MALARIA MANAGEMENT IN A FRACTURED SOCIETY: TREATMENT-SEEKING BEHAVIOUR IN KAKUMA REFUGEE CAMP IN NORTHWESTERN KENYA

By

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ABSTRACT

The effect of social, political, and economic context on treatment seeking and the effective case management of malaria is widely recognised. In refugee settings, the whole balance of society has been upset and both intra and inter- household relationships have been extensively disrupted. Many refugees undergo trauma, which may affect their perceptions of health and ill health. This study, investigated the factors influencing effective case management of malaria in the Kakuma refugee camp using a variety of data collection methods including: in-depth interviews, focus group discussions, observations of clinical management and a parasite prevalence survey. The refugees and the providers of health care in Kakuma perceived that the burden of malaria was high, but the parasitological data were of insufficient quality to confirm these perceptions. Clinical management and parasitological diagnosis of malaria were insufficient and affected by: inadequately qualified and poorly motivated staff, budgetary, logistical and security constraints. Awareness of the symptoms of malaria among the refugees were relatively high, but treatment seeking was affected by the insufficient quality of malaria management, the context of the refugee camp setting, and the experiences suffered in becoming a refugee. In particular, the loss of a sense of agency and the on-going problems of nutritional and physical security influenced the refugees' motivation to seek treatment. The establishment of community health committees could provide a mechanism to address some of these contextual issues by: strengthening the relationships among the refugees health care providers and camp management; providing the refugees with a greater sense of agency; helping in the support and motivation of the health staff and providing a forum for the development of appropriate disease management programmes. This study underlines that understanding the setting and

circumstances of becoming and remaining a refugee is essential to developing effective disease management strategies for refugees.

DEDICATION

This piece of work is dedicated to my husband Johnny Damian and my mum Juliana Lakor

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"Where there is a will, there is a way".

