (PAHO, 2016), for example, was likely achieved with the participation of the local population. Recently, the WHO acknowledged that the success of malaria programs also depends on the participation of individuals living in malarious regions (WHO, 2015b). This study elucidates the particular ways in which malaria and its public health interventions intersect with the lives of the Amazonian riverine people from Brazil.

Methods:

This study draws on ethnographic design. According to Ellis (2004, p. 28), ethnography means, “writing about or describing people and culture, using firsthand observation and participation in a setting or situation”. Overall, ethnographic studies allow, “a real historical agency to the people who figure in them” (Ingold, 2014, p. 385). With that in mind, my ethnographic study was conducted between January and April 2015, in two locations: a peri-urban area of Manaus called the Brasileirinho community and in a rural area of the Careiro municipality, called the Panelão community. Both communities are malaria endemic areas and have been targeted by malaria interventions over the years. The ethnographic design I chose allowed me to attend to multiple ways malaria unfolds in Ribeirinhos’ lives.

I used snowball sampling (Ritchie et al., 2006) as recruitment strategy. Ribeirinhos and endemic disease control agents (EDCA) referred potential research participants to me. A total of 30 Ribeirinhos were followed on a regular basis and interviewed. For the purpose of this paper, I drew on participant observations (Ingold, 2014) reporting how EDCA perform malaria diagnosis in patients’ homes, and conversations and interviews with Ribeirinhos. I also used photographs (Pink, 2014) to

record routines of malaria diagnosis. The interviews (Minayo, 2007) were conducted in Portuguese and were taped recorded. As I participated in Ribeirinhos' daily lives, my observations described their interactions with EDCA, my own interactions with people dealing with malaria, and settings I have visited. Observations were recorded as field notes. Participant observation provided insight into how malaria is experienced from the perspective of individuals who deal with malaria as patients.

I used data triangulation (Denzin, 2009) to analyze the Ribeirinhos' experiences of malaria and their perceptions regarding to biomedical diagnosis, and to attain data saturation. Secondary sources of information, including biomedical textbooks, transcripts of interviews, and field notes were triangulated in this paper. Thematic analysis (Braun & Clarke, 2006) was the method that I used to analyze data from interviews and field notes. In this study, themes were first identified inductively and then deductively. Ribeirinhos' experiences of malaria were organized into themes, which I present in the next section.

Results:

Symptomatology and common ways malaria is experienced through the body

Ribeirinhos who live in the Brasileirinho and Panelão communities were unanimous in saying that malaria is the most common sickness afflicting them. Within these contexts, malaria is defined as sickness that impairs one's liver and that *chupa* [sucks; consumes] one's blood. Ana Maria, a 43-year-old-woman and house worker, noted that, "the pathways by which the blood disappears are unclear since the only occasion I saw blood coming out of my body was when my finger was pricked to do the malaria diagnosis" (Ana Maria, Brasileirinho community). On many occasions Ribeirinhos mentioned that when someone is affected by malaria their eyes and skin

become yellowish, their lips turn purple, their mouths develop a bitter taste, and the person suffers from chills despite the warmth of the Brazilian Amazon. Otávio, a 38-year-old-man, and freelance industrial butcher, described how the first symptoms of malaria manifest:

When I have malaria I feel severe headaches, cold, fever...I feel impatient...I want to eat, but a bitter taste spreads through my mouth even before taking the malaria pills. Then when I take the pills, I have nausea and vomiting...but how can a person who has eaten nothing vomit? Having malaria is an agony...I felt my body asking for something and I could not help myself. (Otávio, Brasileirinho community)

The majority of Ribeirinhos reported that malarial infections debilitate a person physically and emotionally in such a way that their vitality disappears. The main implications of malaria indicated by my research participants are that this sickness weakens the blood and liver. They inferred that malaria causes anemia because they usually experience weakness and paleness during and after having malaria. Research participants also mentioned that they feel that malaria causes inflammation in the liver and that it may stay *incubada* [incubated] in this organ for months or years after a malarial bout. José Mauro, a 64-year-old man and police officer, explained how malaria affects the liver:

Malaria attacks the liver. It takes off the immunity of liver. I don't know what happens inside me when I have malaria, but something changes. Sometimes I

have the feeling that I partially recovered from malaria...I mean after I had malaria I could not eat the food I like, even salt, oil, sugar...all these things made me feel unwell. I also know that malaria can come back again or it can cause hepatitis too. My granddaughter is sick. The doctor said she has hepatitis and that she got it from water. I'm puzzled with this...I mean the water we drink here is good; it is from a 40-meter deep well. To be honest I think my granddaughter developed hepatitis because she had malaria many times and her liver lost its immunity. (José Mauro, Brasileirinho community).

The majority of my research participants indicated that malaria can return even if the person completes the appropriate treatment. To minimize the risk of malaria returning, Ribeirinhos avoid eating *comidas reimosas* (see Table 4.1). Ribeirinhos defined *comidas reimosas* as foods and beverages with properties that are found to trigger inflammatory processes. Milagres, a 46-year-old woman who works as a seamstress in her own sewing workshop, elaborated on the relation between malaria and *comidas reimosas*:

A person who has malaria cannot eat fried eggs, or eat beans and eggs. She needs to eat something light...soup...fish, but sometimes it is difficult to eat light food because a person who has malaria gets debilitated, loses her vitality...so she cannot work and if she does not work, she will not have money to buy food that is not *reimosa*. This is not a question of choice...if a person eats these *comidas erradas* [wrong food or *comida reimosa*], malaria will come back again because

malaria medications clean the blood, but malaria stays in the liver. If you don't eat *comidas reimosas* for a period after having had malaria, you will recover from it, but if you eat them during the time you are not good yet, malaria will return. (Milagres, Brasileirinho community)

Ana Maria shared her experience when she asked a nurse about the influence of *comidas reimosa* in relapses of malaria:

I asked a nurse if I came down from malaria many times because I ate *comidas reimosas*. She told me that these things of *comidas reimosas* causing malaria are *crendices* [beliefs], myths, *coisas da nossa cultura* (elements of our culture)...This is not true, the nurse said. She also told me I could eat wherever food I want. The only thing I cannot do is to visit a place where there is malaria. The problem is that I live in a malarious area! (Ana Maria, Brasileirinho community)

Among health professionals I met during my fieldwork, associating relapses of malaria with ingestion of *comidas reimosas* is seen as an old-fashioned way of knowing about malaria because it has no scientific evidence linking these foods to the disease recurrences. Such understanding is generally attributed to people from poor socio-economic backgrounds. Chico, a 52-year-old man and peasant, explained the reaction of doctors when he mentioned that *comidas reimosas* cause sicknesses:

Food/beverages	Example
Fish	Cat fish and all leather fish species, ray, pirarucu (<i>Arapaima gigas</i>), matrixã (<i>Brycon cephalus</i>), curimata (<i>Prochilodus lineatus</i>), and piranha
Seafood	Shrimp, crab
Game	Armadillo, capybara, and peccaries
Swine	All pork species and products made of pork
Beverages	Coffee, cupuassu (<i>Theobroma grandiflorum</i>), and bacaba vine (<i>Oenocarpus bacaba</i>)
Fruits	Pupunha (<i>Bactris gasipaes</i>), cupuassu bacaba, and watermelon
Others	Amazonian manatee, eggs, tucupi (kind of sauce made of a wild manioc), chelonias

Table 4.1: Examples of *comidas reimosas* mentioned by Ribeirinhos

Doctors say this [*comidas reimosas*] is a foolish thing...that there is nonsense in saying that *comidas reimosas* can provoke sicknesses. I argue with them! I know by myself that *comida reimosa complica malária no corpo* (complicates malaria in the body). (Chico, Panelão community)

The stories told by Milagres, Chico, and Ana Maria attest to multiple ways people embody and understand the occurrence of malaria.

Nosology: Classification of malaria according to experiential knowledge

In the stories Ribeirinhos told me about their experiences of malaria, scientific names like vivax (*Plasmodium vivax*) and falciparum (*P. falciparum*) malaria were rarely mentioned. Instead, Ribeirinhos indicated that the most common types of malaria affecting them were *malária fraca* [mild malaria], *malária forte* [strong malaria], and the *duas malárias de uma vez* [two types of malaria at once]. These three types of malaria are

experienced through a similar symptomatology. The differences among them, however, reside on the severity of symptoms. In fact, Riberinhos reported that individuals affected by strong malaria sometimes yell due to severe headaches, and that they are affected by *leseira* [dizziness], blurred vision, and, in some cases, *a pessoa apaga* [a person loses consciousness]. In contrast, in the case of mild malaria a person experiences pain and dizziness, but they do not pass out. Marcos, a 48 year-old-man and farm caretaker, shared his experience with strong malaria:

It was a malaria I was not prepared for...its symptoms were so strong that I passed out, I was very bad...I had terrible headaches, cold...I felt weak, dizzy, and could not walk without the help of my wife...Even though I had not eaten anything I *provoquei* [vomited] a lot...I *provoquei* a green thing [bile]...it was horrible. (Marcos, Brasileirinho community)

Most Ribeirinhos reported that, strong malaria now rarely appears in their communities. Within these communities, memories of past outbreaks of strong malaria were narrated through a metaphor that weaves together stories of people and animals that were affected by the sickness. Luzinete, a 51-year old woman and peasant, explained:

Some years ago, malaria *não tinha pena de ninguém* [was merciless of us all]. It affected everybody, my family, myself, my neighbours, and my pigs and chickens. I saw the poor animals shivering because of strong malaria. (Luzinete, Panelão Community)

The third type of malaria mentioned by my research participants occurs when an individual develops both the mild and strong forms of the malaria at once, or comes down with a different type of the sickness directly after finishing the treatment for a previous malarial bout. Indications that an individual may have another type of malaria are that malarial malaise does not clear up when they are taking antimalarial medications for either vivax or falciparum malaria, or when the malaise persists after the pharmaceutical treatment ends. I asked Marina, a 25-year-old woman and house worker, how a person knows if they are afflicted by two types of malaria at once, and she explained:

I was taking the pills for a type of malaria but I continued to shiver...I shivered all the time. So my grandmother asked the *agente* [EDCA] to prick my finger again. He did it. Few hours later he came back and told me I had another malaria. He said that it was not the same malaria I was taking the *piulas* [pills]; rather, it was another and I had to take other kind of medication besides the medicines I was already taking. (Marina, Panelão community)

Another way that Ribeirinhos have developed to discern types of malaria is to observe kinds of medications provided to them by malaria services upon microscopic confirmation of the disease. However, Ribeirinhos did not mention the names of the medications used, including chloroquine and primaquine for treating vivax malaria and coartem or lumeter for treating falciparum malaria. Rather, they explained that they were often treated with medications dispensed in five to seven separate small paper bags. They

treated themselves with one bag of pills once a day. Yet, some Ribeirinhos reported that they sporadically received pills packaged in *cartelonas* [large plastic blisters], to be taken in mornings and evenings. Dalva, a 45-year-old woman and peasant, explained how she perceived she was affected by different types of malaria:

The first time I had malaria, I received the *piulas* in *cartelonas* and I took them in mornings and evenings for three days, I think. Those *piulas* [lumeter or coartem pills] were different from the ones I received when I had the second malaria. In the second time the *piulas* came in seven small paper bags. During seven days, I took them once a day. In the first days of the treatment there were a lot of *piulas* inside the bags, I mean the big ones [chloroquine] and the small ones [primaquine]. Near to the end of the treatment there were only two small pills to take. (Dalva, Brasileirinho community)

Ribeirinhos' experiences of malaria show that, in their homes and communities, biomedical categories commonly used to link malarial infections to the infective parasite are not used. Rather, the nuances of the types of malaria relate to the intensity of symptoms, the interval between infections, and the medications taken.

Etiology: Encounters between humans and malaria vectors

Within the study communities, the understanding of how malaria is transmitted to people varied substantially. Irma, a 60-year-old woman and peasant, Lauro, a 51-year-old man and farm caretaker, Patricia, an 18-year-old woman and house worker, and Carlos, a 50 year-old-man and farm caretaker, explained their views of how a person may come down with malaria:

The *agente* told me that we get malaria from *carapanãs* [mosquitoes], and I believe that is true. But I also think we can get malaria from the sun. I say this because once my daughter was playing in the hot sun, and I think within an hour or so, she came back home and *apagou* [passed out]. At that time, there was a malaria facility here in our community, and I took my daughter there. Later on, the *agente* brought medicines because she had malaria. She fainted in the afternoon, and at that time there were no mosquitoes out there. It was the sun that made her sick from malaria. (Irma, Panelão community)

I cannot say exactly from where I can catch malaria because it is *uma doença* (a sickness) nobody knows from where it comes. I speak from myself...I did not see what makes me sick from malaria...because malaria is a kind of *doença* that when a person realizes something is not good with her...it is malaria. So...I think malaria comes in the wind...that there is something in wind that makes me sick from malaria. Sometimes, I think I can get malaria from water because I bathe in an *igarapé* [small river]...perhaps there is a microbe in the water, and when I bathe in it, microbes enter my body. (Lauro, Brasileirinho community)

I had malaria once and I caught it in my mothers' house. She was recovering from malaria and I drank a glass of water that was not clean...I mean there was malaria in the glass. Soon after I drank the water in that glass I began to feel unwell...with headaches. Few days later I did the malaria test, and it was

positive. (Patricia, Panelão community)

In the morning, I went in my backyard to gather *buriti* fruits [tropical fruit from the palm tree, *Mauritia flexuosa*]. When I came back from there I began to feel a strong headache and cold. Since then, I got worse. I put a red cloth in front my house, so the *agente* would know I was sick from malaria. He came over and pricked my finger. In the afternoon, he brought me *remédios* [medicines]. I think malaria was there in the buriti trees when I was gathering the fruits. (Carlos, Brasileirinho community)

The pathways by which malaria gets inside an individuals' body, which were indicated by Irma, Lauro, Patricia, and Carlos, go beyond the biomedical characterization of malaria transmission and include the sun, wind, water, and people who were previously affected. In some cases, malaria is seen as an entity that enters the body by itself. Patricia and Carlos' views also demonstrate that they feel that malaria happened instantly when they came into contact with the potential malarial agent. In addition to mentioning a number of agents involved in malaria transmission, Ribeirinhos highlighted that malaria occurs in specific settings; that is, riverine people are more likely to develop the sickness. This is why they perceived that they themselves are affected by malaria more frequently than individuals who live away from the water, like in the city. Haroldo, a 34-year-old man and steam boiler operator, detailed on the relationship between malaria and places:

The *agente* told me that the malaria *carapanãs* [mosquitoes] live near to *igarapés* [rivers] and forests. If what he said is really true, here there is malaria

everywhere because there are trees and *igarapés* in all places. Of course, it depends on having a carapanã with the malaria virus. In this case, I agree with the *agente* because I had more than 30 malarias [malarial bouts], and I always lived and still live close to *igarapés*. Thus, I believe that we Ribeirinhos can catch malaria more frequently than people who live in the city. (Haroldo, Brasileirinho community)

When malaria-carrying mosquitoes were implicated in the transmission of malaria, Ribeirinhos inferred that these disease vectors usually attack people at specific time ranges from 5:00 pm to 8:00 pm and from 5:00 am to 6:00 pm. Although Ribeirinhos reported time ranges during which the risk of catching malaria increases, in practice, they challenged this information that was passed on them by public health workers. Lidiane, a 43-year-old woman and civil servant, revealed her disagreement with this information:

Public health workers usually say that to prevent malaria we should avoid going to the forest and bathe in the *igarapés* [rivers], especially during the dawn and dusk. I think this is not true because here in my community there are a lot of children, youth, and seniors who came down with malaria, and they don't go to fishing, swimming, or hunting in the forest. So, I think as we live in the forest, malaria can catch us anytime regardless of the activities we engage in. (Lidiane, Panelão community)

Lidiane's risk perception of malaria as a sickness that may affect people at any time of the day highlights that, in Ribeirinhos' communities, biomedical knowledge is not

easily incorporated into their everyday lives because it does not reflect the reality that riverine people experience.

Health care-seeking practices: The place of experience in discerning malarial bouts from other sicknesses at home

In the conversations with Ribeirinhos, I learned that they have developed multiple diagnosis strategies to distinguish malaria from other sicknesses that are endemic in the Brazilian Amazon, such as dengue fever, chikungunya, and influenza (locally called *virose*)³¹. The classical symptoms of these sicknesses described by Ribeirinhos are cold, fever, body pain, and headaches. My research participants argued that these symptoms overlap with those of malaria. Lene, a 48-year-old woman and peasant, explained how she finds that malaria is indeed the sickness affecting her:

Initially I get a bit confused. I wonder myself, do I have a flu? Do I have sinus infection ? Or do I have *virose*? I know I have malaria because it's different! Oh! There is a detail! Fever caused by malaria afflicts you always in the same time, while fever due to *virose* plagues you all time...that is, all day you feel with fever inside you...sometimes it cools you off and you shiver, you feel body pain and, then what do you do? You take *um remédinho para febre* [a fever reducer] or drink a hot tea. As time goes by, you perceive that the fever calms down and ends. Malaria, in contrast, you can drink a hot tea or you can take a fever reducer and then the fever disappears. You think you recovered from it,

³¹ At the time of my fieldwork, Zika has not been detected in the country.

but in the evening or in the next day, you will have fever again... it is in this moment that you know you have malaria. You feel that bad taste in your mouth. You feel chills inside you. It's hard to convince people who do not know malaria, but these differences exist. (Lene, Brasileirinho community)

Helena, a 62-year-old woman and farm caretaker, Vanderléia, a 30-year-old craftswoman, Paulo a 70-year-old retired man, and Haroldo developed another strategy to determining if the sickness they are experiencing is malaria.

Usually, when the symptoms begin, I think it could be *virose*, but malaria has its own way. I mean, its symptoms appear in a specific hour. So, I look at my watch and mark the time I feel bad. In the next day, if the symptoms appear at the same time again, I know it is malaria. In general, I wait 48 hours to ask the *agente* come to my home to prick my finger. (Helena, Brasileirinho Community)

When I have malaria, I feel a lot of pain in my body. I feel like I am being pierced by thorns [tingling sensation]. I also feel cold and weak like I was almost without blood in my body. So, I begin to self-monitor *o que sinto* [my symptoms] for about three days. If these things [symptoms] persist I try to contact the *agente*. I have neither a phone to reach him nor money to go to the city. So, I ask the guy who drives people from here to the city to tell the *agente* that I need to get tested for malaria. (Vanderléia, Panelão Community)

When I want to know if I have malaria or *virose*, I eat one roasted calabreza sausage; it is a kind of *comida reimosa*. After doing so, I feel very bad due to

severe headaches, body pain, stomach discomfort, this happens because malaria comes out of my body. In the case of *virose*, I can eat many roasted calabreza sausages, and I feel good. As I said, *comida reimosa* worsens [symptoms of] malaria but has no effect on *virose*. (Paulo, Brasileirinho community).