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ACRONYMS

ACT: Artemisinin-based Combination Therapy

AIDS: Acquired Immune Deficiency Syndrome

AMREF: African Medical Research Foundation

AQ: Amodiaquine

CHC: Community Health Committee

CHWs: Community Health Workers

CQ: Chloroquine

CRPF: Chloroquine Resistant Plasmodium Falciparum

CMR: Crude Mortality Rate

DDT: Dichloro Diphenyl Trichloroethane

DFID: Department for International Development

DHMT: District Health Management Team

DOMC: Division of Malaria Control

EPI: Expanded Programme of Immunisation

EANMAT: East African Network for Monitoring Antimalarial Treatment

FGD: Focus Group Discussion

FGM: Female Genital Mutilation

GIS: Geographical Information System

GPS: Global Positioning System

GTZ: German Technical Cooperation

HIV: Human Immunodeficiency Virus

HIMS: Health Information Management System

IDP: Internally displaced people/person

IASC: Inter-Agency Standing Committee

IEC: Information, Education and Communication

IOM: International Organisation for Migration

ITNs: Insecticide Treated Nets

IMCI: Integrated Management of Childhood Illnesses

IRC: International Rescue Committee

JRS: Jesuit Refugee Service

KFF: Kaiser Family Foundation

LWF/DWS: Lutheran World Federation/Department for World Service

MARA: Mapping Malaria Risk in Africa

MIM: Multilateral Initiative on Malaria

MISP: Minimum Initial Service Package

MOH: Ministry of Health

MSF: Médicins Sans Frontières

NCCLS: National Committee for Clinical Laboratory Standards

NCCK: National Council of Churches Kenya

NGO: Non-Governmental Organisation

NMCP: National Malaria Control Programme

NRS: National Refugee Secretariat

OAU: Organisation of African Unity

OFDA: Office of U.S. Foreign Disaster Assistance

OPD: Out-Patient Department

OTC: Over The Counter

PHC: Primary Health Care

PTSD: Post Traumatic Stress Disorder

PMO: Provincial Medical Officer

QA: Quality Assurance

RBC: Red Blood Cells

RDTs: Rapid Diagnostic Tests

RTI: Respiratory Tract Infection

RBM: Roll Back Malaria

STDs: Sexually Transmitted Diseases

SP: Sulfadoxine-Pyrimethamine

sq km: Square Kilometer

UNDP: United Nations Development Programme

USAID: The United States Agency for International Development

UNHCR: United Nations High Commissioner for Refugees

UNICEF: United Nations International Children's Emergency Fund

USCR: United States Committee for Refugees

WBC: White Blood Count

WCT: Windle Charitable Trust

WFP: World Food Programme

WHO/AFRO: World Health Organisation/Regional Office for Africa

WHO: World Health Organisation

WVI: World Vision

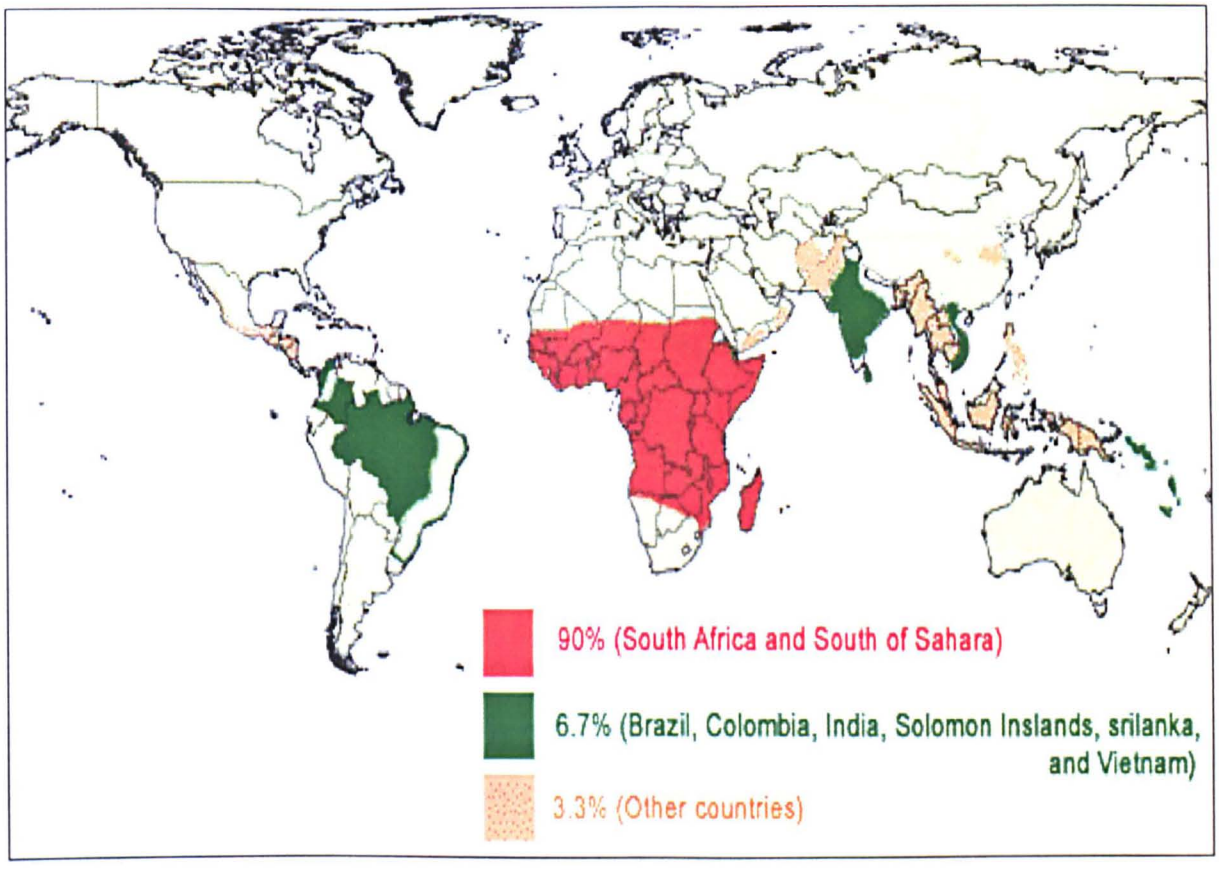
CHAPTER 1: INTRODUCTION AND RATIONALE

1.1 GLOBAL MALARIA BURDEN

Rapid and increased international migration, whether voluntary or forced, has contributed to the reappearance of malaria cases worldwide (Bradley, 1999). Each year, there are an estimated 300-500 million clinical cases of malaria and 90% of these cases occur in Africa, south of the Sahara (UNICEF, 2000). Malaria accounts for 1.5-2.7 million deaths annually, of which an estimated million deaths occur in children under-five years of age. It is estimated that one in every 20 children in Africa is likely to die of malaria-related illness before reaching the age of five (WHO, 1999). In most malaria endemic countries in Africa, 25–40% (average 30%) of all outpatient clinic visits pertain to malaria, with most diagnosis made clinically. In these same countries, between 20% and 50% of all hospital admissions are a consequence of malaria with high case-fatality rates due to late presentation, inadequate management, and unavailability or 'stock-outs' of effective drugs (WHO/UNICEF, 2003).

Despite the few efforts to control malaria in sub-Saharan Africa, the morbidity and mortality rate is rising. More than 40% of the world's population lives in endemic regions and over 100 countries are affected by the disease. Impoverished countries suffer the most from malaria as it is a contributing cause of poverty. It depletes family resources by increasing health care expenditure, decreasing income through sickness and absenteeism and influences the choice of work (RBM, 1998). Below is a world map indicating countries affected by malaria (Figure 1.1).

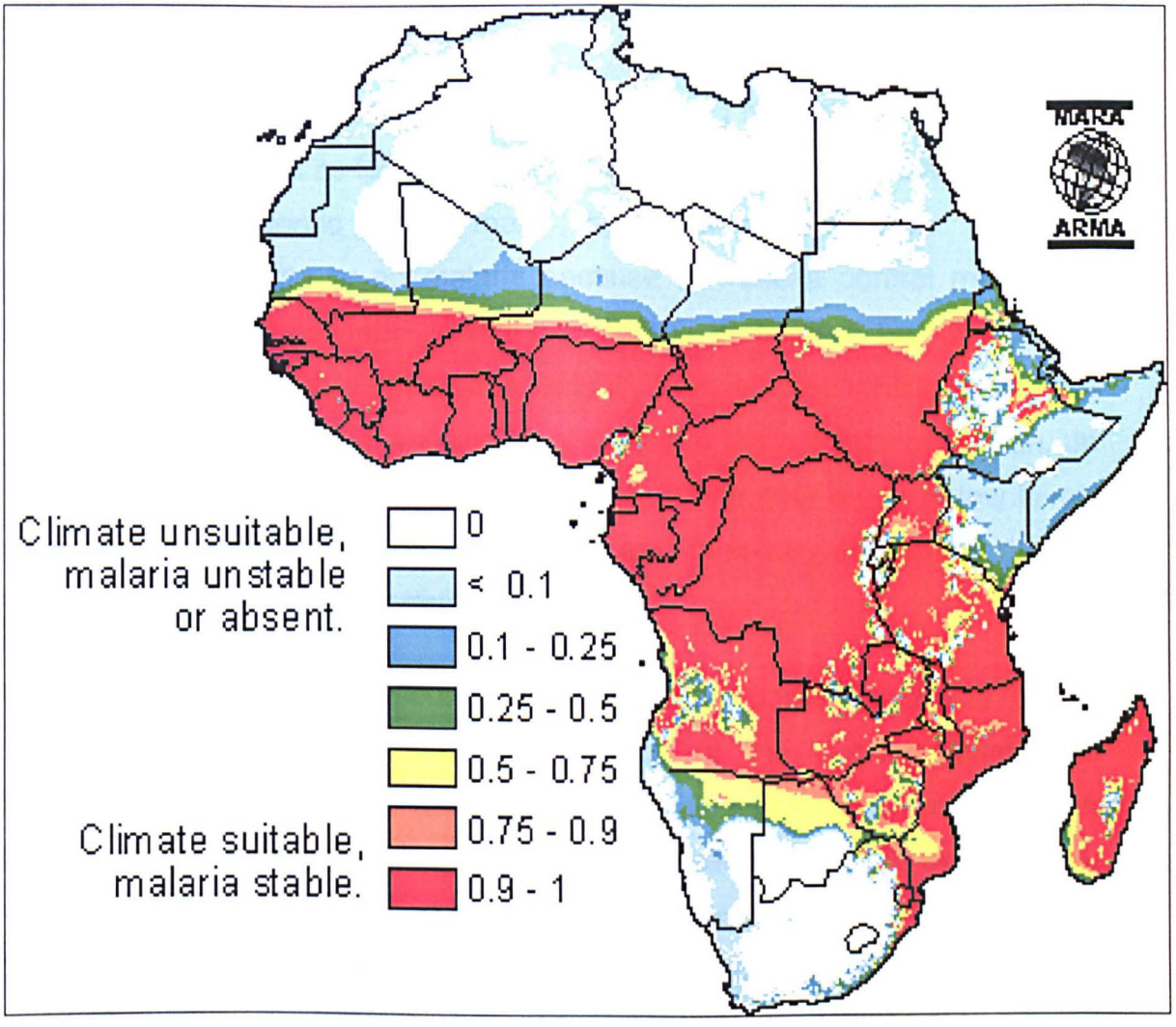
Figure 1.1: Malaria distribution in the world



Source: http://www.pon.nic.in/fil-free/vcrc/malaria3.html

The distribution, transmission intensity, and clinical consequences of malaria in Africa vary greatly from country to country and indeed within countries. Africa experiences a complete spectrum of malaria epidemiology ranging from regions of intense perennial transmission, to unstable, epidemic-prone areas. This, according to MARA (1998), has implications for the planning, targeting and implementation of control activities at continental, national and regional levels. Figure 1.2 below illustrates the distribution of malaria transmission in Africa.

Figure 1.2: Distribution of stable malaria transmission in Africa



Source: http://www.mara.org.za/mapsinfo.htm

The map (Figure 1.2) shows the theoretical suitability of local climates, and the potential distribution of stable malaria transmission in Africa in an average year. The distribution of both parasite and vector populations is strongly influenced by climate, particularly temperature and rainfall. The model developed by MARA (1998) uses curves to translate climate data into a climate suitability index between zero (climate unsuitable) and one (climate suitable). According to Craig *et al.* (1999), the map on distribution of malaria transmission in Africa (Figure 1.2) is a theoretical model based on

available long-term climate data. However, as climatic conditions vary, malaria transmission varies substantially from one year to the next and malaria control activities can also dramatically alter the malaria transmission situation.

MARA (1998) has interpreted the map (Figure 1.2) on distribution of malaria transmission in Africa as follows: "Where climate is 'suitable' (red = 1), malaria is likely to be endemic (hypo-, meso-, hyper- or holoendemic). 'Suitable' areas may have little or no malaria because of malaria control measures. Where climate is 'unsuitable' (white=0), malaria is likely to be epidemic or absent. Some 'unsuitable' areas may actually have endemic malaria because of the presence of surface water in an area where there is little or no rain. In the marginally suitable areas (0.1-0.9), transmission may occur at low levels or in strongly seasonal cycles with great inter-annual variation" (see http://www.mara.org.za/mapsinfo.htm).