I work as a steam boiler operator, and if I am cold near to the boiler, I know this is a symptom of malaria. I do not fail in distinguishing between malaria and *virose*. Malaria is very different from flu or other sicknesses. Having fever is similar, but malarial fever, that is, the cold caused by malaria is a cold, which is very different. It is like you are in Antarctica! Like you are freezing all over. It is rare I feel sick in a malarial way, and the malaria test shows the contrary. (Haroldo, Brasileirinho Community)

Ribeirinhos who have experienced multiple malarial bouts were more likely to resort to empirical diagnosis practices before seeking biomedical diagnosis. In contrast, Ribeirinhos who had no experience with malarial infections commonly associated a malaise with a variety of previously experienced sicknesses, including urinary tract infections, migraines, *virose*, or heart failure. They were also prone to spending more days at home before seeking health care. Indeed, most of them waited long enough to experience intense pain, desperation, emotional distress, and fear of dying, as Luzia, a 41-year-old woman and peasant, explained:

I had severe headaches that I could not open my eyes. I shivered a lot. I thought I was feeling those things [symptoms] due to a heart issue I have. For many days I cried a lot. I thought I would leave my kids here [thought was going to die].

Four days passed, and I was more and more sick. So, my son came to visit me. When he met me he said, “Mom, I think you have malaria”. He took me to the hospital. There, I was told I had malaria. (Luzia, Panelão Community)

The occurrence of malaria also challenges health professionals at the time of diagnosing the disease. Fever, vomiting, headaches, and body pain are sometimes associated with conditions other than malaria. Rosilene, a 22 year-old woman and house worker, shared her experience:

I was not feeling well for about three days. I had headaches, vomiting, and felt an intense cold. My husband took me to a hospital. I told the doctor I was pregnant. So, he required a urine test. After that I was told I had *virose*. One week later, I was more sick. My husband and my daughter fell sick too. A friend suggested we had malaria. We all got very sick...we threw up many times, had chills, and weakness. We didn't have money to pay for a taxi or bus, so a police officer drove us back to the hospital again. That time my husband asked a nurse for a malaria test. All of us had malaria. It took almost two weeks to know it. (Rosilene, Brasileirinho community)

Ribeirinhos' experiences of malaria attest to the key role of experiential knowledge in seeking early diagnosis. Furthermore, the stories told by Luzia and Rosilene demonstrate that, even in a region where malaria is the prevalent sickness afflicting the population, for certain individuals, Ribeirinhos or medical professionals, it can be misinterpreted as other febrile sicknesses/diseases.

Misalignment of body and biomedical diagnosis of malaria: From technologies to (mis)information

The main way to access antimalarial medications recommended by BMPCP is to perform a malaria diagnosis test. However, the decision to be tested for malaria does not necessarily mean that it will be detected early. Many Ribeirinhos indicated that, on some occasions, they were screened for malaria multiple times because the disease was not promptly identified in their blood. From the time that Ribeirinhos experienced malarial symptoms until the confirmation of the disease through biomedical diagnosis (See **figure 4.1**), they struggled to maintain their day-to-day routines and responsibilities, including working, studying, and leisure activities. Giselda, a 49-year-old woman and peasant, shared her agonizing journey until the biomedical confirmation of her malaria.

There has been about two years since I had my first malaria. I felt a malaise...strong headaches, and dizziness. I couldn't walk by myself. I needed someone to hold me otherwise I would fall on the floor. I asked my neighbour to tell the *agente* I was sick. The *agente* came to my place and did the *lâmina*, but the test was negative for malaria. I continued to feel sick...I shivered a lot and was numb. My boyfriend called the hospital in Careiro and an ambulance was sent to pick me up. In the hospital, I was tested for malaria and, again, it was not detected. The doctor said I had urinary tract infection. He prescribed medications and sent me home. Two days after, I got worse...and you know that here everything is difficult...access is difficult...money is not easy too. Anyway, I got a motorcycle-taxi to Careiro and from Careiro I took a bus to Manaus. It

was a long journey because I was feeling depleted of my forces...[I was] very weak indeed, and the ferryboat was not fast. My sister was waiting for me in the Ceasa port in Manaus. From there we went to a hospital, and finally I learned I had malaria...vivax malaria the doctor said. I didn't stay in the hospital, but I did the treatment in Manaus because I didn't trust the malaria services offered here. (Giselda, Panelão Community)

Difficulties arising from current biomedical tools used to diagnose malaria were reported by many of my research participants. Marcos, a 48-year-old man and farm caretaker, attributed delays in detecting malaria to laboratory technicians' lack of skills in analyzing the glass slide and/or the use of old equipment to perform the diagnosis.

I had my finger pricked four times, but malaria was not detected. But I continued to weaken...I went to work and felt terribly bad. When I arrived at home I lay down on the sofa because I was tired, weak, and in pain. My neighbours told me, “*Homem* [man], you should go to the Tropical [FMT]”. I took a day before I felt I needed to go to the Tropical [hospital]. I asked my son-in-law to drive me to the hospital. There I finally learned I had malaria. I do not know why there they [health professionals] found malaria in my blood so quickly. I think their health professionals are more prepared to examine the *lâmina* [glass slide] or the [diagnostic] equipment is better than those of the *casa da malaria* [malaria facility] close to my home. (Marcos, Brasileirinho community)

In a conversation with another Ribeirinho, she also told me that on some

occasions she had her finger pricked more than two times before malaria was identified by the biomedical test. She asked an endemic disease control agent why the disease was not detected in her blood sooner:

The *agente* pricked my finger three times or so and said that I didn't have malaria. The problem was that I continued experiencing strong headaches. I took dypirone [a brand of pain killer used in Brazil], but the pain didn't reduce. I was sure I had malaria. So, I asked him why this happened...I mean...why I felt I had malaria but the test was negative. He said that some medications used to relieve fever or headaches influence the results of the *lâmina*. That is, malaria does not appear in the blood if a person takes strong medications. (Cleide, 27-years-old, Brasileirinho Community)

Many of my research participants followed endemic disease control agents' recommendations of avoiding fever reducers and painkillers prior to performing biomedical diagnosis. Overall, Giselda, Marcos, and Cleide's experiences illustrated the suffering they endured until the disease was diagnosed, as well as their arduous journeys when they have sought malaria care outside of their communities.



Figure 4.1: EDCA collecting blood of a patient presenting malarial symptoms

Malarial infections and the becomings of bodies and experiences

The majority of Ribeirinhos stated that malarial bouts cause physiological and existential changes in them. Thus, some reported that their bodies changed and are still changing after they have been afflicted by malaria. Weakness, fatigue, intolerance to fatty foods and *comidas reimosas*, and occurrences of side effects of malaria medications are some examples of physiological changes indicated by my research participants. In the existential domain, Ribeirinhos mentioned that after the third or fourth malarial bout they

became able to recognize and deal with pain and discomfort caused by the illness. Felipa, a 48-year-old woman and peasant, said:

The person who already had three malarial bouts knows very well *os sintomas desta doença* [the illness symptoms]. I know that when I feel headaches and chills, these are symptoms of malaria, so I call the *agente*. He performs the test and it shows I am positive for malaria. I learned by myself, I mean, malaria taught me its symptoms. (Felipa, Panelão community)

Ribeirinhos' previous experiences of malaria prepared them for perceiving if a relative or friend is sick from malaria, because an individual who is affected by malaria looks tired, pale, sad, and, some become aggressive. Carlos explained how he identifies malaria in himself and in other individuals:

In the first days, a person is being afflicted by malaria, she begins to lose a bit of blood in her face; she becomes pale. I can perceive changes in the hollowing of her cheeks...paleness is on the person's face...these are symptoms of malaria. Further, severe headaches, body pain, and discomfort caused by intense vomiting, cold, and shivering turn an energetic individual into a languid person, a calm subject into an aggressive one, and a dynamic person into a temporarily disabled individual. (Carlos, Brasileirinho community)

I asked Felipa and Carlos about the main implications of becoming able to identify their own possible malarial bout as well as those of others'. They explained to me that by having had many malarial bouts, their role in the community changes. That is, they can help others to both understand what is it to be sick from malaria and share

practices on how to deal with it, such as recommending traditional treatments to help them recover from the sickness.

Vicissitudes of having malaria

Among Ribeirinhos, their first malarial bouts are seen as a rite of passage for individuals who wish or are pushed to live in the peri-urban or rural areas of the Brazilian Amazon. Luzia, and Marlene, a 34-year-old woman and house worker, described how they decided to move to rural and peri-urban communities:

Before living here in the Panelão community, we lived at Careiro in a precarious shack *na beira do igarapé* [on the bank of a river]. Every time the *igarapé* overflowed, it took part of our dwelling along. The shack was close to fall apart. So, we were given a land lot here in the Panelão community. We built another shack and began our own *roçado* [vegetable garden]. We planted manioc, banana, *cupuassu* [a tropical fruit scientifically known as *Theobroma grandiflorum*]. Now we have food to sustain ourselves and to sell. We had health issues in the city but malaria was not a problem there. It is sad to see my children sick from malaria, and I also suffered due to malaria, but we are doing better here than in the city. We will stay here! (Luzia, Panelão Community)

My family and I used to live in Itacoatiara. At that time, it was very difficult for us to feed and clothe our four children because there were no jobs in Itacoatiara. So, we decided to move to Manaus. We thought that in Manaus there were more jobs for electricians and bricklayers. We came to Manaus and stayed in a

relative's home. My husband quickly found a job. Three years ago [2012] we learned that a doctor was looking for a property caretaker. We moved to here and, since then, we have had some struggles with malaria. Last year [2014], my husband, my infant son, and I had malaria. There is an *igarapé* behind the house [she points her finger to show me the small river]. I think we got malaria from there. (Marlene, Brasileirinho community)

Irma used the term *novato* [newcomer] to call my attention to stories of people, like Luzia and Marlene, who moved into their communities and experienced health issues due to their first encounters with malaria. Irma explained that malaria seems to have a preference for *novatos*:

Ah! Malaria loves the *novatos*! I remember a young woman who moved from Manacapuru to here. She was a beautiful woman, and malaria *encasquetou com ela* [stuck on her] [she laughs]. Every time she got sick from malaria the *agente* brought her pills, but she got sick over and over. When she got better her grandson caught malaria too. She was treated for malaria several times, and in one occasion the medications made her urinate blood. She got scared from malaria and moved out. Since then, I never heard from her anymore. (Irma, Panelão community)

The story told by Irma demonstrates that malaria constitutes a serious health issue to individuals who have no experience with the sickness. In contrast, Ribeirinhos, who are used to malaria, do not perceive it as a threat to their lives. In fact, they indicated that AIDS and cancer are more serious sicknesses than malaria because people can die

from these maladies. Moreover, my research participants observed that they know how to deal with malaria, and free medicines are dispensed to sick individuals, and these are delivered to their homes. Patricia shared her experience with malaria:

It is difficult to deal with malaria because it is *uma doença* [illness] that provokes body pain and malaise all the time. But it is not a *bicho de sete cabeças* [big deal]. If a person takes the medications accordingly, eventually it goes away, soon or later it will come back again. This is our reality here.
(Patricia, Panelão community)

I also discussed with my research participants the risks of catching malaria relative to other issues they usually face in their communities. José Mauro, noted:

For me malaria is not a major problem. There are worse issues in our community. Look at the roads...when it rains it becomes extremely dangerous to drive on these roads, and there is not bus to attend to people who live in the *ramals* (inner areas of the Amazon forest). Some days ago, a guy called me at night because he needed my help to drive him to a hospital. Unfortunately, I couldn't help him because it was raining and the road was too slippery. This applies to malaria too...I mean if someone happens to come down from malaria in a rainy day, the *agente* will not reach him...so the guy will have to deal with malaria by himself until the weather clears and road conditions improve. (José Mauro, Brasileirinho community)

Overall, Ribeirinhos pointed out that malaria is a difficult experience for people as it causes turmoil in their lives, but it is a sickness one can learn to deal with.

Discussion:

The purpose of this study was to describe Ribeirinhos' experiences, understanding, health care practices, and vicissitudes of having malaria in the Brazilian Amazon. The finding of the study show that the symptomatology of malaria reported by Ribeirinhos, including headaches, cold, chills, weakness, and vomiting, are in line with studies presenting the clinical characterization of the disease (Anstey, Russell, Yeo, & Price, 2009; Braga & Carvalho-Tavares, 2013; Warrel & Giles, 2002). Despite the fact that Ribeirinhos associated these symptoms with malaria, they often defined the malarial body in relation to blood and liver abnormalities; altered sensorial experiences such as paleness, cold, and changes in taste; and emotional distress resulting in aggressive attitudes triggered by the inability of bearing pain, vulnerability, and loss of vitality.

Instead of using biomedical terms, namely *vivax malaria*, *falciparum malaria*, and mixed malaria, Ribeirinhos developed their own standards to characterize the malarial bouts they experienced. Such standards take into consideration the intensity of symptoms (mild and strong malaria), the interval between infections (two types of malaria at once), and the types of antimalarial medications dispensed by health services. Ribeirinhos also present a peculiarity of views regarding malaria transmission. That is, though Ribeirinhos acknowledged that malaria is transmitted by a mosquito vector, they also indicated other routes malaria can get inside their bodies, such as sun exposition, wind, microbes, person-to-person transmission, and malaria itself as a pathological agent.

The study reveals discrepancies between the notion of risk of malaria transmission informed by public health workers and Ribeirinhos' experiences of malaria. Particularly, from the Ribeirinhos' perspectives, malaria may catch them everywhere,

whereas from the public health workers' viewpoint, the disease risk increases with activities that bring people close to malarious areas. Information passed on to Ribeirinhos is decontextualized in that it serves more to inform people who visit forest areas of the Brazilian Amazon than those who live in malarious risk areas, and are more vulnerable to the sickness. This finding is important, as it can provide guidance to public health professionals to design context-driven educative messages that reflect the local conditions associated with malaria transmission.

The study found that the consumption of *comidas reimosas* is used as an empirical diagnosis strategy and/or as a treatment approach to prevent malaria from worsening, or recurrences. *Comidas reimosas* are defined as kinds of foods that are regularly consumed by individuals, but that become harmful due to health issues, including malaria (Baião, Santos, Líbera, & Machado, 2013; Currier, 1966). The practice of abstaining from eating *comidas reimosas* during a sickness can be understood as a form of Hippocratic-Galenic medieval medicine, which was brought to Latin America through Spanish and Portuguese settlers (Foster, 1987). This ancient medical practice is based upon the principle of opposites, such as hot/cold or humoral pathology; its principles are widely disseminated in the country, particularly in the states of the Brazilian Amazon (Woortmann, 2008). Murrieta (2001) observed that the *reima* is characterized by binary oppositions between harmful and non-harmful foods. However, in Ribeirinhos' views, the temperature of *comidas reimosas* is not seen as detrimental to their health. Rather, they contrasted strong nutritional characteristics of these foods against a weak/fragile individual's body.

Ribeirinhos were consistent in saying that malaria is the prevalent sickness

affecting them. They also stressed that malarial symptoms are similar to other febrile sicknesses occurring in the Brazilian Amazon. Therefore, Ribeirinhos developed empirical diagnostic techniques to confirm if the malaise they experienced was malaria. In this sense, Ribeirinhos' attuned attention to the specific hours a malaise occurs, the time length symptoms persist, the milieu in which the sickness manifests, and the influence of *comidas reimosas* on malarial symptoms, constitute the multiple ways in which malaria is experienced/pre-objectified outside of clinical settings. The body, as the perceiver subject, plays a key role in the distinction of malaria from other sicknesses. Perception, as Merleau-Ponty conceptualizes it, is "a sort of life of significations that renders the concrete essence of the object [in my study the object is malaria] immediately readable and that allows its "sensory properties" to appear through it" (2014, p. 133). As this study shows, individuals who had no previous experiences with malaria were not able to identify the sensorial properties of malaria; hence, they were found to spend more days at home before seeking health care assistance. This finding highlights the relevance of experiential knowledge in distinguishing/detecting malaria and in seeking biomedical diagnosis.

The empirical diagnosis strategies that this study reports are examples of Ribeirinhos' embodied skills, which were likely built on their own experiences of malarial bouts and social interactions with other individuals who had also dealt with the sickness. From an anthropological perspective, the process of learning through lived experiences can be understood through the concept of enskillment, that is, "the embodiment of capacities of awareness and response by environmentally situated agents [individuals]" (Ingold, 2000, p. 5). Besides, as Csordas (2002, p. 2) argued,

understanding events (a sickness for instance) through an embodiment lens “leads not to the irreducible objective reality of a biological body, nor to the indeterminacy of endlessly iterated subjectivity, but to a necessarily indeterminate reality”. Acknowledging the existence of these multiple realities is the first step towards the decolonization of people’s knowledge about sicknesses. As Farley (2003) reminded us in his historical account of bilharzia and imperial tropical medicine in British and American empires, since the advent of the enlightened medicine, people’s practices of sicknesses were deemed useless, harmful, and meaning nescience or rejection of scientific achievements. By describing people’s empirical practices of diagnosing malaria, I do not characterize them as inappropriate or non-modern. On the contrary, I understand that these practices attest to the creative entanglements between popular and biomedical knowledge, and between biological and social domains.

This study documents research participants’ perceptions of the low effectiveness of biomedical diagnosis due to multiple times they had to repeat the blood smear test. Although the biomedical literature reports the difficulty in identifying malaria parasites using current diagnostic methods (Ferreira and Castro 2016), studies have often overlook people’s struggles with such diagnostic technologies. This study, in contrast, described the ups and downs of individuals who agonized until the disease was confirmed. People having to repeat the biomedical diagnosis of malaria multiple times is evidence that, “disease is never just one thing, technology delivery does not translate into patient care, and biology and technology interact in ways we cannot ways predict” (João Biehl & Petryna, 2013, p. 4).

Accordingly, Ribeirinhos indicated that endemic disease control agents

frequently recommended they to avoid taking painkillers and/or fever reducers one day before they seek biomedical diagnosis. This recommendation is not, however, supported by clinical evidence, and is not addressed in the guidelines informing diagnosis procedures (Brasil, 2002, 2006). This recommendation illustrates gaps in translating biomedical knowledge into quality information for patients. That is, though the majority of endemic disease control agents are trained to collect blood and fill out disease notification forms, they are minimally prepared to answer questions regarding the clinical manifestation of malaria asked by their patients. I shed light on issues of knowledge translation (Straus, Tetroe, & Graham, 2009) to call attention to inadequacies in the training of the primary professionals in charge of providing health care to patients with malaria, as well as the patient's rights of access to quality health information. In particular, this finding can provide context for the content of training offered to endemic disease control agents, as it attests to the need of disseminating reliable information on malaria and its clinical manifestations.

This ethnographic study also sheds light on work, housing, food, and clothing insecurities that motivated people move to rural and peri-urban communities where malaria is endemic. People's stories of encounters with malaria highlight the lack of government policies addressing socio-economic insecurities that exposes people to malaria pathogens and its disease vectors. Overall, the findings of this study provide us with a sense of the social dynamics that are tightly entangled with malaria occurrence in the Brazilian Amazon.