Malaria is a disease caused by the protozoan parasites of the genus *Plasmodium (P).* There are four species of the genus *plasmodium* responsible for the malarial parasite infections that commonly infect human beings. These are: *P. falciparum, P. vivax, P. malariae and P. ovale* (RBM, 1998). The most important of these is *P. falciparum* because it can rapidly lead to death, while the most effective malaria vector is *Anopheles gambiae,* which is the most widespread in Africa and the most difficult to control (WHO/UNICEF, 2003). Greenwood and Mutabingwa (2002) report that the most important reason for the persistence of malaria in Africa is the presence of the vector *Anopheles gambiae.* However, social and economic factors also play an important role.

1.2 MALARIA AND CONTROL HISTORY

For hundreds of years, malaria has been treated by extracts from plants such as quinine from the cinchona tree and ginghaosu from Artemisia annua, some of which are still active, but after the discovery in 1897 that malaria is transmitted by mosquitoes, attempts to prevent malaria through the control of

mosquito populations began. Following some early successes and the production of dichloro diphenyl trichloroethane (DDT) and other synthetic insecticides in the 1930s and 40s, the principle of malaria eradication was adopted in 1955. It made significant progress in the 1960s, but did not have a major impact in tropical Africa. However, the emergence of drug and insecticide resistance, coupled with concerns about the feasibility and sustainability of tackling malaria in areas with weak infrastructure and high transmission led to resurgences of malaria in the 1970s, and brought an end to the eradication era as well as to the bulk of international funding for malaria control and investment in malaria research (WHO/UNICEF, 2003). In the late 1970s, the concept of eradication was replaced with that of control as a part of primary health care. Despite international indifference in subsequent years, progress continued to be made in understanding the problem of malaria and strategies for its control. By the early 1990s, the international community began to appreciate that the malaria burden was unacceptably high and worsening, particularly, in Africa, and that real reductions in malaria mortality and morbidity were possible with existing but under-utilised tools and strategies (WHO/UNICEF, 2003).

1.2.1 Malaria and immunity

Frequent and repeated exposure to the malaria parasite helps develop immunity to the disease in humans. Artavanis-Tsakonas and colleagues (Artavanis-Tsakonas *et al.*, 2003) report that people living in malaria endemic areas with repeated exposure to the disease gradually acquire mechanisms to limit the inflammatory response to the parasite that causes the acute febrile symptoms. However, Gilles and Warrell (1993) indicate that complete immunity to parasitisation is almost impossible to achieve but even if it is achieved, the immunity may not be stable and immune subjects who travel outside the endemic area are prone to malaria on re-exposure.

In highly endemic areas, the risk of severe malaria and death is most common among young children between six months and five years of age, the periods

during which they have lost the immunity transferred from their mothers and have not yet developed their own immunity. Children are said to remain relatively protected from malaria by the immunity transferred from their mothers for a period of three to six month after birth (Gilles and Warrell, 1993). Similarly, Bloland and Williams (2003) report that most clinical malaria and malaria associated mortality in highly endemic areas occur in children under-five whose immunity has not yet developed. According to Greenwood *et al.* (1987), malaria associated mortality decreases rapidly with increasing age. Severe malaria in adults is seen in areas of low endemicity, where people may reach adulthood without immunity. Pregnant women are highly susceptible to malaria infection since their natural defense mechanisms are reduced during pregnancy. *P falciparum* malaria in non-immune pregnant women may lead to death, abortion, pre-maturity or low birth weight. Among the semi-immune inhabitants of highly endemic areas, malaria represents a serious risk in the first and second pregnancy as they are more frequently infected, and are susceptible to anaemia, hypoglycaemia and other complications. Malaria is also an important cause of low birth weight and high neonatal mortality in first and second born babies in endemic areas (Steketee *et al.*, 2001).

In response to a growing concern about the continuing and increasing burden of disease and death due to malaria, especially in Africa, the Roll Back Malaria (RBM) partnership was initiated in 1998. The main focus of RBM is to reduce malaria related mortality by half by the year 2010 and to further reduce morbidity in the succeeding years. RBM recommends and focuses on control strategies which include: provision of prompt access to effective treatment, promotion of insecticide-treated mosquito nets, improvement of vector control, prevention and management of malaria in pregnancy and improvement in the prevention of and response to malaria epidemics, and malaria in complex emergencies (RBM, 1998)

1.3 ANTIMALARIAL DRUG RESISTANCE

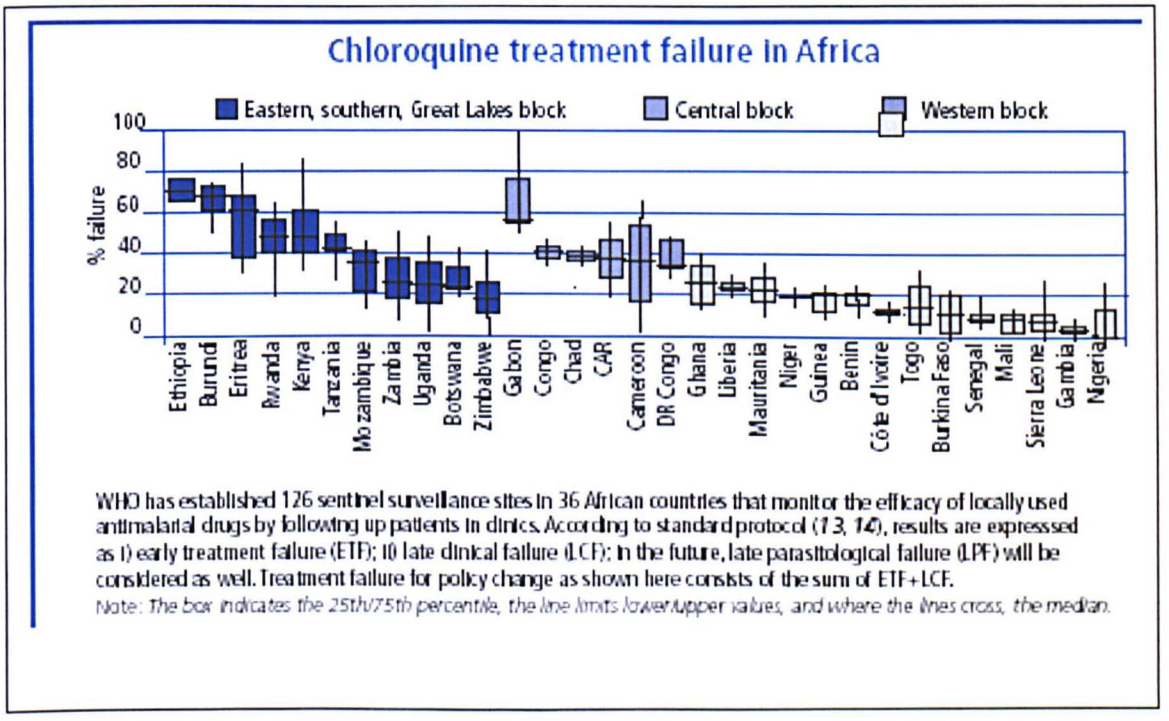
The choice of the first-line drug for treatment of uncomplicated malaria is a key part of a national malaria control strategy but has been increasingly constrained by the development of antimalarial drug resistance (Hanson *et al.*, 2004). Drug resistance of malaria parasites has been defined as the ability of a parasite strain to multiply or to survive in the presence of concentrations of a drug that normally destroy parasites of the same species or prevent their multiplication (D'Alessandro, 1998). Resistance occurs through spontaneous mutations that affect the susceptibility of the parasite to a given drug. The resistance in some drugs can occur after a single-point mutation, while with others, more than one mutation may be required (Bloland, 2001).

The emergence and spread of malaria parasites that are resistant to commonly available and relatively inexpensive antimalarial drugs has become the major challenge in management and control of the disease. It not only increases morbidity due to malaria, but also increases malaria specific mortality (Trape, 2001; Trape *et al.*, 1998). Chloroquine (CQ), which was introduced in the late 1940s, and served as a cheap and widely used drug for malaria treatment for many decades, is now proving ineffective in many parts of the world, particularly against the most severe form of malaria: *Plasmodium falciparum* (Bloland *et al.*, 1998; Trape *et al.*, 1998; Warhurst, 2001). Chloroquine resistant *P. falciparum* (CRPF) first developed independently in 3 to 4 foci in Southeast Asia and South America in the late 1950's and early 1960's (Harinasuta *et al.*, 1965; Moore and Lanier, 1961). Since then, CQ resistance has spread to nearly all areas of the world where *P. falciparum* malaria is transmitted.

In Africa, CRPF was first confirmed in non-immune tourists to Kenya and Tanzania in 1978 (Campbell *et al.*, 1979; Fogh *et al.*, 1979), and in semi-immune Kenyans in 1982 (Spencer *et al.*, 1982). Subsequently, CRPF spread rapidly throughout sub-equatorial Africa affecting a number of sub-Saharan African

countries. Figure 1.3 below illustrates some of the countries in Africa that have encountered failure in treatment of malaria with CQ from 1997-2002.