Conclusion:

My goal in this paper was to provide insight into the experiential knowledge of

malaria circulating in riverine communities, the interactions between individuals afflicted by this sickness and health care services offering malaria diagnosis, and vicissitudes of having malaria in the state of Amazonas, Brazil. This paper characterized the genuine ways that Ribeirinhos developed to distinguish malaria from other febrile sicknesses occurring in the Brazilian Amazon, and how these strategies work in coordination with biomedical diagnosis. The study described gaps in the training of endemic disease control agents. I suggest that the Brazilian Malaria Prevention and Control Program has contributed to the misinformation about malaria that circulates in communities where the disease is endemic, regarding uses of painkillers and fever reducers.

Herein, I described issues related to the accuracy of malaria diagnosis methods and how these issues affected individuals presenting malaria symptoms. Biomedical diagnosis is the “access door” to free medications for treating malaria in Brazil. Failures in the prompt detection of the disease raise questions regarding to quality of malaria services offered to Ribeirinhos, and focus of the Brazilian Malaria Prevention and Control Program (BMPCP) in containing the disease, rather than addressing root causes of malaria as well. In this article, I also highlighted individuals’ life journeys that led them into malarious areas. A close examination of these paths reveals the “naturalization” of malaria transmission among people who live in the peri-urban and rural areas where I did my ethnographic study. The fact that Ribeirinhos are liable to experience malaria as part of their lives calls attention to public health discourses that depicted malaria as a typical disease of the Amazon region, rather than a result of fragile and social-political-economic-ecological and biological factors.

Chapter 5

Manuscript title:

Entangled pharmacopeias: Ribeirinhos' experiences and treatment practices for
Plasmodium vivax malaria in the Brazilian Amazon

Abstract

This paper examines Ribeirinhos' experiences and practices of treatment for vivax malaria in the Brazilian Amazon. Adherence to pharmaceutical treatment for malaria has been a tremendous concern in public health, as it is a key strategy to treat sick individuals, and to control the spread of the disease. This paper describes, i) pharmaceutical treatment for vivax malaria as it is experienced by Ribeirinhos; ii) traditional treatments to cure and prevent malaria; and iii) the interface of antimalarial drugs and traditional treatments. The study draws on findings from ethnographic research conducted in two communities of the state of Amazonas, Brazil. In the country, medications to treat malaria are dispensed to patients after microscopic diagnosis, which is performed by endemic disease control agents. Medications used to treat vivax malaria were found to cause varying degrees of itching, insomnia, and gastrointestinal disturbances, among other health issues. These side effects were described through the metaphor of agony. The agony experienced by Ribeirinhos is likely associated with chloroquine-induced pruritus, which causes intense itching and sleep deprivation. Ribeirinhos treat remaining symptoms of malaria and the side effects of antimalarial drugs by themselves. Among Ribeirinhos, traditional treatments for malaria are seen as resources to assist recovery from the sickness, and these highlight community support and solidarity for those dealing with malaria. This paper calls attention to the use of antimalarial medications, and the restrictive focus of malaria programs on controlling and eliminating the disease, without attending to ways these pharmaceuticals take part in the lives of afflicted individuals in both positive and negative ways.

Keywords: Ethnomedicine, Ribeirinhos; Brazilian Amazon; vivax malaria; Pharmaceutical treatment; Chloroquine-Induced Pruritus; Homemade treatments

Background:

Malaria transmission in Brazil is clustered in the Amazon region, where 99.5% of cases are reported (Ferreira and Castro 2016). *Plasmodium vivax* is the predominant parasite species causing malarial infections in the country (Ministério da Saúde, 2015). Though, vivax malaria is accountable for few fatalities, disease relapses frequently occur within months or years after the initial infection (Vitor-Silva et al., 2016). In this paper, I am concerned with how riverine people of the Brazilian Amazon, known as Ribeirinhos, pursue treatment for vivax malaria in their homes and communities. Complexities associated with clinical manifestations of vivax malaria reinforce the need for qualitative studies focusing on ways malaria is dealt with beyond clinical settings. Indeed, there are plenty of studies describing how socio-cultural factors influence people's therapeutic practices of malaria (Agyepong, 1992; Langwick, 2007; Lipowsky et al., 1992; Muela Ribera et al., 2016); however, the experiences of and treatment practices for vivax malaria in the Brazilian Amazon lack definition.

In Brazil, people have universal access to malaria diagnosis and treatment. These interventions comprise the primary ways malaria prevention and control policies reach out people in the Brazilian Amazon. These constitute, in Biehl's words (2004), a form citizenship through patienthood, in which the state provides patient-centered care based on identification of the disease and dispensation of medications. I use the word dispensation to nuance that in Brazil doctors and dentists are the only professionals authorized by the government to prescribe medications (Brasil, 1998). However, in the country, physicians and nurses are rarely involved in the diagnosis and treatment of non-complicated malaria (Osorio-de-Castro et al., 2011). Rather, endemic disease control agents (EDCA) are the

professionals in charge of screening the majority of patients with non-complicated malaria. Some of these are trained as laboratory technicians with a specialty in microscopic identification of hemoparasites like plasmodium. EDCA dispense medications to sick individuals after the disease is confirmed by microscopic analysis.

Particularly in the state of Amazonas, malaria services are offered in urban and rural regions where the disease is endemic. Antimalarial treatment follows the Brazilian Malaria Prevention and Control Program (BMPCP) protocols (Brasil, 2010), and chloroquine and primaquine are the pharmaceuticals employed in the treatment for vivax infections. Standard treatment regimens for vivax malaria recommend 25 mg/kg of chloroquine during the first three days, and 0.5 mg of primaquine over seven days (Ibid). Appropriate and timely treatment for malaria is the main axis of BMPCP, as it aims to ensure rapid and long-term clinical cure, prevent the development of the disease into severe forms, complications and death, reduce occurrence of malaria-related anemia, and prevent development of drug resistance, among other issues (Brasil, 2010; Osorio-de-Castro et al., 2011).

My analysis focuses on people's experiences of treatment for vivax malaria exploring it in two ways: as a public health intervention to control malaria, and as a form of existence in which individuals are taken from their daily routines and become patients. In this new form of existence, Ribeirinhos experience health issues that surpass health care assistance provided by the BMPCP. This paper attends to individual and contextual aspects that lead people from the Brazilian Amazon to seek traditional treatments for malaria. A number of studies undertaken in Brazil have documented that Ribeirinhos rely on herbal preparations to relieve fever, headaches, chills, and body pain, among other

malarial symptoms (Botsaris, 2007; Cosenza, Somavilla, Fagg, & Brandão, 2013; Hidalgo, 2003; Milliken, 1997; Nogueira, 2010; Scudeller, Veiga, & Araújo-Jorge, 2009; Veiga & Scudeller, 2015). These studies, however, fail to show that local people often use herbal preparations to relieve side effects of antimalarial medications and clinical complications due to malaria. The use of plants in the treatment for malaria is not a new phenomenon. The first plant-based treatment dates back 3,000 years to China, where infusions made of qinghao (*Artemisia annua*) were broadly used to fight fevers in the country (Camargo, 2003). In 1972, Chinese scientists identified a natural molecule of artemisinin (Tu, 2011). Since the 17th century, *Cinchona officinalis* or Jesuits' bark was used in the treatment for fevers worldwide.

With recent evidence of partial resistance of *falciparum* malaria to artemisinin, the WHO has banned its use without partner drugs; also banned is the use of the whole plant, *Artemisia annua*, which does not show this resistance (Elfawal et al., 2012; WHO, 2012, 2016a; Wilcox et al., 2007). A different stance is taken by humanitarian groups, such as the Global Initiative for Traditional Systems of Health, which suggests that herbal preparations, made of the whole plant *Artemisia annua*, may be recommended as the first treatment for malarial infections, especially in remote areas where access to diagnosis and treatment are not consistently available (Wilcox et al., 2007). The BMPCP recognizes biomedical treatments endorsed by the WHO as the exclusive therapeutic methods to cure malaria. However in the Brazilian Amazon, traditional treatments are broadly employed in combination with biomedical treatment. In this paper, I shed light on various therapeutic resources to which Ribeirinhos resort to recover from malaria. In doing so, I contribute to the exploration of medical pluralism in the Brazilian Amazon. As Stoner (1986, p. 47)

reminded us, “[p]luralism can now be examined as a multiplicity of healing techniques, rather than of medical systems”. This paper draws on medical anthropology, ethnobotany, and biomedical studies to examine, i) how pharmaceutical treatment for vivax malaria is experienced by Ribeirinhos; ii) traditional treatments to cure and prevent malaria; and iii) the interface of antimalarial drugs and traditional treatments.

Methods:

Ethnographic design was chosen to examine how Ribeirinhos pursue treatment for malaria in their homes and communities. Ethnographic studies provide thick descriptions of people’ experiences within the settings they live, and from the perspective of those individuals (Ingold, 2014). This study was conducted from January 2015 to April 2015 in two locations of the state of Amazonas, Brazil, the Brasileirinho and the Panelão communities. Further details on study settings and population are described in Chapter 3 of the dissertation.

The findings discussed in this article were obtained through participant observations (DeWalt & DeWalt, 2002; Ingold, 2014), semi-structured interviews (Minayo, 2000), and photographs (Pink, 2014). Participant observation revolved around conversations about the use of antimalarial pharmaceuticals, benefits and disadvantages of these medicines, and use of homemade treatments. During visits to my research participants, I observed whether they had leftover medications, packaging from consumed antimalarial pills, and herbal preparations in their homes. My research participants showed me plants they cultivated and used in homemade preparations. On some occasions, Ribeirinhos, who presented malarial symptoms, rode with me to malaria facilities from

Brasileirinho community or Careiro, or to return home from these facilities. On these occasions, I waited for them until they were discharged upon receiving the results of diagnosis. While I waited for Ribeirinhos, I talked to endemic disease control agents and other people who were in the malaria facilities. Notes of participant observation were registered in a field diary.

The interviews were conducted with 30 Ribeirinhos who were followed on a regular basis. During the interviews, I invited them to recall experiences of pharmaceutical treatment for malaria, how medications were administered, changes in their daily routines associated with medications, if treatment was interrupted or completed accordingly, how they perceived themselves after the pharmaceutical treatment ended, and if they resorted to alternative treatments to recover from malaria, among other questions. The interviews were performed in Portuguese. They were recorded, transcribed, and translated into English. I also employed photographs to register, and to initiate discussions on malaria treatments. Photographs of medications, herbs, and trees used to prepare homemade treatments and infusions were taken during participant observation and interviews. Ribeirinhos looked at the photographs and shared their experiences in relation to the images with me. Their views were registered in a field diary.

I used data triangulation (Denzin 2009) to cross-check Ribeirinhos' realities captured through interviews, notes from participant-observation, biomedical texts about malaria treatment, treatment guidelines for malaria, and data bases about medicinal plants. I searched popular names of plants mentioned by Ribeirinhos in the following publications: Hidalgo (2003); Lorenzi and Matos (2002); Oliveira, Junqueira, Stehmann, & Bradão (2003); and Scudeller, Veiga, & Araújo-Jorge (2009). I confirmed the spelling

of plant names on the International Plant Name Index (IPNI, n.d.). Thematic analysis (Braun & Clarke, 2006) was used to interpret Ribeirinhos' experiences and treatment practices of malaria. The steps I used to perform thematic analysis were: i) reading and re-reading of transcripts and notes of participant observation and photographs; ii) generation of initial codes; iii) collation of codes into potential themes; and iv) definition of five themes, which are described in the next section.

Results:

Malaria pills: Essential but unpleasant

Stories Ribeirinhos recounted about experiences of pharmaceutical treatment for vivax malaria bring into view two main perspectives about antimalarial medicines: First, that they are essential to “combat” the sickness, and second, that they are unpleasant.

Paulo, a 70-year-old retired man, shared his dissatisfaction with antimalarial medicines:

Sometimes I ask myself why they [doctors] study a lot, but so far, they have not reduced the size of white pills [chloroquine]. Those pills are large and hard to swallow! They do not go down easily...they often get stuck in my throat. I also know people who cannot swallow the whole pills. So, they cut them into smaller pieces or crush them...Besides large size, the pills are bitter like *fel* [bile]. They hurt my stomach. (Paulo, Brasileirinho community)

Challenges associated with pharmaceutical treatment of malaria go beyond taste and difficulties to swallow pills. Many of my research participants drew my attention to side effects of malaria medications by saying that these drugs affect both their minds and

bodies.

Perceived side effects of antimalarial pills

Experiences of side effects of antimalarial medications were often narrated through the word *agonia* [agony]. Many Ribeirinhos indicated that the likely cause of their agony is that the pills kill malaria in their bodies, so in the process of killing it, malaria or its microbes/virus/bacteria bounce back, and a person feels unsettled. Indeed, Ribeirinhos often stated not knowing what is worse: taking the pills or dealing with the sickness itself. Doralice, a 54-year-old woman who works as a peasant, elaborated on the agony she experienced:

At the beginning of malaria treatment, I felt really bad. I couldn't stand for long, so I lay on a hammock. Few minutes later, I couldn't bear the hammock anymore, so I got up. I felt warm, then I looked at the cold floor, I laid down on the floor for few minutes until I felt cold. So, I went outside to get warm in the sun. Few minutes later, I felt that even the sun was bad for me...I felt anxious. I wished to walk, but I felt weak. So, I stayed inside home but the noise of people talking or watching television disturbed me. Then, I thought a bath would help me to relax, but I felt cold again...These pills caused a tremendous agony...it lasted for three days...after that time it calmed down. (Doralice, Panelão community)

Ribeirinhos also used the word agony to describe experiences of *pinicada* or *espinhada* [itching], the sensation of insects crawling or stinging their bodies, red or purple-like spots and itchy bumps on the skin, stomach pain, and sleep deprivation

triggered by malaria pills. Lara, a 43-year-old woman who works as a community health agent, described the suffering or agony she lived through when she was in treatment for malaria:

When I began to take the pills to treat vivax malaria my hands, feet, ribs...my whole body itched. I felt like someone was piercing me with needles or thorns. I could not sleep and had to take medications to sleep and relieve *pinicação ou espinhada* [itching]. Each time I fall sick from malaria I feel very bad...I feel *uma agoniação* [agony]. (Lara, Panelão Community)

Ana Maria, a 43-year-old woman and house worker, Marina, a 25-year-old woman and also a house worker, and Lidiane, a 40-year-old woman who works as a civil servant, commented that they looked for medical care as a means of getting a prescription for skin irritation and inability to sleep brought on by antimalarial medications.

When the *agente da malária* [EDCA] brings me malaria pills, I only take them after I see a doctor in the hospital. I am allergic to malaria medications, and if I do not take an anti-allergy medicine my body will *pinicar muito* [itch a lot]. I also explain to the doctor that I cannot sleep while I am taking the pills. So, he prescribes me sleeping pills. (Ana Maria, Brasileirinho community)

Last year [2014] in the second day my seven-year-old daughter was taking malaria pills, she had small red spots on her skin. I did not think that could be

related to malaria medications, though. In the third day, her body was all over cover with purple-like spots. I was not sure if I should take her to the hospital, but I did it anyway. When we arrived in there the nurse told me, “if you had not brought your daughter here, the allergy could have reached her throat and she could have complications”. The doctor prescribed an anti-allergy medicine and recommended that she should finish her treatment for malaria. When we came back home, my mother did not allow me to give the malaria pills to my daughter. I gave the anti-allergy medicine to the girl and threw away the remaining malaria pills. (Marina, Panelão community)

My husband and I had malaria at the same time last year [2014]. We did the *exame da malária* [malaria diagnosis] in Manaus and, received the pills from the *casa da malária* [malaria facility]. In the second day of treatment my feet and my hands began to itch. My husband also developed allergy, but his was very serious. His body was covered with red rashes and his lips swelled up. We went back in the *casa da malária* and the *agente* asked us to go to the Tropical hospital [FMT]. In the hospital, the doctor said we had allergy due to medications for malaria. He prescribed us some anti-allergy medications...I don't remember the name of these medicines, though. We finished the treatment for malaria with the support of these medicines. (Lidiane, Panelão community)

On one occasion when I visited Carlos, a 50-year-old man and farm caretaker, he showed me leftover pills of primaquine he saved in his cupboard. He pointed out that

suffering associated with itching prevented him from finishing the treatment:

I could not bear to take these two pills. I tried over and over, but I could not take them. The pills caused intense itching all over my body. I was desperate...I scratched myself without any relief of *pinicada* [itching]...I did not know what to do...When I stopped to scratch I began to beat myself like I was killing mosquitoes, but there were no mosquitoes stinging me. During three nights, I did not sleep because of that ‘damn itching’. I did not take the pills...I needed to relieve myself from that suffering. (Carlos, Brasileirinho community)

In addition to insomnia and itching, ribeirinhos pointed out other adverse effects of malaria medications, such as dizziness, loss of appetite, gastrointestinal issues, trembling sensation, peeling of skin on hands and feet, and changes in taste. Lene, a 48-year-old woman and peasant from the Brasileirinho community, explained that, “a lemon tastes sweet in the bitter mouth” to describe changes in tasting provoked by antimalarial medications. Chico, a 52-year-old man and peasant, explained his experience with malaria medications:

When I take the pills, I feel an intense pain in this region [places his hands on the upper region of his stomach and liver]. I feel uncomfortable like my stomach and liver were swelled up. I cannot sleep face down because I cannot even touch my abdomen ...it hurts too much. (Chico, Panelão community)

Despite difficulties associated with adverse reactions of malaria pills, most of my research participants reported taking the medications as directed by malaria services. Yet, in the discussions about adherence to pharmaceutical treatment for malaria, Ribeirinhos called my attention to treatment practices of people who are alcoholics. Marcos, a 48-year-old man who works as a farm caretaker, and who overcame alcoholic addiction shared his experience:

There are three years since that I stopped to drink alcohol. When I was alcoholic, and got sick the *agente da malária* brought me the pills. When I was not feeling feverish anymore, I stopped taking them. Usually I took two to three doses of malaria medications only and began to drink again. As I did not take the pills appropriately, I was always sick from malaria... it was the same malaria that came back over and over. (Marcos, Brasileirinho community)

Within the communities where I did my study, alcoholism and drug addiction were generally perceived as behaviours that could lead to the interruption of pharmaceutical treatment for malaria. Another interesting aspect of malaria treatment was raised on an occasion when I visited José Mauro, a 64-year old man and police officer, who also owns a grocery store in the Brasileirinho community. We sat on the verandah of his grocery store and began our conversation about antimalarial medications. A 60 year-old woman who was buying vegetables heard the conversation and joined us:

The three first doses of malaria medications that contain the white pills

[chloroquine] are the most important pills in the treatment for malaria. They *bate[m] a infecção no corpo* [fight malarial infection in the whole body], while the small ones [primaquine] *sara[m] o fígado* [treat the infection in the liver].

(Field note: Each medicine plays a part in the treatment. January, 2015)

José Mauro reasserted the words of his customer and said:

I always finish the white pills, and sometimes think that it is not necessary to take the small pills, but I take them anyway...they [EDCA] say that the small pills are important too.