Figure 1.3: Countries in Africa reporting chloroquine treatment failure



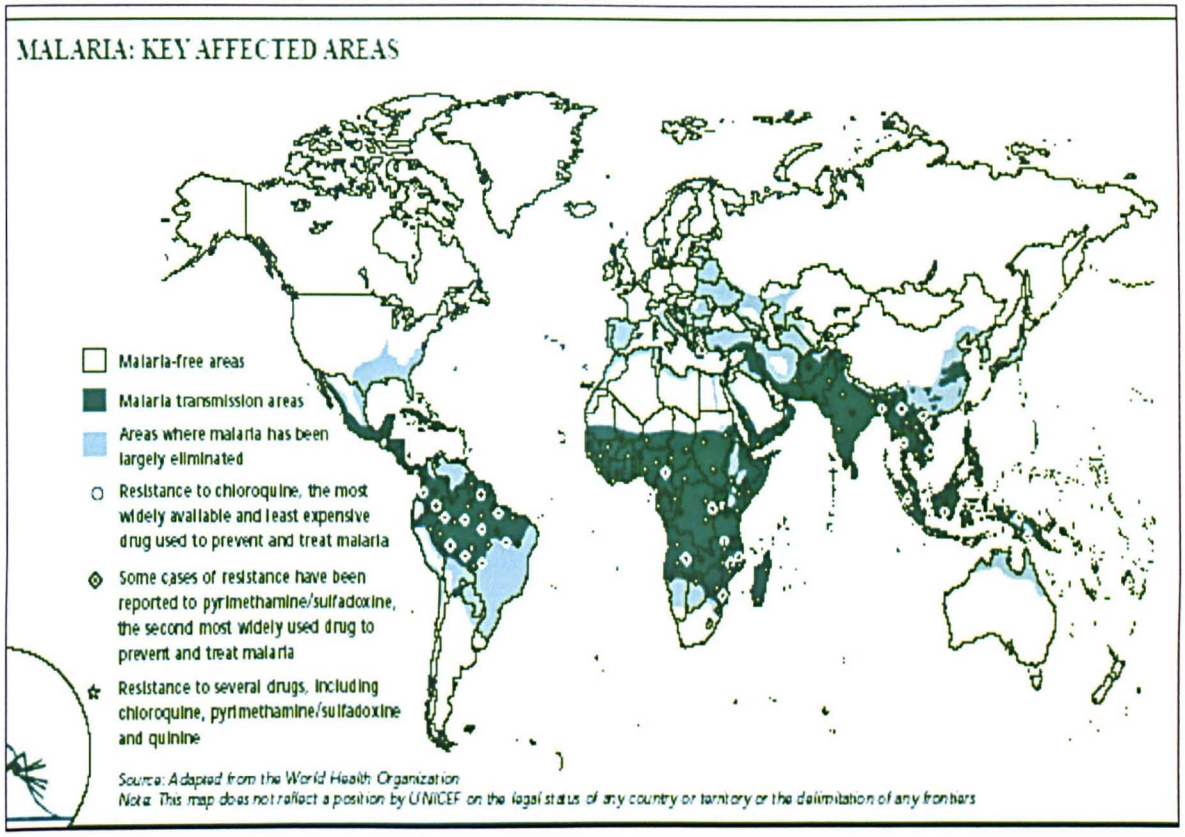
Source: WHO regional office for Africa, 1997-2002

Levels of drug resistance can vary both within and between countries. For example, in Kenya differences in CRPF has been reported between the north, where malaria transmission is low, and the south-west, where transmission is very high. In the early 1990s, CRPF was about 18% around Lake Turkana, while in Kisumu, on the shores of Lake Victoria, it was around 70% (Bloland *et al.*, 1993; Clark *et al.*, 1996).

Despite the widespread occurrence of CRPF in endemic countries, CQ is still the most frequently used drug for the first-line treatment of malaria infections (Bloland *et al.*, 1998; D'Alessandro and Buttiens, 2001; WHO, 1996). However, a

number of countries in sub-Saharan Africa have abandoned the use of CQ as the first-line treatment for malaria. These countries include: Malawi, Kenya, South Africa, Botswana, Tanzania, Uganda, Ethiopia, Eritrea, Rwanda, Burundi, Zambia, and Zimbabwa (Hanson *et al.*, 2004). The choice of replacement has been dictated primarily by economic considerations, and sulfadoxine /pyrimethamine (SP) has been considered the only practicable and affordable alternative in East and Central Africa (EANMAT, 2001). Unfortunately, SP is particularly prone to the rapid emergence of resistance (Winstanley, 2000). Figure 1.4 below is a map illustrating malaria distribution including the distribution of drug resistance *P. falciparum* parasites.

Figure 1.4: World map showing malaria characteristics in different parts of the world, including drug resistance to the parasite

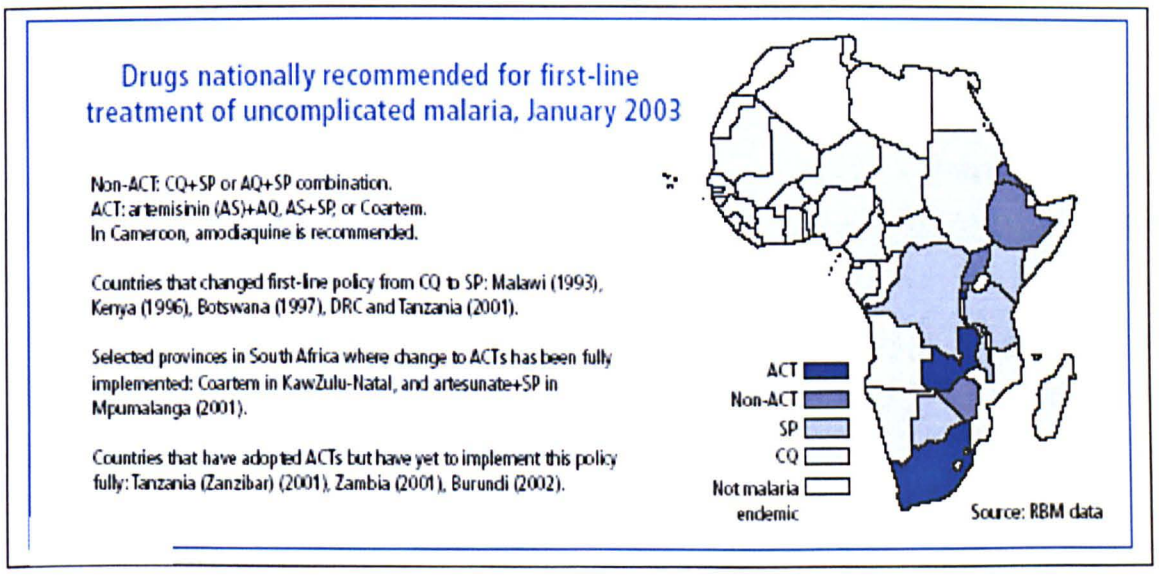


Source: http://www.doh.gov.za/issues/malaria/red_reference/case_management/cm7.pdf

While some countries in Africa including: Malawi, Kenya, Botswana, Democratic Republic of Congo (DRC) Tanzania and Ethiopia have changed first-line treatment policy for malaria from CQ to SP monotherapy, (Hanson *et al.*, 2004), other have changed from CQ to a combination of drugs. Uganda shifted to a combination of CQ and SP (Kamya *et al.*, 2002), while Rwanda shifted to a combination of amodiaquine (AQ) and SP (WHO/UNICEF, 2003). In south Sudan, although in the national policy CQ still remains the first-line treatment for malaria, NGOs such as MSF Holland have shifted to amodiaquine as the first-line treatment for malaria in areas (eastern Upper Nile) in which they are carrying out

a primary health care (PHC) programmes. The government of Sudan has just recently introduced a combination of artesunate and SP as the first-line treatment of malaria (MOH-Sudan, 2004). In South Africa, selected provinces (e.g. KwaZulu-Natal) have shifted to artemisinin-based combination therapies (ACTs) such as coartem (artemether plus lumefantrine), while other provinces have shifted to a combination of artesunate plus SP (WHO/UNICEF, 2003). Figure 1.5 below illustrates some of the countries in Africa that have shifted the first-line treatment of malaria from CQ to SP, a combination of the two drugs, or to ACTs.

Figure 1.5: African countries that have replaced CQ with other antimalarials



Source: http://www.rbm.who.int/amd2003/amr2003/pdf/ch3.pdf

Resistance to SP, the only cheap currently available alternative to CQ, is widespread in south-east Asia and South America. In Africa, resistance to SP is rapidly developing in Eastern/Great Lakes, and Central and Southern African regions (Talisuna *et al.*, 2004). For example, in Uganda, resistance to SP is said to be increasing, with 18% failure in Kampala (Dorsey *et al.*, 2002), and 6-19% in other sites in East Africa (Kamya *et al.*, 2002). Resistance to more expensive but

previously effective antimalarial drugs is also growing. According to Singhasivanon (1999) mefloquine resistance to malaria parasite is now common in the border areas of Thailand with Cambodia and Myanmar. The parasite sensitivity to quinine is also declining in several other countries of south-east Asia and in the Amazon region where it has been used in combination with tetracycline for the treatment of uncomplicated malaria (WHO, 1998). These developments threaten to reduce the availability of effective and affordable prevention and treatments for malaria. The need for new and effective malaria drugs or drug combinations is, therefore, a vital consideration in the management and control of the disease (World-Bank, 1999). The use of antimalarial drugs in combination might increase their efficacy and might also delay the emergence of resistance because the drugs may have different modes of action and different mechanisms for resistance (White, 1999).

Several factors contribute to the development, spread and intensification of drug resistance. These include vector and parasite biology, pharmacokinetics, human economic barriers, population movement and drug use patterns (Bloland, 2001; Wernsdorfer, 1994). It is widely believed that human behaviours leading to inadequate dosing, incomplete courses of therapy and inappropriate drug use have contributed to the emergence and spread of resistant parasites (Bjorkman and Phillips-Howard, 1990). Population movement can increase the spread of drug resistance by introducing new and resistant parasite genotypes that can be rapidly selected according to the amount of drug used (Talisuna *et al.*, 2004).

Economic constraints are a major factor influencing the use of effective antimalarial drugs. Decreasing economic opportunities have constrained most African countries experiencing CRPF from changing their first-line treatment from CQ to a more effective and efficient drug.