I asked an endemic disease control agent who is a Ribeirinho, and is responsible for dispensing antimalarial medications about the effectiveness of these medicines to treat vivax infections. Before she answered my question, she showed me the treatment protocol table for vivax and ovale malaria that was provided by the Brazilian Malaria Prevention and Control Program. She then said:

As far as I know, chloroquine is a medicine to treat vivax malaria and prevent its clinical complications. And primaquine is the drug used to eliminate forms of vivax parasites that stay in the liver. (EDCA, Laboratory Brasileirinho community)

She explained that she uses the treatment protocol table to dispense medications to patients, observing parasite species identified by microscopy, age of patient, and

weight. She emphasized that pregnant women follow a different protocol in which primaquine is not dispensed to them. I also asked the EDCA if patients were often complaining about allergies from the antimalarial medications. She commented that she was not be aware of this specific issue, but that children frequently vomit from the medications: “We spend more medicines with children because they often vomit and we have to replace the medication”.

Malaria pills: Suffering to be endured

Ribeirinhos have developed strategies to counteract diarrhea, stomach pain, heartburn, and vomiting induced by malaria medications. The common practices they rely on include avoiding taking the pills while fasting, and creating a schedule to take medicines accordingly. My research participants explained that malaria pills on an empty stomach cause a person to experience dizziness and vomiting, a side effect that Dalva, a 54-year-old woman who and a peasant from the Panelão community, described as *pilora*. To avoid pilora, Ribeirinhos take the pills with one of their main meals (breakfast, lunch, or supper). They also reported drinking herbal preparations to relieve gastrointestinal disturbances brought on by the drugs. Lauro, a 51-year-old man and farm caretaker, explained how he prepared an infusion:

When I take malaria *piula* [pills], I usually drink a preparation made of orange peel. I put orange peels and fresh water into a jar. I let it soak for an hour or so. Sometimes, I mix orange peels with boldo tea [*Vernonia condensata*]. I drink the orange peel infusion instead of water. These preparations relieve the bitter taste of my mouth and stomach bloating and pain. (Lauro, Brasileirinho community)

Research participants also explained that in the case where a person vomits or loses medications, they should let an *agente da malária* know they need additional pills to complete the total dose of the treatment. Though, this practice is not followed by many Ribeirinhos. In fact, as most of them had experienced multiple malarial bouts since their childhood, they have developed an aversion to malaria pills. Marina and Elisângela, a 36-year-old woman and house worker, explained:

I have been taking malaria pills since I was a child and at that time it was very difficult for me to bear their bitter taste and pain they caused in my stomach. My mother gave the pills to me and I often pretended to take them. When my mother was not close to me I threw the pills away. Even now that I am an adult I just call the *agente da malária* when I cannot bear malaria symptoms anymore. When I think about those pills I begin to...[takes a deep breath and shows a facial expression of disgust and repugnance] feel nauseate...ill. (Marina, Panelão community)

When I threw up the medications I did not tell the *agente* because I knew beforehand that he would bring me more pills. I did not want to take more of those because they *ofendiam* [harmed] my liver. (Elisângela, Brasileirinho community)

The interviewees also reported following certain dietary restrictions during and after malaria treatment. Salty and fatty foods, as well as *comidas reimosas*, as mentioned

in the previous chapter, are perceived to negatively influence malaria recovery.

Ribeirinhos also pointed out the need of abstaining from hard work during malaria treatment. Noé, a 91-year-old retired man, shared his experience:

During the treatment, I could not work for about six days. I tried to work in my manioc plantation, but I couldn't. It was hot and the sun made me felt weak and dizzy. I also learned from an *agente* that it is important to avoid the sun when taking the medication. According to him, the sun makes the effects of malaria and the pills worse than they already are. (Noé, Panelão community)

Ribeirinhos' experiences with pharmaceutical treatment for vivax malaria illustrated both struggles they lived through when taking malaria pills, and strategies to increase adherence to antimalarial medications. Though pharmaceutical treatment is not the only resource Ribeirinhos rely on to deal with malaria, they also resort to homemade preparations and over-the-counter medications to recover from malaria.

Healing from inside out: Invigorating the sick individual

A common issue revealed in the conversations I had with Ribeirinhos is that they did not feel fully recovered from malaria after the treatment ended. They explained still feeling unwell, which they associated with inflammation of the liver and symptoms of anemia. Doralice and Ana Maria explained how malaria affects their bodies:

Malaria causes an inflammation in the liver. It accumulates in the liver. Thus, a person needs to drink bitter teas that cure the inflammation in the liver. To end

malaria in the body, it is essential to treat the liver...*o fígado tem que estar sarado* [the liver needs to be cured], otherwise malaria will return again. (Doralice, Panelão community)

I think malaria afflicts the liver, but it also causes anemia. Everybody who is sick from malaria gets yellowish, but as I am brown, I turned greenish, my lips lacked their red color; it seemed like I have lost lots of blood. My lips, hands, feet peeled. I felt ugly. I am not sure if it is malaria or its medications that caused these problems. (Ana Maria, Brasileirinho community)

Ribeirinhos' experiences of malaria as a sickness that affects the liver and blood lay the ground for the preparation of an array of *tratamentos complementares* [complementary treatments] to cope with these issues (Table 5.1 provides a list of complementary treatments mentioned by Ribeirinhos). Ribeirinhos explained to me that complementary treatments are made of herbs, tree barks, animal parts, and over-the-counter medication. They are taken on a regular basis, and on many occasions, I witnessed my research participants drinking these preparations (**Figure 5.1**). Most herbs and barks used in the herbal preparations are gathered from the forest and backyards. However, some Ribeirinhos reported buying plants in popular tea stores of Manaus and Careiro, or receiving plants from friends, relatives, and neighbours.

José Mauro, Hiléia a 27-year-old woman and peasant, and Noé, explained how they prepare homemade treatments:

I usually prepare a tea of avocado leaves (*Persea americana*) to treat anemia. I also take vitamins and tonic solutions like Biotônico Fontoura to recover my energy and weight. I take the tea until I perceive that the colour of my face and my willingness to work are back into the normal. (José Mauro, Brasileirinho community)

My father-in-law extracts paracanaúba bark (*Aspidospermum sp*) from the forest. I make an infusion with the bark. I soak a small piece of its bark in two liters of water. I drink it on a daily basis. It helps to restore my liver; hence, I didn't have malaria anymore. (Hiléia, Panelão community)

Four days after a person finishes taking the pills, they can take a *purgante de sucuuba* [sucuuba laxative] (plant scientifically known as *Himatanthus sucuuba*). It is made of sucuuba bark. It has a “milk” [white secretion] that cleans the intestine. It is too bitter, it cleans the body. If the person's blood is strong [impure], it will become light [clean or pure]. Many people dealing with malaria come to my home asking me to teach them to prepare this purgative. I learned to prepare it when I was a rubber tapper. Nowadays, I share my knowledge of medicinal plants with those that need it. (Noé, Panelão community)

Helena, a 62 year-old-woman and farm caretaker from the Brasileirinho community, is used to preparing a detoxifying infusion, which is made of senne, lavender, and milk of magnesia. Helena explained that detoxifying preparations force remaining

malaria microbes/virus/bacteria out of the body through two routes: vomiting and diarrhea. She commented that, “the yellow substance that comes out of stomach (bile or digestive juices) is as a signal that malaria is being discharged from the body. Similarly, diarrhea is also a way to wash malaria out of one’s body”. The detoxifying preparations made by Noé and Helena feed back to a common concern raised by Ribeirinhos; that is, the need of purging their bodies right after finishing the pharmaceutical treatment for malaria. In this case, *limpeza* [cleanliness] is seen as a practice of restoring the immunity of liver and body. In general, positive effects of homemade treatments are confirmed by long periods without catching or coming down with malaria, and the invigorating willingness to work, study, and play.



Extraction of sucuuba bark using a machete.



Infusion of quina-quina



Cipó tuira, a plant used to treat digestive issues



Infusion made of copaiba

Figure 5.1: Examples of plants and barks common used in homemade treatments

Despite of popularity of homemade treatments, three of interviewees stated that malaria pills are the effective way to treat malaria. One, Carlos, shared his frustration of having had many malarial bouts since he moved to Brasileirinho community. I discussed with him about the use of herbs to treat malaria:

Luciane: Carlos your neighbours taught me many homemade treatments for malaria. Did you already try to treat malaria with teas or other preparations? After I questioned him, he stood up and walked into the direction of an old fridge. From there he picked a small plastic bag containing dark dried green herbs. He then sat down again, opened the plastic bag, and put a small portion of the herbs on his hand (**Figure 5.2**). He thought for a moment and, then answered my question.

Carlos: Yes, I already heard about teas to treat malaria. A friend of mine brought me this tea, but didn't prepare it because I don't believe in homemade treatments. To take these teas, *o cara* [the guy] needs to believe that the teas are effective against malaria or other health issues...the guy needs to believe that the tea has [the healing] power to cure him. In my case, I believe in [the positive effects of] malaria pills only. I feel terrible when I take them, but after the third day, I begin to feel better and can go back to work in my garden again.



Figure 5.2: Carlos showing a tea to treat malaria

Malaria and homemade treatments as relations

Homemade treatments are often disseminated to Ribeirinhos by other community members through informal conversations, for instance; in bus shelters, streets, or in their homes during a visit. Giselda, a 49-year-old woman and peasant, explained how she

learned about homemade treatments:

In day-to-day conversations, neighbours and friends say they took homemade preparations and did not fall sick from malaria anymore. They asked me, “how many times have you had malaria?”. I said I was sick from malaria about one month ago and in the next month I had malaria again. Then one of my neighbours said, “you have to take a tea because the malaria you were suffering from was in your liver...when you took the pills, malaria did not completely die in your body”. Then, my neighbour recommended a tea made of quina-quina (*Geissospermum sericeum*). I did not have the bark to prepare it, so she brought it to me. (Giselda, Panelão community)

The sharing of both practices to foster adherence to pharmaceutical treatment and homemade treatments shows Ribeirinhos’ agency with regards to malaria, as well as their solidarity in supporting others who are also dealing with malaria. In fact, Ribeirinhos rely on both pharmaceutical treatments to “kill malaria”, and complementary treatments to fully recover from the remaining effects of the sickness and side effects of antimalarial medications. In short, Ribeirinhos recovering from malaria often require the use of technological resources (antimalarial medicines) and traditional treatments.

Discussion:

Ribeirinhos’ stories about their experiences with antimalarial medications indicated that they were treated for vivax malaria. The Brazilian malaria prevention and control program recommends chloroquine and primaquine as standard treatments for vivax

infections. Though these medications reduce malarial symptoms, including fever, arthralgia, and back pain, they are also found to cause a significant increase of gastrointestinal symptoms, abdominal pain, bitter taste in the mouth, insomnia, and itching (Braga et al., 2015; Pinto, Azevedo, Silva, & De Souza, 2003).

The analysis of Ribeirinhos' experiences with pharmaceutical treatment for malaria demonstrated the development of intense itching, tingling sensations, and insomnia during the first days of drug treatment. These experiences were described by Ribeirinhos through the metaphor of agony. Experiences of itching and tingling sensations, during pharmaceutical treatment for vivax malaria are defined in the biomedical literature as pruritus (Bussaratid et al., 2000; Osifo, 1984). The pruritogenic potential of chloroquine is well documented, especially among African individuals (Aghahowa, Obianwu, Isah, & Arhewoh, 2010; Essien, Ette, Thomas, & Brown-Awala, 1989; Fa, Olayemi, Osungbade, & Tongo, 2004). Primaquine by contrast is not associated with pruritus; yet, its side effects are also of concern by numerous scholars (Beutler & Duparc, 2007; Burgoine, Bancone, & Nosten, 2010).

In this study, 12 out of 30 research participants (40%) reported to have experienced a varying degree of itching; two (6.7%) adhered to treatment with support of prescribed medications; two (6.7%) interrupted the treatment, 14 (46.6%) did not report allergies to malaria medications. A previous study conducted in a reference center for tropical medicine in Manaus, Brazil, demonstrated that 104 (20.4%) out of 510 patients reported chloroquine-induced pruritus, 51 (40%) experienced pruritus impaired sleep, and 2 (0.4%) interrupted the treatment (Ballut et al., 2013). Scholars argue that chloroquine-induced pruritus may lead to a decrease in treatment adherence, mainly during the period

patients are advised to complete a full course of primaquine (Taylor & White, 2004). Though chloroquine-induced pruritus is described in the biomedical literature, I suggest that its occurrence in the communities where I did my study often goes unnoticed due to two main issues: i) endemic disease control agents are not trained to identify and report these events, and ii) patients are not followed up by a nurse during the treatment, for example.

This study shows that allergy to medications is a main factors that may lead to interruption of pharmaceutical treatments for malaria. Similar findings were reported by Pereira, Ishikawa, and Fontes (2011) and Almeida, Rodrigues, and Vieira (2014). Both studies showed a significant percentage of individuals who did not comply with malaria treatment, but tell us little about individuals' experiences that lead to non-adherence to treatment regimens. In contrast, in this paper I described how side effects of antimalarial medications influence Ribeirinhos' adherence to pharmaceutical treatment particularly in rural and peri-urban areas of the state of Amazonas where medical assistance is limited.

Another important finding of this study refers to Ribeirinhos perceptions that parasite clearance is not translated into full recovery from malaria. To underline the importance of this finding is the fact that neither doctors nor medicines to treat side effects of antimalarial drugs are incorporated in BMPCP interventions offered in rural and peri-urban settings, and this may exasperate non-compliance. Thus, to deal with remaining symptoms of malaria and side effects of antimalarial medications, Ribeirinhos may, i) see a doctor in an urban center, ii) make use of available over-the-counter medications, such as laxatives, anti-allergy pills/solutions, and vitamins, and/or iii) resort to homemade treatments like herbal infusions, decoctions, paca's bile, and preparations that mix herbs

and over-the-counter medicines.

The use of medicinal plants to treat malaria has been analyzed by numerous scholars. Qinghao (*Artemisia annua*) and *Cinchona officinalis*, for example, have been broadly addressed in the scientific literature due to their antimalarial properties (Greenwood, 2003; Harris, 2010; Hsu, 2010; Meshnick & Dobson, 2001; Su & Miller, 2015; Tu, 2011; White, 2008). The evaluation of effectiveness of medicinal plants used by Ribeirinhos in the treatment of malaria is beyond the scope of this study. Rather, the focus here is to show how experiences of malaria as hepatic and blood sicknesses have supported the formulation of homemade treatments to provide immunity to the liver, recover from anemia, and detoxify the body. Even though my research participants lived in different geographic areas, the majority employed similar homemade treatments.

Most Ribeirinhos reported, for instance, resorting to bitter-tasting plants, including boldo (*Vernonia condensata*), quina-quina (*Geissospermum sericeum*), saracura-mirá (*Ampelozizyphus amazonicus*), and paracanaúba (*Aspidospermum sp*), to treat the liver and prevent new bouts of malaria. Studies show that some of these plants possess antimalarial properties, while others are effective in the treatment of digestive disorders (Botsaris, 2007; Cosenza et al., 2013; Santos, Kahwage, Coelho-Ferreira, & Sampaio, 2005). My research participants also reported using roots of açai (*Euterpe precatoria*) and/or leaves of avocado (*Persea americana*) to treat malaria-related anemia. These plants have also been found effective against malaria-related anemia, in a recent survey on ethnobotany and popular medicines to treat malarial infections in a riverine community of the Brazilian Amazon (Veiga and Scudeller 2015).

In relation to animal parts used in the traditional treatment for malaria, research

participants mentioned to drink paca's bile (*Cuniculus paca*) to recover from hepatic issues caused by malaria, as well as to avoid new bouts of the sickness. Particularly, Ribeirinhos reported to resort to paca's bile because its bitter substance is believed to provide immunity to the malaria-impaired liver. Similar findings were reported in two other studies, which found that paca's bile is broadly used by people of the Brazilian Amazon to treat malaria (Milliken, 1997; Tomchinsky, 2014). These studies, however, did not describe the rationale underlying the use of paca's bile in the treatment for malaria.

Equally important was the practice of detoxifying the body after the pharmaceutical treatment of malaria ended. The use of these detoxifying preparations is supported by an understanding of diseases as resulting from intrusion of something (pathogens or objects) inside one's body (Pellegrino, 2006). This way of knowing disease causation reinforces the idea that vomiting and diarrhea rid the body of impurities and disease agents (Montagner, 1991). By the same token, Ribeirinhos use detoxifying preparations to "wash" malaria out of the liver and blood. By doing so, they felt that their vitality was restored.

The findings of this study highlight that traditional treatments for malaria are taken simultaneously, in combination with, or right after finishing antimalarial drugs. As a result, Ribeirinhos' treatment practices for malaria constitute an example of syncretism (Pool & Geissler, 2005) or hybridization (Zhang, 2007) in the healing of the sickness. The analysis of Ribeirinhos' experiences and treatment practices for vivax malaria shows that even in a context where Western medicine strongly recommends the use of antimalarial drugs as the exclusive treatment for malarial infections, traditional medicine is broadly employed as a resource to relieve side effects of antimalarial medications, which are

usually dismissed by the Brazilian Malaria Prevention and Control Program, prophylaxis, and a way to show solidarity to other afflicted individuals. Paying attention to people's diverse health care practices and embodied experiences of treatment for malaria may provide new insight into therapeutic and preventive strategies for intervening in malaria, particularly in the current scenario where malaria is pervasive and pathogens are continuously evolving.

Conclusion:

My goal in this paper was to draw attention to important issues related to the patient-centered approach adopted by BMPCP, namely dispensation of medications to patients with malaria without monitoring the emergence of side effects. Disembodied biomedical descriptions of side effects of antimalarial medications do not provide us with a sense of how medications affect individuals' everyday lives. In contrast, the stories narrated by Ribeirinhos break with the idea of treatment for malaria is easily articulated into patients' lives. The analysis of Ribeirinhos' experiences and treatment practices for malaria suggests that the notion of health imbued in malaria programs is one that equates health to parasite clearance rather than to well-being of patients.

The experience of treatment for malaria discussed here shows that Ribeirinhos created a multiplicity of treatments to attend to health issues brought on by the sickness and its medications, which are overlooked by BMPCP. This article provides important findings regarding to ways people from the Brazilian Amazon articulate pharmaceutical and traditional treatments to restore their health, which Ribeirinhos understand as resource to work, study, and enjoy leisure activities. In a broad sense, pharmaceutical interventions to treat malaria comprise entanglements that connect remote contexts, individuals,

parasites, and malaria-carrying mosquitoes to national and international policies and interventions to contain the disease. Following a vertical organization, BMPCP joins global health interventions that disregard local realities, and that deny other forms of intervening in the disease than biomedical ones.

Supplementary information:

Table 5.1. Most used home treatments of malaria reported by Ribeirinhos

Popular name	Scientific names	Preparation and uses
Avocado	<i>Persea americana</i>	Boil its leaves. Uses: Treats anemia caused by malaria.
Andiroba	<i>Carapa guianensis</i>	Grab a small piece of andiroba bark and pound it with a hammer. Then, soak it in 2 liters of water. Let it stand for some hours. Keep refrigerated and drink it as water. Uses: Relieves liver issues. It has anti-inflammatory properties.
Açaí	<i>Euterpe precatoria</i>	Boil açai roots. Drink the tea. Its roots can be mixed with other plants as well boldo (<i>Vernonia condensata</i>). Uses: Treats anemia.
Capeba	<i>Pothomorphe umbellata</i>	Soak macerated leaves in cool water. Let it stand for some hours. Drink the infusion for same days. Uses: Cleans the liver. It sometimes provokes vomiting.
Copaíba	<i>Copaifera multijuga</i>	Soak a small piece of copaíba bark in 2 liters of water. Let it stand for some hours. Keep refrigerated and drink it as water. Uses: Cures liver inflammation
Cipó tuira	<i>Bonamia ferrugineus</i>	Boil cipó tuira leaves and drink the tea. It can be mixed with other

		herbs such as boldo and roots of açai Uses: Gastrointestinal issues.
Paca bile	<i>Cuniculus paca</i>	Take the animal's bile, as soon as the it was slaughtered, without chewing it. Uses: Its bitter substance provides immunity to a liver damaged by malaria.
Jambu	<i>Spilanthus oleracea</i>	Boil fresh leaves and flowers of jambu with roots of açai Uses: Prevents malaria from "circulating" in the liver.
Orange peel and boldo	<i>Citrus sinensis</i> and <i>Vernonia condensata</i>	Boil leaves of boldo. After boiled add orange peels to the tea. Keep refrigerated and drink as water especially during the drug treatment for malaria. Uses: Relieves gastrointestinal issues.
Paracanaúba also known as carapanaúba	<i>Aspidospermum sp</i>	Soak a small piece of paracanaúba bark in two liters of water. Let it stand for some hours. Keep refrigerated and drink it as water. Uses: It has anti-inflammatory properties that relieve liver issues. Prevents malaria.
Quina-quina	<i>Geissospermum sericeum</i>	Soak a piece of quina-quina bark in two liters of water. Let it stand for some hours. Keep refrigerated. Drink it everyday regardless of having malaria. Uses: Immunization of liver. Prevent malarial bouts.
Saracura-mirá	<i>Ampelozizyphus amazonicus</i>	Go to the forest and take a liana of Saracura-mirá. At home, wash and scrape it with a knife. Soak it in two liters of water. It will produce a like-beer foam. Keep it in the refrigerator and drink a glass of this water twice a day until the malaise disappears. Uses: It has anti-inflammatory properties that help the liver to recover from malaria. It also prevents malarial bouts.

Senna, alfazema (also known as lavender), and milk of magnesia	<i>Senna alexandrina</i> and <i>Lavandula augustifolia</i>	Boil leaves of senna and lavender in two liters of water. In addition to the herbal preparation take one-to-two doses of milk of magnesia, which is sold in drugstores. Uses: Detoxify the liver. Provokes diarrhea and vomiting. Prevent malarial bouts.
Sucuuba	<i>Himatanthus sucuuba</i>	Peel the sucuuba trunk. Take a handful of peeled barks and soak them in a glass of water. Drink the infusion in the next day. Uses: Depurative effect, purifies the blood.

Chapter 6

Manuscript title:

Porous malaria vector control interventions: An ethnographic tale of clever malaria mosquitoes and tenacious Ribeirinhos from the Brazilian Amazon

Abstract

In this paper I investigate entanglements among humans, malaria-carrying mosquitoes, and vector control strategies aimed to reduce malaria transmission in the Brazilian Amazon. To do so, I explore, i) anti-mosquito practices Ribeirinhos rely upon to minimize malaria transmission, ii) Ribeirinhos' experiences of vector control interventions introduced by the Brazilian Malaria Prevention and Control Program, and iii) risk perceptions of malaria as transmitted by mosquitoes. Entangled stories of Ribeirinhos and mosquitoes that carry malaria (or not) are not always characterized as antagonistic; rather, I argue that Ribeirinhos lean into and get involved with mosquitoes, especially when they try to avoid contact with them. Ribeirinhos' interest in knowing of mosquitoes biting habits, breeding sites, preferences (for people with "sweet blood"), revulsions (smoke and scents of plants), skills to pass through the mesh of mosquito nets and, gaps in walls and rooves, characterize examples of social intimacies inter-species. This paper also draws attention to how vector control interventions such as, time monitoring recommendations (TMR), indoor residual spraying (IRS), and insecticide-treated nets (ITN), are articulated into Ribeirinhos' daily routines. Far from arguing in favour of vector control interventions, in this paper, I set the ground for a debate about ways of cohabiting with mosquitoes that carry malaria (or not). Though I acknowledge the suffering and deaths caused by malaria, my argument runs in defense of the *Anopheles darlingi* mosquito. My understanding is that, the existence of malaria mosquitoes is entangled with the conservation of the Amazon forest, also known as "o pulmão do planeta" (the lungs of the planet), and all biodiversity that lives there and beyond, including humans.

Keywords: Medical anthropology; Anthropology of life, Interspecies entanglements,
Malaria; Ribeirinhos; Brazilian Amazon, Vector control interventions

paper, I examine every day routines and malaria vector control interventions where Ribeirinhos and malaria-carrying mosquitoes' lives become entangled.

Capasso's (1998) historical account of the emergence of human malaria documents complex interspecies entanglements in which ancestors of humans and modern humans shared their environment with primates, including baboons, apes, and monkeys. The shared environment has allowed ancient forms of plasmodium to switch from non-human primates to humans through intermediate hosts, namely mosquitoes. Activities such as agriculture and construction of settlements probably supported the host change from *Plasmodium falciparum* to humans. Capasso (1998, p. 169) argued that *Plasmodium vivax*, *Plasmodium malariae*, and *Plasmodium ovale* are likely to have, "coevolved with humans and with the Primate ancestor of man, infecting the ancestor of our species during the hunter-gatherer phase". It is important to note that the origin of *Plasmodium vivax* is still debatable. Numerous scholars claim that this parasite originated in the Asian continent (Escalante et al., 2005; Mu, 2005). Either way, the emergence of malaria is tied to entanglements between humans and nonhumans sharing the same environment.

The main malaria vector in the Brazilian Amazon is the *Anopheles darlingi* mosquito (Deane, 1986; Tadei et al., 1998). This mosquito species is found in forest areas only because its existence depends on non-polluted water, trees, adequate temperature, and other animals. *Anopheles darlingi*'s main breeding sites include partially shady, large, deep, clean bodies of water; fish-farming tanks; mining pits; aquatic vegetation; sunny streams with sandy bottoms; and pools of water left after the Amazonian rivers retract, (Forattini, 1962; Rachou, 1958; Tadei et al., 1998). In other words, malaria-

carrying mosquitoes inhabit the same landscape as Ribeirinhos.

Anopheles darlingi mosquitoes are highly anthropophilic because they prefer to feed on human blood rather than on other animals (Hiwat & Bretas, 2011). This mosquito species is able to maintain malarial endemicity, even when its population density is low (Quintero, Thatcher, & Tadei, 1996). Poor living conditions, high bite rates of *Anopheles darlingi* mosquitoes, the disease vector's preference for feeding on human blood, the presence of symptomless individuals; that is, individuals who are infected with plasmodium parasites, but who do not develop the illness; among other factors, play a part in the vulnerability of Ribeirinhos to malaria (Ferreira and Castro 2016; Martins-Campos et al. 2012; Tadei et al. 1998).

In the country, interventions to control malaria fall under the Brazilian Malaria Prevention and Control Program (BMPCP), and are in line with the WHO's policies aimed at reducing morbidity, mortality, and socio-economic burden associated with the disease (Brasil 2003). The vector control interventions recommended by BMPCP to contain malaria in Brazil are indoor residual spraying (IRS) and insecticide-treated nets (ITN). Insecticides used in public health interventions, including ITN, are supported by the WHO Evaluation of Pesticides Scheme (WHOPES), which ensures the safety of insecticides to human health and the environment (WHO, 2010).

Malaria is a treatable disease and efforts to control its spread rely mostly on IRS and ITN. Particularly, IRS intervention takes advantage of the indoor feeding and resting habits of *Anopheles* species mosquitoes in the Brazilian Amazon (Martins-Campos et al., 2012). In other words, IRS intends to exterminate malaria vectors when they land on walls right after finishing their human blood meal. Side effects of insecticides, including

threats to human health, chemical poisoning of the environment, and the possibility of mosquito resistance, still stir debates on public health reliance and benefits of this chemical tool (Carson, 2002; Kelly-Hope, Ranson, & Hemingway, 2008). While IRS is a strategy planned to offer spatial protection, ITN are intended to protect individuals from bites of malaria-carrying mosquitoes. Numerous studies address the advantages of ITN, such as increased protection against new malaria bouts, severe anemia, childhood mortality, and morbidity, especially in areas of falciparum malaria transmission (Ng'ang'a et al., 2009; Ruyange et al., 2016; Vitor-Silva et al., 2016).

Effectiveness of vector control strategies is related to socio-political-economic and human factors, which influence availability, access, and adherence to these interventions (Dubos, 1964). Particularly, low community adhesion to IRS and ITN is an issue that public health policies have often faced. Official estimates report that in 2014, approximately 1% of the Brazilian Amazon population was covered by IRS and 3% received ITN (WHO, 2015b). BMPCP recommends that insecticides be sprayed at least three times a year, while ITN are estimated to last for at least two years (Brasil, 2009a; OMS, 2002). To date, no studies exist evaluating cost-effectiveness of malaria vector interventions in Brazil. Recently, scholars have advocated for the incorporation of durable solutions to reduce malaria transmission globally. The argument put forth is based on studies that have evaluated the positive impact of installation of ceilings and closing gaps in walls and rooves in the reduction of malaria incidence (Anderson, Simpson, & Stephens, 2014; Lindsay et al., 2003).

Overall, vector control interventions are aimed to building barriers between humans and malaria-carrying mosquitoes. Analyzing human-animal entanglements and

their impact on human health, Nading (2013) observed that vector control policies are grounded in a concept of health as synonymous with the disentanglement of people, disease vectors, and pathogens. Such a concept, I contend, is continuously challenged by the ways human and non-human lives flourish. A closer examination of how vector control interventions are implemented shows that these interventions are porous barriers, which can limit, but not prevent human-mosquito contact. Insight from Ingold's (2011) anthropological study highlights that, life is not a result of isolation or separation of human and nonhuman beings (see pages 3-4). In fact, the life cycles of all beings are entangled in a continuous process of becoming (Ingold, 2013). In this sense, malaria can be taken as an example of how living conditions and everyday routines bring humans and malaria-carrying mosquitoes together. With that in mind, in this paper I explore, i) anti-mosquito practices Ribeirinhos rely upon to minimize malaria transmission, ii) Ribeirinhos' experiences of vector control interventions introduced by public health, and iii) risk perceptions of malaria.

Methods:

The findings I reported in this paper were obtained through an ethnographic research carried out between January 2015 and April 2015 in the Brasileirinho and Panelão communities. These communities are located in the municipalities of Manaus and Careiro, state of Amazonas, Brazil. Further details on study design, settings, population, and sampling are described in the Chapter 3.

Ribeirinhos' experiences and practices of malaria vector control interventions were addressed through participant observation (DeWalt & DeWalt, 2002; Ingold, 2014),

semi-structured interviews (Minayo, 2000), and photographs (Pink, 2014). Participant observation was the main strategy I relied on to learn from Ribeirinhos. These consisted of participating in their daily activities, paying attention to their living conditions, the structure of their dwellings, walking with them around their backyards and community to learn about potential vector breeding sites, and observing the absence and/or number of mosquito nets in their homes. On some occasions, I talked to endemic disease control agents in malaria facilities and Ribeirinhos' homes while these agents were distributing mosquito nets and spraying houses (in Brasileirinho community only). Notes of participant observation were registered in my field diary.

In addition, I interviewed 30 Ribeirinhos. Interviews revolved around learning from Ribeirinhos how malaria-carrying mosquitos come into contact with them, where malaria carrying mosquitoes are likely to be found or reproduce, strategies they rely on to deal with malaria vectors, perceptions of effectiveness of public health strategies, and ways to avoid malaria, among other aspects. Interviews were carried out in Portuguese and lasted 1 to 1.5 hours. They were recorded, transcribed, and translated into English. I also utilized photographs to register mosquito-breeding sites, Ribeirinhos' dwellings, indoor spraying intervention, and mosquito nets. These pictures were taken during conversations and interviews. I used a Tablet to register the images. Ribeirinhos looked at the images with me and shared their interpretations. Our conversations about the photographs were registered in a field notes. The use of multiple sources of data allowed me to perform data triangulation (Denzin, 2009). For the purpose of this paper, I triangulated transcripts of interviews, notes of participant observations with Ribeirinhos and EDCA, photographs, medical entomology texts, and guidelines of vector control

interventions for malaria. The collected data was analyzed following the steps of thematic analysis proposed by Braun and Clarke (2006), which is described in Chapters 3, 4, and 5 of the dissertation. I identified four themes to illustrate Ribeirinhos' experiences and vector control practices, which I present in the next section.

Results:

Cohabiting with mosquitoes

Ribeirinhos who live in the Brasileirinho and Panelão communities are used to sharing their living spaces with numerous nonhuman beings, including *carapanãs* [mosquitoes]. On verandahs, patios, porches, or under trees, mosquitoes always joined my conversations with Ribeirinhos. In these instances, Ribeirinhos pointed out that mosquitoes are not only annoying because they bite people, but essentially they can also transmit diseases. Noé, a 91-year-old retired man, said:

We are used to mosquito bites during day and night. Now [late morning] I am talking to you, and there are ones biting my legs [slaps his legs while he is speaking with me], and I do not know if these *carapanãs* are those that transmit dengue [fever], malaria, or other diseases. The only thing I know is that these pests [mosquitoes] are in whatever place I am! (Noé, Panelão community)

In these discussions about malaria-carrying mosquitoes, the majority of Ribeirinhos had not singled out a mosquito species that transmits malaria. Instead, they explained routes mosquitoes get infected with malaria. Haroldo, a 34-year-old man and a

steam boiler operator in a slaughterhouse, and I sat on a bench in the verandah of his home. We met at his lunch break. Our conversation revolved around mosquitoes. Haroldo told me about multiple times he caught malaria. I asked him why he came down with malaria many times, and he promptly replied:

I think malaria *carapanãs* love my blood. I say so, because I used to live with a lot of people, and only I caught malaria. I think that there is a [kind of] blood that is good for *carapanãs* and a [kind of] blood they don't like. I have a sweet blood, this is why malaria-*carapanãs* often sting me. The other reason is that I'm a Ribeirinho, and where there is water, there are *carapanãs* too. (Haroldo, Brasileirinho community)

I came back to the question of mosquitoes and invited Haroldo to reflect on ways mosquitoes become malaria-*carapanãs*. He thought for a moment and commented, “when a *carapanã* [mosquito] bites a person who has malaria, it gets malaria from that person, and will become infected too. So, the *carapanã* will bite other person and will pass the malaria on her”. A Ribeirinho, who was nearby, walked in our direction, and stood on the verandah; he heard the conversation and joined us:

Malaria *carapanãs* have their own reproductive cycle. They lay eggs and from [these] eggs more *carapanãs* are born. From one batch of eggs one *carapanã* has malaria or will get [infected with] malaria. If all *carapanãs* had malaria, *todo mundo vivia só doente* [everybody would always live sick]. (Field note:

Becoming a malaria carapanã. April, 2015)

Ribeirinhos have plenty of stories about clouds of mosquitoes, mosquitoes with fierce beaks (mosquito's proboscis), ingenious mosquitoes that enter clothes, ears, mouths, and that outmaneuver mosquito nets and insecticides. Patricia, an 18-year-old and house worker, shared her experience with mosquitoes:

Here [Brasileirinho community] we are used to clouds of *carapanãs* especially at dusk. It has so much *carapanãs* that I have to watch out for my mouth, eyes, and ears to prevent from them getting in. At dusk, we usually close doors and windows, and stay inside home. We wait until 7:30 to 8:00 pm, and then we come outside again because mosquitoes are gone by this time. (Patricia, Panelão community)

To protect against mosquitoes, Ribeirinhos count on everyday mosquito deterrence practices, as well as on public health technologies, such as time monitoring recommendations (TMR), indoor residual spraying (IRS), and insecticide-treated nets (ITN).

Everyday practices of chasing mosquitoes away

My visits to Ribeirinhos took place during daytime hours. I noticed that in many houses I visited, there was a smoky fire nearby. I asked Ana Maria, a 43-year-old woman and house worker from Brasileirinho community, why she lit the fire. She smiled at me and said that, “this fire is to burn our garbage and to repel *carapanãs*”. The general

understanding in the communities where I did my study is that smoke could deter *carapanãs*, including the malaria-carrying ones, from biting humans. Thus, Ribeirinhos mentioned burning egg cartons, dry vegetation, and/or tree branches outdoors as a means of producing a thick smoke. My research participants also reported applying fumes of garlic husks and andiroba dregs (*Carapa guianensis*), among other fumes in their homes. They explained to me that the scent of these plants repels mosquitoes from indoor rooms. Luzinete, a 51-year-old woman and peasant, explained how she prepares the fumes:

My mother extracts andiroba oil and saves andiroba dregs for me. I usually gather leftover andiroba dregs (**Figure 6.1**) and let them dry. At sunset, I burn dry wood sticks in a pot and throw the andiroba dregs into the pot. It produces fumes. I apply the fumes in my entire house to chase *carapanãs* away.

(Luzinete, Panelão community)



Figure 6.1: Andiroba dregs used in the preparation of fumes to repel mosquitoes.

Ribeirinhos also mentioned resorting to conventional mosquito control products to repel and kill nuisance insects. My research participants showed me over-the-counter-spraying insecticides and diesel they had in their homes. Paulo, a 70-year-old retired man, said:

For me the medicine [insecticide] to kill *carapanãs* is diesel. I put diesel in a flit gun sprayer and spray it in the house twice a week. The strong scent of diesel *espanta* [repels] *carapanãs*. (Paulo, Brasileirinho community)

My research participants indicated that removing potential mosquito breeding sites, such as egg and fruit shells (cupuassu shells (*Theobroma grandiflorum*)), bottles, tires, flower pots, and cleaning abandoned fish-farming tanks and wells, are ways of preventing the proliferation of malaria-*carapanãs*. Vanderléia, a 30-year-old handicrafts woman, and Ana Maria elaborated on these practices:

When it rains, water accumulates in cupuassu shells and I already saw *carapanã* larvae inside these shells. I think among these, some larvae are from malaria *carapanãs*. Since then, when I find a cupuassu shell I turn it upside down.
(Vanderléia, Panelão Community)

Here on the farm there is a well that my husband's boss built to store feces of pigs. The boss changed his mind and did not invest in pig farming anymore. Now the well serves only to accumulate malaria *carapanãs*. Thus, my husband usually applies *óleo queimado* [motor oil] in the well. (Ana Maria, Brasileirinho community)

In addition to the reservoirs, mentioned above, my research participants perceived the accumulation of medium and high size vegetation as potential sites that attract and shelter malaria-carrying mosquitoes. Thus, many Ribeirinhos perceived

themselves at risk of falling sick from malaria due to others' untidiness with land lots.

Milagres, a 46-year-old woman who works as a seamstress, said:

My husband often cuts the vegetation in our backyard to avoid malaria catching us. Three months ago our daughter had malaria. I was wondering where she got it...she is always at home or at school. Sometimes, I think she caught malaria inside our home because our neighbour does not weed his land lot...We do our part in cleaning our backyard, but if others do not do theirs, we can catch malaria anyway. (Milagres, Brasileirinho community)

Besides everyday mosquito-deterrence practices, research participants also have access to malaria control strategies provided by the BMPCP, such as time monitoring recommendations, indoor residual spraying, and insecticide-treated nets.

Public health strategies to fight malaria-carrying mosquitoes

Time monitoring recommendations

A strategy broadly known by Ribeirinhos is to monitor the time malaria-carrying mosquitoes are more active. I registered in my field notes many occasions when endemic disease control agents (EDCA) recommended Ribeirinhos to pay attention to the “time of malaria”. On one of these occasions, I observed the way an EDCA explained to a Ribeirinho, who came down with malaria, how he should avoid malaria:

EDCA: Bro [brother] here where you live is a place that has trees nearby the house. It is a shadowed and humid place; it is perfect for mosquitoes. Bro... the

only way to prevent malaria that I can tell you is to pay attention to the “time of malaria”. Here is a dangerous area...I mean it is a malaria zone. Thus, [you should] avoid walking around the property from 5:30 to 7:30 pm. The only way to avoid malaria is to stay away from the forest [he repeated emphatically]. If you have a bed net, you must stay under it during the time of malaria. Do you have a bed net?

Patient: No, I don’t...I don’t have even a hammock to hang a bed net! (Field note: Time monitoring recommendation. February, 2015)

Ribeirinhos explained to me that the time monitoring recommendation requires that they stay away from outdoor settings during the period mosquitoes are perceived to be abundant. Furthermore, research participants were told that malaria-carrying mosquitoes have a preference for biting at sunset and sunrise. In this regard, Vanderléia said:

My family and I bathe in the *igarapé* [river]. We go there around 4:30 to 5:00 pm. We do not spend much time there because after 5:00 pm malaria *carapanãs* begin to pile up *na beira* [on the riverbank]. (Vanderléia, Panelão community)

Time monitoring recommendation is broadly known in Ribeirinhos’ communities. I discussed with Dalva, a 54-year-old woman and peasant from Panelão community, about the pertinence of this recommendation:



Figure 6.2: Ribeirinho's home

Dalva: The man [EDCA] told me I should close doors and windows at 4:30 – 5:00 pm to avoid malaria *carapanãs* enter in my house.

Luciane: Do you do this every day?

Dalva: Well, I try to do so [she laughs], but my grandchildren open the door regardless of the time of malaria.

Luciane: Dalva let's look at this picture (**See figure 6.2**). I showed Dalva a picture of her home. She attentively looked at it. I asked her if she feels protected against mosquitoes during the time of malaria when she is inside her home.

Dalva: Now that I'm looking at my house in this picture, I am not sure if this thing [recommendation] really works because my house has gaps in the walls and the roof. So *carapanãs* will come in through the gaps anyway.

The time of malaria coincides with the time many Ribeirinhos wrap up chores in their plantations, feed animals, go fishing or hunting, go to school, and play soccer, among other activities. Lene, a 48-year-old and peasant, said:

I try to stay at home at the time it has more malaria *carapanãs* outside but to be honest I am not able to stay under a bed net until 6:00 am or at 5:00 pm...I grow vegetables to sustain my family and sell...I cannot interrupt my work because a *carapanã* may bite me. Of course, I try to avoid malaria by wearing long-sleeve shirts and trousers, but in reality, nobody knows where or when malaria will catch a person. (Lene, Brasileirinho community)

Limiting one's exposure to malaria-carrying mosquitoes, based on the time monitoring recommendation, is not a task to be easily achieved. Indeed, Ribeirinhos emphasized that their precarious housing and everyday chores expose them to malaria vectors and other mosquitoes. Ribeirinhos' practices of coping with malaria-carrying

mosquitoes are complemented with IRS and ITN.

Indoor residual spraying (IRS)

Ribeirinhos stated that they were familiar with IRS intervention because EDCA usually spray their dwellings two to three times a year. I followed IRS interventions in Brasileirinho community (see **Figure 6.3**), and took notes on how an interviewee prepared her dwelling to receive the IRS intervention, the interaction between the EDCA and the Ribeirinho, and information the EDCA gave to the interviewee, in terms of effects of IRS, required precautions, and replacement of the former insecticide, which was reported to cause allergies.

When I arrived at Elisângela's home to interview her, an EDCA was spraying insecticide in the bottom area of her wood shack. Elisângela was in the only room of the shack, which is located at the upper area of her dwelling. I was invited to enter. Elisângela's shack had no ceiling; its walls and floor have gaps. In the middle of her things on the floor there was an old ripped bed net that belonged to her husband and her. Her four children, who shared the same room, did not have bed nets. She was sweaty and tired of removing objects, such as mattresses, clothing, shoes, bottles, burned candles, from the floor and walls so that the EDCA could apply the insecticide. When she lifted her mattress, a lot of bugs were under it; they ran in our direction. I helped her to lift and carry her objects outside. Her children attentively watched us from outside the shack. When the bedroom was done, we went outside to get fresh air and talk. When the EDCA finished spraying the insecticide in the whole property, he

approached us while we were sitting in a tree branch that was on the ground, and said to Elisângela:

EDCA: Ma'am I'm done here! You have to wait about 30 minutes for putting your things back in place. In 30 minutes, the insecticide will be dry. You cannot sweep the walls, if you do so the insecticide will be removed, and it will miss its efficacy. You can sweep the floor...only the floor okay!

Elisângela: Okay.

EDCA: Don't let the children enter in the room before 30 minutes, he said cautiously. Within four months I will be back. Four months is the period in which the insecticide is active, he explained...Four months, he highlighted.

Don't let the kids go up there [he repeated]!

Elisângela: Ok, I got it, she promptly replied.

EDCA: Remember that this is a new insecticide³² [Lambda-cyhalothrin (ICON)]. It does not burn [you]. The issue with this insecticide is that when it falls on the floor it turns into [a] white [substance]...this is the only problem with it. (Field note: Spraying insecticide. March, 2015)

Despite the introduction of a new insecticide, my research participants from Brasileirinho community reported experiencing a mild degree of skin allergies and eye irritation. Cleide, a 27-year-old woman and house worker, shared her dissatisfaction with IRS:

³² Prior to ICON another insecticide, namely *cipermetrina*, was used in IRS.

That thing [indoor residual spraying] is not good. When the guy [EDCA] sprays it in my home I cannot touch the walls, if I do so accidentally, I get burned. It hurts my family and me...it has a strong smell...it is not good. Sometimes I don't allow the guy to spray that thing in my house. (Cleide, Brasileirinho community)

Issues associated with IRS intervention go beyond allergies. Research participants expressed frustration with the IRS, because this intervention causes both disorganization of the house due to the need of removing furniture to apply insecticide on the walls, and it attracted other nuisance insects to their homes. Marlene, a 34-year old woman and house worker, and Irma, a 60-year old woman and peasant, shared her views on IRS:



Figure 6.3. Example of IRS intervention routine.

I do not like the mess the man [EDCA] leaves in my home when he comes here to spray insecticide. He removes almost everything from its place. When he finishes his work, he goes away and I have to put all things back in their places by myself. Next time, I will not let him spray insecticide in my home. (Marlene, Brasileirinho community)

After the insecticide was sprayed in my house, a lot of *baratinhas* [small cockroaches] invaded my home. We could not leave leftovers on the table because these cockroaches ate everything. It was nasty to see them in the kitchen running over our food, kitchen utensils, pots, and other goods. (Irma, Panelão community)

Moreover, Ribeirinhos experiences of IRS interventions are that they are most effective against mosquitoes right after it is sprayed in their dwellings. As time goes by, IRS is understood to lose its effectiveness, Marina, a 25-year-old woman and house worker, said:

Insecticides are good only in the first days it is sprayed. It really chases *carapanãs* away. The problem is that when its effect ends, *carapanãs* come back to my home again. (Marina, Panelão community)

Some research participants were not convinced of positive effects of IRS interventions. Elisângela said:

I am not sure if it [IRS] really works...I think it has effect at the time it is sprayed on the walls, but after that [time] I am not sure it will kill *carapanãs*...I do not like it, I accept it because I feel it is my duty to do so. If I do not accept it, they [health workers] may not like my attitude. Thus, I feel I have to accept it even if I am not sure it is good for my family's and my own health. (Elisângela,

Brasileirinho community)

Elisângela's experiences of IRS brings into view power relationships that pervade IRS interventions. In our conversations about IRS, many Ribeirinhos reported feeling obliged to engage in public health mosquito control strategies even if they did not fully agree with them. Furthermore, Ribeirinhos indicated circumstances other than unwillingness that can influence their adherence to IRS interventions. Among these circumstances is the presence at home of newborns, puerperal women, individuals affected by cancer, and those dealing with respiratory issues, among other maladies. In these instances, it is felt that the toxicity of IRS interventions is worse than the threat of catching malaria. In addition to IRS interventions, ITN were distributed in the two study communities.

Insecticide-Treated Nets (ITN)

In the Brazilian Amazon, people are used to sleeping in hammocks and beds. Attending to this regional specificity, BMPCP has distributed hammocks and bed nets to Ribeirinhos. Of 30 research participants in this study, 20 (66.7%) reported sleeping under nets; of these, one (3.3%) slept under a non-treated bed net, and three (10%) stated that they continue to sleep under nets even though they have experienced a degree of skin allergy and/or eye irritation. Four (13.3%) research participants, who have lived in the study communities for at least one year, mentioned they do not sleep under a net because they do not have one, and six (20%) research participants said they own ITN, but do not use them due to allergies, warmness, or because they have done improvements in their houses, such as installing a ceiling. Rosilene, a 22-year old woman and house worker,

and Doralice, a 54-year old woman and peasant, said:

I am living in a temporary settlement, and a lot of people including my family and I caught malaria in 2014. Since we received *os mosquiteiros* [ITN] we did not catch malaria since then. It really protects us. (Rosilene, Brasileirinho community)

We always sleep under a bed net. We do so not only to avoid malaria *carapanãs*, but to protect us from insects like spiders, butterflies, and geckos, too. When someone comes to visit us, I also encourage them to sleep under a mosquito net [ITN]. After all, *o pessoal da saúde* [health workers] gave mosquito nets to us and, we have to use them. (Doralice, Panelão community)

The majority of research participants who owned ITN mentioned experiencing burning sensations in their eyes and face, as well as skin rashes on body parts that touch the ITN. Ribeirinhos usually mentioned the term *empolado* to refer to skin rashes. Hiléia, a 27-year-old woman and peasant, and Otávio, a 38-year-old man and freelance industrial butcher, shared their experiences with ITN:

Bed nets are difficult to sleep under. I tried to do so but I wake up the following morning feeling like someone had applied crushed pepper in my face. I felt like fire had burned my face... it was a terrible sensation. This is the reason I did not use bed nets anymore. (Hiléia, Panelão community)

Mosquito nets caused allergies in my wife and me. The poison [insecticide] burned our skin and eyes...we got *empolados* [red bumps], it caused itching on us. We continue to sleep under it anyways. (Otávio, Brasileirinho community)

It is important to note that most Ribeirinhos reported experiencing allergies when the ITN are new. The passing of time, they noted, reduces discomfort associated with the ITN. To reduce dermal exposure to ITN, research participants were recommended to wash the nets before sleeping under them. In this regard, Irma said:

These bed nets have insecticide [veneno] in them to kill *carapanãs*. Thus, the EDCA said we must wash the net with water and a small amount of soap to remove half of its insecticide. If we do so the insecticide will not burn or cause itching on us. (Irma, Panelão community)

In addition to allergies, most Ribeirinhos stated that the rectangular bed nets that were distributed to them are short and unsuitable to their dwellings (see **Figure 6.4**). In fact, the interviewees showed a preference for canopy nets rather than rectangular ones. Canopy shaped nets are both larger and easier to install because it is only necessary to hang them on the ceiling, and when not in use, canopy nets can be tied to their own frames. Moreover, the amount and type of ITN (single and/or full bed, hammock nets) do not correspond to Ribeirinhos' needs. Luzinete and Paulo, a 70-year-old retired man, said:

I like to sleep under a net. The problem is that bed nets are short. To install them I put nails in the walls and tie them [bed nets] on. When I go to bed I cannot sit on it because the net touches on my head. So, I asked the agent [EDCA] to give me the double of nets I needed to protect my husband and I. I sewed two bed nets to cover my bed. (Luzinete, Panelão community)

I received rectangular bed nets...those that it is necessary to tie on the walls. So, every day when I get up, I have to untie them to have room to walk in the house. At night, I have to install them again. I have to do it every single day...this is annoying! I do not know why they [health professionals] bought these kinds of bed nets rather than *cortinados* [canopy ones³³, see figure 6.5]. I have complained to EDCA, and they said that if I was displeased with the mosquito nets I should return them. (Paulo, Brasileirinho community)

³³ This picture was obtained from a research project investigating the effectiveness and adherence to mosquito nets in a riverine community of São José do Jabote, state of Amazonas, Brazil, which was under my coordination. The project was financially supported by BASF from Brazil. In the communities I did my fieldwork in 2015, I did not find any canopy mosquito nets.



Figure 6.4: Dwellings with and without bed nets



Figure 6.5: Canopy mosquito net. Credits: BASF, Brazil

Luzinete and Paulo's experiences of ITN bring up two issues: first, ITN are not fully adequate to Ribeirinhos' everyday routines; and second, that Ribeirinhos are expected to integrate ITN to their lives, but they cannot give any suggestions regarding

nets' sizes and shapes that fit better into their dwellings and everyday routines. Despite ITN inadequacies, most Ribeirinhos reported sleeping under ITN. However, I observed that in some dwellings only adults sleep under ITN, while their children sleep unprotected. A Ribeirinho, I talked to on the road, said:

We do not have bed nets for all of us. So my wife, our youngest child, and I sleep under a bed net. The rest of our five children sleep unprotected, though. We need more bed nets. We have asked for more, but so far, the EDCA did not bring them. (Brasileirinho community)

Another issue raised by Ribeirinhos concerns the perceived low effectiveness of ITN, which in general is associated with the large size of mosquito netting mesh:

Bed nets do not offer full protection against malaria. The agent [EDCA] explained to me that bed nets have *um veneno* [insecticide] in their nets. This *veneno* is supposed to kill *carapanãs*... but this is not true. Every night, I see *carapanãs* landing on my bed net, they enter inside the bed net through the large holes of the netting [mesh], and they do not die. (Haroldo, Brasileirinho community)

My research participants emphasized that neither IRS nor ITN are appropriate protections against malaria vectors. Rather, they stated that housing improvements are likely to increase protection against malaria-carrying mosquitoes:

The best way to prevent malaria is not sleeping under the bed nets or apply insecticides in our houses but to improve our housing [structure]. I mean...[to] close gaps in the walls and install a ceiling in the house. I'm retired so I can provide for my family, but housing repairs are out of my financial resources. (Paulo, Brasileirinho community)

Ribeirinhos' experiences of vector control interventions indicate that, despite public health technologies and their own mosquito-deterrence practices, controlling malaria also requires improvements in their living conditions.

Malaria: Treatable but not preventable

Ribeirinhos mentioned that controlling malaria is a complex issue because mosquitoes usually outwit local mosquito-deterrence practices, IRS, and ITN:

I do what I can do to protect myself. I sleep under a bed net and some persons recommended me to use that thing...repellent. I used repellent but I got sick from malaria anyway. Thus, I came to the conclusion that all things [tools/interventions] that were created to avoid malaria *carapanãs* are not fully useful against them...I mean, malaria *carapanãs* are strong and intelligent beings. I say that because within a few minutes I apply repellent on me, *carapanãs* land on my skin. I sleep under a bed net, and *carapanãs* are inside the bed net with my wife and me. In fact, we need *uma injeção* [a vaccine] to permanently protect us [Ribeirinhos] against malaria. This is the solution for us

[Ribeirinhos] who live on the edge of rivers. (Haroldo, Brasileirinho community)

The majority of my research participants stated that it is not possible to prevent malaria because they cohabit with malaria-carrying mosquitoes. Carlos, a 50-year-old man and farm caretaker, and Felipa, a 48-year-old woman and peasant, explained:

For me, there is no prevention for malaria. I think the only way to avoid it would be if I changed my life; if I win the lottery, then I would not need to be living here in the forest anymore. But while I am here in this life, not just me but others too, we are subject to catch malaria. Because the malaria *carapanã* is from the forest, the forest belongs to it, we entered its environment, then all of a sudden it stings *o cara* [the guy], and he catches malaria. I think so...we [Ribeirinhos] need to be here, so do *carapanãs*. When we [Ribeirinhos and malaria *carapanãs*] meet it stings us, and we [Ribeirinhos] catch malaria again. (Carlos, Brasileirinho community)

Here is a rural area so *carapanãs* are everywhere. If a malaria *carapanã* stings me, and I get sick from malaria, I know I have to be treated for it. Our lives [as Ribeirinhos] are like that; if we catch malaria we receive the pills to treat it. If we catch malaria again we receive the pills again and again. (Felipa, Panelão community)

Overall, research participants comprehended that there is no simple solution to avoiding malaria because the life cycle of malaria-carrying mosquitoes is entangled with

Ribeirinhos' lives in the landscape that they both inhabit.

Discussion:

This paper draws attention to a multiplicity of entangled relations involving malaria-carrying mosquitoes, people of the Brazilian Amazon, and government disciplinary vector control interventions. The findings presented here suggest that being a Ribeirinho who lives in the forest, implies sharing the landscape with other beings, like mosquitoes that carry malaria (or not), through working, leisure, and subsistence activities. Kirksey and Helmreich (2010, p. 552) noted that, “ ‘[l]iving with’ [other selves], [...] takes a variety of forms”. I suggest that in the case of Ribeirinhos, these forms range from considering mosquitoes as pests to appreciation of their intelligence and strong biological traits. As Kohn (2013, p. 1) reminded us, “encounters with other kinds of beings force us to recognize the fact that seeing, representing, and perhaps knowing, even thinking, are not exclusively human affairs”.

Such understanding invites us to rethink the privileged position of humans in the environment, to one in which they dwell, and are becoming with nonhuman beings. In his essay on “The temporality of the landscape”, Ingold (2000, p. 200) remarked that, “ in dwelling in the world, we do not act *upon* it, or do things to it; rather we move along *with* it. Our actions do not transform the world, they are part and parcel of the world’s transforming itself”. Similarly, I suggest that Ribeirinhos do not solely do things against mosquitoes, nor do malaria-carrying mosquitoes to Ribeirinhos; rather, in this interspecies relationship, Ribeirinhos and mosquitoes are coming into being.

Accordingly, I argue that the entangled stories of Ribeirinhos and mosquitoes are not always antagonistic, rather of social intimacy. Antagonistic relationships towards

insect vectors of diseases are demonstrated in Hatley's (2011) essay on ticks. Though Hatley calls attention to humans' hostile attitudes towards suffering and causalities caused by tick bites and its related diseases, he also observed that these 'unloved others' are one of our many co-evolved Earth beings. Similarly, in public health campaigns, malaria-carrying mosquitoes are depicted as enemies of humans. This representation, perhaps, fosters Ribeirinhos to see all mosquitoes as disease-carrying beings. Hence, Ribeirinhos create mosquito deterrence strategies, such as smoke, the application of fumes of plants in their houses, removing potential mosquito breeding sites, or/and adhere to malaria control interventions to minimize encounters with these unloved beings.

Three vector control strategies were identified in the two communities where I did my study: time monitoring recommendations, IRS, and ITN. Among Ribeirinhos the time monitoring strategy is colloquially known as the time of malaria. Probably, endemic disease control agents introduced this recommendation to Ribeirinhos. It is based on entomological evidence of *Anopheles* species' biting preference during the sunset and sunrise; *Anopheles darlingi* mosquitoes are found to feed all night as well (Tadei et al., 1998). Ribeirinhos emphasized challenges of attending to the time of malaria since most of them have daily chores in the same hours when mosquitoes are more active. Those who follow this recommendation showed concern for both their precarious housing, which does not prevent encounters with malaria-carrying mosquitoes, and lack of ITN.

In relation to IRS, Ribeirinhos noted that this intervention has a short-lived effectiveness and attracts nuisance insects to their homes. Estimating adherence of Ribeirinhos to IRS is out of the scope of this study. However, I showed that dermal and

eye irritation caused by the insecticide, disorganization of homes left after the IRS, dwellings being overrun by nuisance insects, and the presence of newborns and convalescent individuals in the home, can lead to non-adherence to IRS in the Brazilian Amazon. The analysis of Ribeirinhos' experiences with IRS suggest that those who do not perceive positive effects of IRS intervention feel obliged to adhere to it. Yet, this finding illustrates unequal power relationships where Ribeirinhos feel they have no other choice than to allow EDCA to spray their houses with insecticides.

Along with IRS, ITN were implemented in Ribeirinhos' dwellings. Overall, Ribeirinhos related the use of ITN to protection against all kinds of small reptiles, nuisance insects, and malaria. In this study, I characterized Ribeirinhos' preference for hammock and canopy nets. However, at the time of my fieldwork, BMPCP distributed rectangular ones, which are reported to be small and not easily articulated into everyday routines. My study also demonstrates that many Ribeirinhos reported often spotting mosquitoes inside their nets. This fact leads to the perception of low effectiveness of nets against clever mosquitoes. Equally important, I described unequal coverage of ITN, with children being more likely to sleep without a mosquito net than adults. In this study, I highlighted some issues with ITN reported by Ribeirinhos: inadequate shape and size, allergies to the insecticide, inappropriate size of the meshing, and unequal distribution of nets. These issues, I suggest, demonstrate gaps between malaria policy recommendations, and the real needs on the ground.

Despite the wide implementation of vector control interventions in the two study communities, my research participants indicated that housing improvements offer better protection against malaria than IRS and ITN. The majority of Ribeirinhos live in poorly

constructed houses with gaps in walls, no existing ceiling, and in some cases incomplete walls. Precarious living conditions of Ribeirinhos draw attention to social, material, and ecological conditions that bring humans and malaria-carrying mosquitoes together. These findings also provide a picture of what Krieger (2004) calls pathways of embodiment; that is, societal and ecological circumstances that expose people to malaria. Historical accounts describe that housing improvements led to elimination of malaria in Europe and the United States (Hackett, 1937; Packard, 2007). More recently, numerous studies provide evidence that house design is an important risk factor for malaria (Anderson et al., 2014; Snyman et al., 2015; Tusting et al., 2015). For example, studies carried out in African countries indicate that simple housing improvements, such as installing a ceiling and closing gaps, reduced contact with malaria mosquitoes and other disease vectors, such as *Mansonia* sp. As a result, malaria, lymphatic filariasis, and other arboviruses decreased (Atieli, Menya, Githeko, & Scott, 2009; Lindsay et al., 2003). Furthermore, housing improvements are not aimed to kill malaria-carrying mosquitoes, but prevent spreading of malaria pathogens.

This study draws attention to the fact that, from a public health standpoint, malaria vectors can be fought mostly with insecticides and ITN, while from Ribeirinhos' perspectives malaria is an unavoidable. Ribeirinhos' assumption of the impossibility of avoiding malaria is grounded on the understanding that they share the environment with malaria-carrying mosquitoes; hence, they perceive themselves to be vulnerable to the disease. Yet, most Ribeirinhos indicated that the only way to avoid or prevent malaria forever is to leave the place where their lives are entangled with those of malaria vectors. Few research participants mentioned that vaccines are a permanent solution to malaria

transmission among riverine populations. In particular, Ribeirinhos locate the risk of catching malaria upon their living conditions, which weave their lives to the malaria-carrying mosquitoes, and where most of them cannot easily get away. In short, for Ribeirinhos, malaria is a treatable disease, but still unavoidable.

Nevertheless, within the Amazon context, malaria-carrying mosquitoes are not always seen as villains. Rather, by causing malaria in people who enter the Amazon forest and destroy the environment, they are depicted as the protectors of the forest as the song, “mosquito da malaria” [malaria mosquito] shows. I, however, was unable to capture such meanings in the conversations and interviews with Ribeirinhos because neither my attention nor my questions were elaborated to explore the cultural dimension embedded in human-mosquito relations during my fieldwork.

However, the findings of my study characterize social intimacies between Ribeirinhos and malaria-carrying mosquitoes, in which Ribeirinhos lean into and get involved with mosquitoes, especially when they try avoiding contact with them. I argue that local mosquito deterrence practices are an expression of Ribeirinhos intimacy with insects, in which Ribeirinhos enter the realm of mosquitoes to learn their biting habits, breeding sites, preferences (for people with “sweet blood”), revulsions (smoke and scents of plants), skills to pass through the mesh of mosquito nets and, gaps in walls and rooves. Hustak and Myers (2012), for instance, presented a new interpretation of Charles Darwin’s work on pollination of orchids. Rather than describe Darwin’s biological experiments as mechanical and disengaged from plants and pollinator insects, Hustak and Myers highlight sensibilities in which “the human is no longer the measure for the non-human; rather, the forms and movements of animals and plants reinscribe human

sensibilities” (2012, p. 92).

Nading (2012) used the metaphor “dengue mosquitoes are single mothers” to describe social intimacies between women *brigadistas* of Nicaragua and female dengue mosquitoes. This metaphor, Nading argues, “assign familiar human motivations to nonhuman beings” (2012, p. 587). Likewise, by recognizing that malaria-carrying mosquitoes are clever beings that outwit vector control interventions, Ribeirinhos attribute to these nonhuman beings skills that surpass human inventions intended to eliminate them. I suggest that this attuned attention to dispositions of other selves attests to Ribeirinhos’ sensibilities of living in a beyond human-world.

Conclusion:

In this article, I drew attention to Ribeirinhos’ stories of entangled relationships with malaria-carrying mosquitoes. Rather than characterize these relationships exclusively as antagonistic, I described living conditions, subsistence activities, and mosquito deterrence practices through which Ribeirinhos and malaria-carrying mosquitoes involve themselves in one another’s lives. I defined these entangled interspecies relations as social intimacies. In contrast, this paper also discussed how vector control interventions are experienced and negotiated in the daily lives of Ribeirinhos. I stressed the main issues associated with vector control interventions: non-universal coverage and adherence to IRS; inadequacy of ITN to people’s everyday routines; precarious living conditions; mosquitoes outsmarting vector control interventions; and an environment that allows cohabitation of humans, malaria-carrying mosquitoes, and malaria pathogens.

Far from arguing in favour of vector control interventions, in this article, I set the

ground for a debate about ways of cohabiting with mosquitoes that carry malaria (or not).

While I acknowledge the suffering and deaths caused by malaria, my argument runs in defense of *Anopheles darlingi* mosquitoes. At the very end, the existence of malaria mosquitoes is entangled with the conservation of the Amazon forest, also called “o pulmão do planeta” [the lungs of the planet], and all biodiversity that lives there and beyond, including us.

Conclusion

This thesis sought to understand how Ribeirinhos from the Brazilian Amazon negotiate universalistic public health interventions and their own experiential knowledge of malaria, and make decisions over which interventions/practices they incorporate (or not) in their everyday routines. I began this thesis by looking at the historical emergence of malaria and contemporary health policies to contain it. I then drew attention to the main strategies of Brazilian Malaria Prevention and Control Program (BMPCP) to “fight” malaria in the Brazilian Amazon, namely diagnosis and treatment, and vector control interventions. Based on the analysis of Ribeirinhos’ experiences of malaria interventions and my own perceptions of these interventions in the two communities where I carried out my research study, I came to the conclusion that public health policies to control malaria in the Brazil are fairly desocialized. Indeed, malaria transmission is cast as a fact of nature occurring in Brazilian states with tropical climate, rather than a complex problem entangled with social-political-economic, and environmental factors.

Particularly in Brazil, diagnosis, treatment, and vector control interventions are the building blocks of BMPCP. Though these interventions attempt to control the transmission of malaria, they are palliative measures that focus essentially on the patient, pathogen, and mosquito vector. The historical account I provided in the literature review of this dissertation, for instance, shows that in the beginning of the 20th century, Brazilian physicians Oswaldo Cruz and Carlos Chagas indicated the need of thinking/addressing the issue of malaria in the Brazilian Amazon as part of social-ecological entanglements. However, from that time to the present day, malaria interventions are solely based on the

treatment of patients and vector control interventions. As I described in the first manuscript of the thesis, current diagnosis methods have shown to be decreasing in accuracy, and Ribeirinhos are asked to repeat the diagnosis until the disease is detected. During this period, Ribeirinhos are faced with the difficult decision of waiting until the disease is detected by malaria services in their communities or seek treatment in urban centers, since rural communities are generally found underserved by healthcare assistance.

This thesis demonstrated some shortcomings associated with treatment of malaria. The second manuscript shows that BMPCP dispenses medications to Ribeirinhos upon microscopic confirmation of malaria. Though these medications are free, there is no follow-up on how they affect Ribeirinhos' health. Side effects of antimalarial medications are neglected by BMPCP. Furthermore, medications become the primordial solution to prevent both clinical complications related to malaria and spread of the disease. Hence, Ribeirinhos repeatedly said, “if we catch malaria, we receive pills to treat it. If we catch malaria again, we receive the pills over and over, this is our life here”. The issue I want to emphasize is that Ribeirinhos have adapted themselves to malaria.

Ribeirinhos' adaptation to malaria is reinforced by public health interventions that blame malaria-carrying mosquitoes for transmitting the disease. In the third manuscript, I characterized three vector control interventions I found in the communities where I did my study. These interventions are time monitoring recommendations (TMR), indoor residual spraying (IRS), and insecticide-treated nets (ITN). “Putting a bandage of exposed fracture” was the metaphor that came into my mind when I examined such interventions against the poor living conditions of the majority of Ribeirinhos. These

vector interventions, I suggest, are still dissociated from the needs on the ground, because insecticides lose their effectiveness and cause allergies, bed nets are short and in insufficient quantities, and following time monitoring recommendations is unfeasible.

Furthermore, Ribeirinhos' preference for more durable solutions to control malaria-carrying mosquitoes, like housing improvements, are not supported by public health policies. Rather, malaria policies are still tied to the magic-bullet approaches grounded on the delivery of reductionist health technologies, that target the malaria vector and neglect the conditions that foster the disease transmission (Cueto, 2013). Though the WHO recommends the active community engagement in malaria programs (WHO 2015), in the everyday interventions of BMPCP individuals are expected to play an obedient role in the program, namely seeking diagnosis, taking medications appropriately, and adhering to TMR, IRS, and ITN. In short, populations subjected to public health programs, the "others" in Harding's words, have much to comply with and little to say about health policies that make their bodies public health's objects and a governmental issue (Harding, 2008; Nading, 2014).

The discussion of this thesis also moved beyond universalized public health interventions to an introduction of a multiplicity of ways that Ribeirinhos of the Brazilian Amazon related to malaria. In the first manuscript, for instance, I characterized Ribeirinhos' genuine ways of knowing about malaria transmission, in which elements of nature such as the sun, wind, water, pathogens, mosquitoes, and humans are implicated as agents that cause malaria. In this manuscript, I also described empirical diagnosis practices Ribeirinhos developed to distinguish malaria from other febrile sicknesses, and how these practices are used in coordination with biomedical diagnosis of malaria. This

finding both challenges the public health discourse that depicts people as obstacles for malaria interventions, and attests to the need for public health officials to take on Ribeirinhos as partners of malaria programs.

In the literature review section, I mentioned that Fraxe (2004) and Nogueira (2010) suggest the replacement of traditional healthcare practices of malaria by biomedical interventions in riverine communities of the state of Amazonas. The second manuscript, however, shows the contrary. That is, Ribeirinhos' treatment practices of malaria encompass the use of antimalarial medications and traditional treatments, including herbal preparations, over-the-counter medications, ingestion of paca's bile, and avoidance of *comidas reimosas*. Thus, I argue that Ribeirinhos treatment practices of malaria attest to medical pluralism in the treatment for malaria in the Brazilian Amazon.

In the third manuscript, I analyzed human-nonhuman entanglements from a public health and anthropology of life stances. I characterized, among other aspects, social intimacies between Ribeirinhos and mosquitoes that carry malaria (or not). My argument is that living in the forest implies cohabitation with other beings, such as mosquitoes. *Anopheles darlingi* mosquitoes are only found in forest areas of the Amazon, their existence is entangled with the conservation of the forest and life forms that inhabit there, and beyond. Overall, through the perspective of entanglement, life is not seen as a vital process to be secure, but as "unfolding, often incidental attachments and affinities, antagonisms and animosities that bring people, nonhuman animals, and materials into each others' worlds" (Nading, 2012, p. 574).

The perspective of entanglement counters standardized public health interventions that assume environment and health as separate domains. Paying attention

to how malaria interventions were experienced by Ribeirinhos shows that these interventions are not able to keep up with life dynamics and contextual specificities. In fact, these interventions single out biological features of malaria among a multiplicity of factors that bring people, malaria-carrying mosquitoes, and pathogens together. Such interventions are anchored in a biological framework that equals malaria prevention to killing mosquitoes and pathogens, and detaching people from their daily activities and places they live. Furthermore, people, pathogens, and mosquitoes are not fixed entities; yet, these are open-ended to each other and always negotiating ways to flourish within a socio-cultural-political-economical environment. Accordingly, this study makes numerous contributions to the field of malaria, of which four important ones might stand out. First, peoples' experiences and practices of malaria in the Brazilian Amazon is an understudied topic. Describing this disease through approaches that are rarely applied to the study of malaria, such as phenomenology, embodiment, and anthropological studies provides a new lens to the understanding of how this disease is handled by patients at their homes and communities.

Second, studies investigating treatment practices of malaria usually analyze biomedical and traditional treatments as dissociated from one another. This study examines the interface of Western and traditional medicine on the treatment of vivax infections. By weaving these two therapeutic approaches together, this study contributes to discussions on this topic. Third, vector control interventions are mostly described in studies aimed to evaluate people's perceptions and adherence to IRS and ITN. Rather, this study analyzes vector control interventions in the entanglements of everyday lives thus, remaining closer to what is going on in reality. Bringing light to these fragile

entanglements is also a contribution of this study. Fourth, this study shows that despite the WHO's call to patient-centered health care approaches in malaria interventions, in practice, strategies to control the disease in the Brazilian Amazon remain tied to a strict biomedical framework, which disregards broader entanglements that maintain malaria transmission in the area.

The three papers together express how lived experience is crucial to ways of dealing with malaria and public health interventions. Equally important, the main argument of this thesis invites us to think of healthy ways of living with other selves, such as *Anopheles darlingi* mosquitoes, since their existence is not dissociated from the conservation of the Amazon forest. The thesis sheds light on the broader entanglements that need to be taken into consideration while targeting or singling out a disease. The discussions presented here give perspective on how controlling diseases is more a question of continuously negotiating and improvising ways of remaining healthy in flexible ways, than exterminating or eradicating disease-vectors and pathogens.

Policy implications

By paying attention to Ribeirinhos' experiences and diagnostic, treatment, and control practices of malaria, this study provides insight into blind spots in the current interventions to control this disease in Brazil, which can offer some recommendations to the malaria control programs, in particular to BMPCP:

Introduce durable solutions, such as housing improvements and other housing policies, to reduce people's exposition to malaria and other disease vectors.

Create a participatory evaluation of malaria interventions in which Ribeirinhos

can discuss with malaria policy makers, government sectors responsible for housing programs, poverty alleviation programs, such as the *Bolsa Família*, and universities, among other sectors.

Offer better training to endemic disease control agents which are the primary professionals dealing with people presenting malaria.

Create a system to monitor and provide adequate care to individuals who experience severe side effects of antimalarial medications.

Financially support social sciences and humanities research studies to investigate how interventions to control malaria are experienced by afflicted populations, and how these can be improved to attend to the needs of vulnerable population.

Future research

Research into the field of population's experiences and practices of malaria are vast. However, most publications describe infections caused by *Plasmodium falciparum*. In the Americas, most infections are caused by *Plasmodium vivax*. Thereby, I make the following recommendations:

Extend this study to other states of and populations living in the Brazilian Amazon, such as indigenous populations and miners.

Investigate methodologies to integrate afflicted populations into the evaluation of malaria control programs.

Study the role played by the EDCA in the care of malarial patients in rural settings.

Evaluate factors that lead to non-use of ITN among infants and its impact on childhood malaria in the Brazilian Amazon.

Investigate how human-nonhuman entanglements may result in the occurrence of malaria.

Study how to build better communication and community involvement in malaria control.

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Appendix A

REB Certificate

Ethics certificate from University of Ottawa

File Number: 1010-14-10

Date (mm/dd/yyyy): 12/02/2014



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Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

During the course of the project, the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the project (e.g., change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, including consent and recruitment documentation, should be submitted to the Ethics Office for approval using the "Modification to research project" form available at: <http://www.research.uottawa.ca/ethics/forms.html>.

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: <http://www.research.uottawa.ca/ethics/forms.html>.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Ethics certificate from Brazil

DETALHAR PROJETO DE PESQUISA

— DADOS DA VERSÃO DO PROJETO DE PESQUISA

Título da Pesquisa: Experiências e práticas de malária de populações ribeirinhas que vivem na Amazônia Brasileira

Pesquisador Responsável: Luciane Machado Freitas de Souza

Área Temática:

Versão: 2

CAAE: 37864014.9.0000.0005

Submetido em: 12/11/2014

Instituição Proponente: Fundação de Medicina Tropical do Amazonas - FMT/IMT/AM

Situação da Versão do Projeto: Aprovado

Localização atual da Versão do Projeto: Pesquisador Responsável

Patrocinador Principal: Fundação de Amparo à Pesquisa do Estado do Amazonas - FAPeAM



Comprovante de Recepção:  PB_COMPROVANTE_RECEPCAO_380747

Appendix B

Detailed information of the research participants

Table B.1: Socio-demographic characteristics of the research participants

Occupation	Men (n)	Women (n)
Civil servant		2
Elderly (Retired)	2	
Farm caretaker	3	1
House worker		7
Industrial worker	2	
Peasant	1	9
Police officer	1	
Seamstress		1
Handcraft woman		1
Total	9	21

Appendix C

List of research participants who were regularly followed during fieldwork and interviewed

Table C.1: Research participants from Brasileirinho community

Brasileirinho Community	
Research participant	Brief description
Cleide	27-year old woman, married, mother of six children, and has three years of schooling. There has been two years that she lives in the community with her husband, children, and father. Cleide is a house worker, and received <i>bolsa família</i> benefit for her six children. During the weekends, she works in a water park located in her property.
Paulo	70-year old man, married, and father of seven children. Paulo did not attend school, but learned to read and write by himself. There has been 17 years that he lives in the community with his wife, children, and grandchildren. He is retired, but continues to work in his farm selling bread, tropical fruits, and poultry. He had malaria last year, and said having lost count of how many malarial bouts he already had. The last time he had malaria was in 2014.
Ana Maria	43 year-old woman, married, mother of four children, and has three years of schooling. Ana Maria is a former endemic disease control agent. There has been three years that she lives in the community with her partner, in a house that they both take care. Ana Maria is a house worker, and to increase the family income, she sells popsicles, juices, and tropical fruits. She had malaria in 2014.
Lene	48 year-old woman, married, mother of 14 children, and has three years of schooling. There has been 14 years that she lives in the community with her husband, children, grandchildren, mother, and uncle. Her husband and herself grow vegetables to supply their needs and sell produce in Manaus. She had malaria four times, and the last time she came down with the disease was in 2014..
Milagres	46 year-old woman, married, mother of three children, and has three years of schooling. There has been three years that she lives in the community with her husband and daughter. Milagres works as a seamstress. She had malaria in 2013.
Marcos	48-year old man, in common-law union, father of five children, and has two years of schooling. There has been five years that he

	lives in the community with his wife. Marcos works as a farm caretaker and receives a monthly salary. He had more than 30 malarial bouts. His wife and himself had malaria in 2014.
Marlene	34-year old woman, married, mother of five children, and has five years of schooling. There has been five years that she lives in the community with her husband and children. Marlene is a house worker, and receives <i>bolsa família</i> benefit for her five children. In 2014 and 2015 her husband, 1-year-old son, and herself had malaria. Her son had three malarial bouts in a row.
Elisângela	36-years old woman, in common-law union, mother of eight children, and has eight years of schooling. There has been two years that she lives in the community with her partner, four children, and two stepchildren. Elisângela is a houseworker and has not income. Her children are not covered by <i>bolsa família</i> benefit yet; in fact two of them have no birth certificates. Three of her four children and herself had malaria in 2014. Two children were hospitalized due to malaria and anemia. She moved out of the community in April 2015.
Rosilene	22-year old, in common-law union, mother of two children, was pregnant, and has five years of schooling. There has been one year that she lives in an <i>invasion</i> in the community with her partner and children. Rosilene is a house worker and receives <i>bolsa família</i> benefit for one child. In 2014, her four-year-old daughter, her husband, and herself had malaria.
Lauro	51-year old man, in common-law union, father of five children, and has three years of schooling. There has been five years that he lives in the community with his partner. Lauro works as farm caretaker and receives a monthly salary.
Jose Mauro	64-year old man, married, father of four children, and has six years of schooling. There has been 14 years that he lives in the community with his wife, children, and grandchildren. He owns a grocery store and is a police officer in leave entitlement. He had malaria in 2014 and 2015.
Otávio	38-year old man, married, father of five children, and has five years of schooling. There has been ten years that he lives in community with his wife and children. Otávio has a grocery store and works three times a week as a freelance industrial butcher in a slaughter house in the community. Two children and himself had malaria in 2014.
Haroldo	34-year old man, married, father of four children, and has four years of schooling. There has been six years that he lives in the community with his wife and children. Harold works as a steam boiler operator in a slaughterhouse in the community. Harold reported to have had at least 30 malarial bouts. The last time he came down with the disease was in 2014.
Carlos	50-year old man, single, and childless. Carlos did not attend

	school and is illiterate. There has been 4 years that he lives in community. He takes care of small farm, but is not paid for his work. Carlos lost count of how many malarial bouts he already had. He was sick from malaria multiple times in 2014 and in March 2015.
Helena	62-year old woman, married, mother of five children, and has two years of schooling. There has been 23 years that she lives in the community with husband, children, and grandchildren. Helena works as a farm caretaker, bonesetter, and herbalist. She had multiple malarial bouts. The last time she fell sick from malaria was in 2013. One of her grandchildren had malaria in January 2015.

Table C.2: Research participants from Panelão Community

Panelão Community	
Research participant	Brief description
Patricia	18-year old woman, mother of two children, in common-law union, and has attended to the first year of high school. There has been one year that she moved to the community. She is a house worker and lives with partner in his family's house. She has no income.
Luzinete	51-year old woman, married, mother of two children, and attended to high school. There has been nine years that she lives in the community with her family. She is a peasant and works in the family's vegetable garden.
Noé	91-year old man, married, and father of five children. Noé was attending the community school and recently learned to write and read. There has been 16 years that he lives in the community with his wife. Noé is retired, but continues to work in his family's vegetable garden. He is an herbalist. When he was young he worked as rubber tapper. He had multiple malarial bouts and the last time he came down with malaria was in December 2014.
Lidiane	40-year old woman, married, and mother of two children. She works as civil servant in Careiro and is attending university. There has been two years that she lives in the community with her son. Her husband lives in Manaus. Recently, Lidiane turned her property into a fish farm. Lidiane had her first malaria in 2014.
Lara	43-year old woman, married, and mother of four children. She is attending university in Careiro. She works as community health agent. There has been seven years that Lara lives in the community with her husband and children. She had malaria in 2014. Her son had malaria in 2014 and 2015.
Irma	60-year old woman, married, and mother of eight children. She did not attend school, but writes and reads. There has been 14 years that she lives in the community with her husband and two grandchildren. Irma is a peasant who works in the family's vegetable garden. To increase the family income, she sells tropical fruits. Irma had malaria five times and, in the first time I met her, her grandson and herself were in treatment for the disease.
Luzia	41-year old woman, married, mother of six children. Luzia did not attend school but reads and signs her name. There has been one and a half years she moved from Careiro to the Panelão community with her husband and children. She is a peasant and sells produce and tropical fruits. Luzia receives <i>bolsa família</i> benefit for her four children. She had two malarial bouts, in 2014 and other in 2015. Her four children and husband also had malaria. In the first time I visited her, her son was in treatment for malaria and she had just

	finished hers.
Chico	52-year old man, married, father of seven children, and has eight years of elementary school. There has been 16 years that he lives in the community with his wife. He is a peasant and works in his vegetable garden. Chico had malaria four times. The last time he was affected by the disease was in 2013.
Felipa	48-year old woman, married, mother of three children, and has three years of schooling. There has been eight years that she lives in the community with her husband. She is a peasant who works in the family's vegetable garden. Felipa had more than 30 malaria bouts; the last one was in 2013.
Giselda	49-year old woman, married, mother of two children, and is attending high school in Careiro. There has been five years that she lives in the community with her husband and 9-year old grandson. She is a peasant and also works as broker selling poultry and tropical fruits in Manaus. She had malaria in 2014, which was misdiagnosed by urinary tract infection.
Vanderléia	30-year old woman, married, mother of four children, and has five years of schooling. There has been eight years that she lives in the community with her husband and children. Vanderléia is a handicraft woman and also receives <i>bolsa família</i> benefit from her four children. She had malaria in 2013 and her son came down with malaria in 2015.
Doralice	54-year old woman, widow, mother of ten children, and has four years of schooling. There has been six years that she lives in the community with her two children, five grandchildren, and a daughter-in-law. She is a peasant and works in her vegetable garden. She makes a living from a small widow's pension benefit. Her grandchildren and herself had malaria in 2014.
Dalva	54-years old, single, mother of eight children, and has one year of schooling. There has been four years that she lives in the community with her two-grandsons. She is a peasant and receives <i>bolsa família</i> benefit for her grandchildren. Her grandsons and herself had malaria in 2014 and 2015.
Marina	25-year old woman, single, mother of two children, and seven years of schooling. There has been 20 years that she lives in the community with her parents and children. She has been living in the community even before it became an agricultural settlement. Marina is a house worker, who receives <i>bolsa família</i> benefit for her daughter. Her daughter had malaria in 2014 and herself had multiple malarial bouts during her childhood. She also coped with the disease in 2014 when she was pregnant.
Hiléia	27-year old woman, married, mother of three children, and has nine years of schooling (now elementary schooling). There has been two years that she lives in the community with her husband and three children. She is a peasant and helps her husband in the family

	garden. Hiléia had malaria in 2014. Two of her children had malaria in 2014 and one was in treatment for the disease in the first time I visited them. In the second time I went to her home, one child was repeating the treatment for malaria because she did not recover from the disease.
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Appendix D

Interview guides

Interview guide: English version

- 1) Please tell me what stands out for you about your experience of getting sick from malaria?
- 2) How do you know that you have malaria?
- 3) Can you distinguish malaria among other diseases? How do you do this?
- 4) Do you take medications to treat malaria? What are these medications? How do you get them? How do you take the medications in your everyday?
- 5) When you have malaria does anything change in your daily activities? If so, what were those changes?
- 6) How many days do you need to rest in order to recover from a malarial infection?
- 7) Do you do anything to prevent malaria in your everyday activities? If so, what do you do? Do you do this by yourself or do you need others' help? How do you do this?
- 8) Can you notice if someone else has malaria? How do you notice this? What do you do when you notice that someone has malaria?
- 9) Who takes care of you when you get sick from malaria?
- 10) Do you take care of other people when they have malarial infection?
- 11) Is there any serious problem in your community? What is this problem?

Interview guide: Portuguese version

- 1) Por favor, o que é mais marcante para você quando você adoece por malária?
- 2) Como você sabe que você está doente por malária? (Diagnóstico)
- 3) Você pode distinguir malária entre outras doenças que causam febre? Em caso de resposta afirmativa eu perguntarei: Como você faz isso?
- 4) Você toma medicamentos para tratar malária? Quais são estes medicamentos? Como você os obtém? Como você tomar estes medicamentos?
- 5) Quantos dias você precisa repousar para se recuperar da malária?
- 6) Quando você tem malária o que muda em suas atividades diárias? Em caso de resposta afirmativa eu perguntei: Como você administra as mudanças provocadas pelo adoecimento por malária?
- 7) Você adota medidas para prevenir malária? Em caso de resposta afirmativa eu perguntei: O que você faz para prevenir malária? Você faz isso por si mesmo ou você precisa de ajuda de outras pessoas? Quando a pessoa respondeu que ela não adota medidas de prevenção eu perguntei quais as razões para ela não fazer isso.
- 8) Você percebe se alguém está doente por malária? Como você percebe isso? O que você faz quando percebe que alguém tem malária?
- 9) Quem cuida de você quando você adoece de malária? Em caso de resposta afirmativa eu perguntei: O que a pessoa que cuida de você quando você está doente de malária faz para ajudá-la a se recuperar da doença?

10) Você cuida de outras pessoas quando elas adoecem por malária? Em caso de resposta afirmativa eu perguntei: Como você cuida desta pessoa doente?

11) Qual é o problema que mais a/o incomoda aqui na sua comunidade? Por que você considera esta problema grave? Quando a resposta não indicou que a malária é uma o problema na comunidade eu perguntarei: Por que a malária não é um problema nesta comunidade?

Appendix E

Informed consent forms



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Title of the study: Riberinhos' Lived Experiences and Practices of Malaria in

You are invited to participate in a study to understand the experiences of becoming ill from malaria and practices of diagnosis, treatment and preventive measures against this disease. This study will be developed by myself as a PhD candidate from the Institute of Population Health and supervised by professor _____ from the Department of Sociology and Anthropology at the University of Ottawa in collaboration with the Fundação de Medicina Tropical Dr. Heitor Vieira Dourado. This study aims to understand how people experience malaria daily in their homes and community. Based on this knowledge we intend to contribute to the advancement of research for controlling this disease in Brazil.

Participating in this research involves sharing your experiences through interviews, showing me some practices you or others follow to attend to malaria. If you agree, you could also give me permission to take photographs of certain practices associated with tending to malaria as well as I would like to take some notes about these practices and your everyday activities. In interviews you will be invited to recall your experiences of malaria. The interviews will last approximately 90 minutes with the possibility of two further interviews should you accept to continue in the study. We can agree upon a good time and place preferred for doing the interview.

The experiences, opinions, and ways of attending to malaria that you share with me will be used in the study only. To protect your identity, I will replace your name by another name. In photographs that you can be identified, I will choose with you which images you would like I use in the study.

Your participation in this study is voluntary. For your participation in this study you will not receive any compensation, but even not having direct benefits, some people find it to participating in a research helpful.

You will have no expenses for participating in this study; but in the case of expenses as a result of this research such as ground transportation and meals, you

will be reimbursed.

I will password protect the computer and hard drive in which interviews, field notes, and pictures will be stored. During the study in Brazil your narratives and pictures will be securely kept in a locked room, which will also serve as my office. The data will be conserved for 25 years. At the end of the conservation period, printed documents regarding the research will be destroyed by shredding and digital data will be deleted from computers.

You have the right to access the research results.

You can withdraw from the study at any time and/or refuse to answer any questions without suffering any negative consequences. If you choose to withdraw, all data gathered until the time of withdrawal will be destroyed.

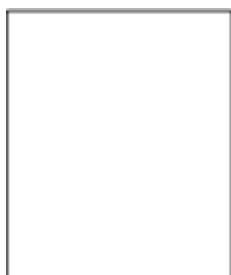
If you have any questions about the study you may contact by phone Dr. _____ or the researcher responsible for the study (phone.....) in Manaus. In Canada you may contact by phone _____. You can also clarify any questions about the ethical conduct of this study in the Protocol Officer for Ethics in Research from the University of Ottawa by phone 1(613) 562-5387, by email ethics@uottawa.ca.

There are two copies of the consent form, one of which is yours to keep.

I authorize my participation in the study “Riberinhos’ experiences and practices of malaria in the Brazilian Amazon”. I also declare that I have received a copy of this consent form.

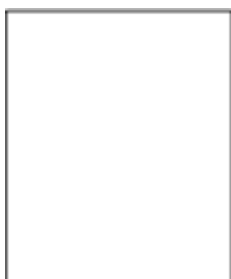
Signature:..... Date: / /.....

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Specifically in relation to the use of my images: () I agree with the use of my image. () I do not agree with the use of my image.

Signature:..... Date: /..... /.....



Right thumb

Researcher's signature:..... Date: /..... /



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Consent form: Portuguese version

Título do Estudo: “Experiências e Práticas de Malária dos Riberinhos que vivem na Amazônia Brasileira”

TERMO DE CONSENTIMENTO LIVRE E ESCLARECIDO

Você está sendo convidado(a) a participar de um estudo para compreender as experiências de adoecimento por malária e as práticas de diagnóstico, tratamento e medidas de prevenção contra esta doença. Este estudo será desenvolvido pelo Instituto de Saúde das Populações da Universidade de Ottawa em colaboração com a Fundação de Medicina Tropical Dr. Heitor Vieira Dourado. Este estudo objetiva conhecer como as pessoas experienciam a malária no dia-a-dia, em suas residências e comunidade. Com base neste conhecimento pretende-se contribuir para o avanço da pesquisa para o controle desta doença.

Se você concordar em participar deste estudo você será entrevistado (a), observado (a) e fotografado (a). Nas entrevistas você será convidado (a) a lembrar as suas experiências com malária. As entrevistas terão uma duração aproximada de 90 minutos e você será entrevistado (a) pelo três vezes durante a realização da pesquisa. As entrevistas serão agendadas e realizadas em sua casa ou em outro local que você sugerir. As observações serão realizadas durante as entrevistas e visitas em sua casa. Caso você concordar, fotografias de sua residência e de suas atividades diárias serão tiradas e neste caso suas imagens serão usadas apenas com o seu consentimento.

Todas as informações coletadas serão usadas somente no estudo. Nós não compartilharemos suas informações e um código será usado para identificar você em vez de seu nome. No caso das fotografias as imagens em que você poderá ser identificado (a) só serão utilizadas com a sua permissão.

Você não terá nenhuma despesa por participar deste estudo, contudo em caso de despesas em decorrência da pesquisa tais como deslocamento e alimentação, você será ressarcido (a). Este estudo não oferece riscos a sua saúde, contudo em caso que você venha sofrer qualquer dano por causa da pesquisa, você será indenizado (a).

Pela sua participação no estudo você não receberá qualquer valor em dinheiro, mas mesmo não tendo benefícios diretos, indiretamente você estará contribuindo para a compreensão de como a malária é enfrentada nas residências e comunidades e para a produção de conhecimento científico sobre esta doença. Você tem o direito de ter acesso aos resultados da pesquisa, se assim desejar.

A sua participação neste estudo é voluntária e se você não quiser mais fazer parte da pesquisa poderá desistir a qualquer momento. Com isso, todos os seus dados serão retirados do estudo. Essa decisão não prejudicará de forma alguma o seu relacionamento com os pesquisadores.

Quaisquer dúvidas em relação à pesquisa poderão ser esclarecidas pelo(s) pesquisador (es) _____ pelo telefone _____ ou com a pesquisadora responsável pelo estudo pelo telefone _____. O Comitê de Ética em Pesquisa com Seres Humanos da Fundação de Medicina Tropical Dr. Heitor Vieira Dourado também poderá prestar esclarecimentos ou receber qualquer reclamação a respeito desta pesquisa em Manaus (endereço: _____) ou pelo telefone (92) 2127 3470. Este documento será impresso em duas vias. Uma ficará com o (a) pesquisador (a) e outra com o (a) participante da pesquisa.

Eu, _____, entendi tudo sobre o estudo “Experiências e Práticas de Malária dos Riberinhos que vivem na Amazônia Brasileira” e por isso autorizo a minha participação no estudo. Eu também declaro ter recebido uma cópia deste termo de consentimento.

Assinatura do(a) voluntário(a): _____

Data: / /



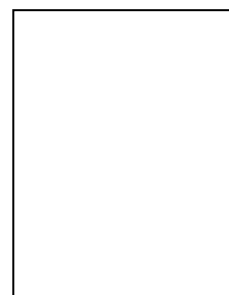
Polegar direito

Especificamente em relação ao uso de minhas imagens:

() Concordo com o uso da minha imagem.

() Não concordo com o uso da minha imagem.

Assinatura do (a) voluntário (a): _____



Polegar direito

Assinatura do (a) pesquisador (a): _____

Data: / /