1.3.1 Antimalarial treatment policies

A national antimalarial treatment policy is a set of recommendations and regulations concerning the availability and rational use of antimalarial drugs in a country (WHO, 1994). It is the responsibility of national programmes to develop a policy for malaria disease management including the selection of appropriate drugs, since early diagnosis and adequate treatment remain the basic elements of any malaria control action (WHO, 1993). The basis of the national drug policy should be a set of defined criteria concerning the availability and rational use of antimalarial drugs in a country (WHO, 1994). These policies are important to enable the population at risk of malaria infection to have safe, good quality, effective, affordable and acceptable antimalarial drugs which will: ensure a rapid and long lasting clinical cure for individual malaria patients; prevent progression of uncomplicated malaria to severe disease and death; shorten clinical episodes of malaria, and reduce the occurrence of malaria associated anaemia in populations residing in areas of high malaria transmission; reduce the consequences of placental malaria infection and maternal malaria associated anaemia through chemoprophylaxis or preventive intermittent treatment during pregnancy; and delay the development and spread of resistance to antimalarial drugs (WHO, 2001).

Many of the factors influencing the national drug policy, such as parasite drug susceptibility, drug pricing and availability will fluctuate overtime, and national guidelines for malaria treatment will require periodic re-assessment and revision (WHO, 1996; 1999a). This should be done on the basis of reliable information, and according to WHO (2001), should include:

- Analysis of the epidemiological situation, including type of parasite species
- Analysis of the levels of resistance to currently used antimalarial drugs
- Evaluation of the properties of available alternative drugs

- Analysis of treatment-seeking behaviour provider and consumer behaviours, which may reflect whether the existing policies are rational and thus also influence how they will be implemented
- Analysis of the cost-effectiveness of alternative therapies; the costs of implementing antimalarial treatment policies include the administrative and the logistic costs, while costs for changing policies should include the actual cost, dissemination of revised guidelines and training
- Analysis of the health system capacity to implement the revised policy, including the necessary regulatory and legislative framework

To measure drug susceptibility, the information should be collected by means of an appropriate surveillance system (D'Alessandro, 1998).

The essential components for developing and updating national treatment guidelines for antimalarial drugs, according to WHO (2001a), include:

- Clear analysis of the technical, social and economic issues related to malaria control, antimalarial drug resistance, potential interventions and the consequences of action or inaction
- Analysis of the decision-making environment
- Consensus-building among relevant stakeholders (policy makers, researchers, control staff, donors etc)
- A supervisory body to oversee the development, implementation and revision of the policy and a regulatory body to ensure adherence to policy components

Changing drug policy is a major undertaking that can take several years. Some of the factors influencing change in policy have been mentioned above. For example, in Kenya although CQ resistance was first detected in 1978 and escalated during the 1980s, CQ remained the treatment of choice for uncomplicated malaria infections until 1998 when revised guidelines were launched. The delay was characterized by difficulties in translating sensitivity data with gross geographical, temporal and methodological variations into

national treatment policy. The process was constrained by limited options, unknown adverse effects of replacement therapies, costs, as well as limited guidance on factors pertinent to changing the drug policy for malaria (Shretta *et al.*, 2000).

Once the drug policy has been changed, implementing the new drug policy is also a complex process. It is influenced by several factors including: effectiveness of the proposed treatment, financial resources required to implement the policy, human and technical resources, health care infrastructure capacity, inter-country actions and information exchange, education and training of health care staff, distribution system and monitoring, and evaluation of the policy and its impact (WHO, 2001). For example, in Ethiopia difficulties encountered in implementing the new malaria treatment guidelines in 1999 included: dissemination of the new recommendations to health workers and ensuring acceptance of the new policy, given human resource and financial constraints, and lack of appropriate protocols for monitoring the therapeutic efficacy and safety of CQ and SP (WHO, 2001). In addition, while most sub-Saharan African countries have laid down policies in treatment of malaria, in many countries no strong measure has been put in place to make sure that the policies are being strictly followed. A study carried out in Congo found out that 77% of general practitioners did not know the national drug policy and that they continued to apply a strategy abandoned seven years before (Baudon, 1995). Many other studies have demonstrated that in practice at the peripheral level the standard treatment regime is often not followed (Font *et al.*, 2001; Gilson, 1993a; Krause *et al.*, 1998; Nsimba *et al.*, 2002; Ofori-Adjei and Arhinful, 1996). Furthermore, as most malaria treatment in sub-Saharan Africa takes place at home, changing the first-line drug in the public sector alone may not have a substantial impact. The role of the private sector is crucial in ensuring that drug distribution systems reflect public health policy and that the recommended treatment is available through all types of health care outlets used by the population. This is important as studies (Foster, 1995; Ndyomugyenyi *et al.*,

1998; Ongore and Nyabola, 1996) have indicated that shops are the main source of antimalarial drugs in Africa. Developing and implementing an appropriate treatment-policy in Africa for a common disease, such as malaria, is still a major challenge. This is due to poorly financed health systems and drug budgets, and growing threats posed by multi-drug resistant *P. falciparum* malaria (EANMAT, 2001).

1.4 EFFECT OF POPULATION MOVEMENT ON MALARIA BURDEN

Population movement has been identified as one of the factors contributing to the reemergence of malaria (Martens and Hall, 2000). Data on population movement across international borders has identified human migration as a major factor in the dispersal of malaria, including resistant parasite strains (Singhasivanon, 1999). Large unplanned movements can increase both the risk of acquiring malaria and the risk of epidemics (Bloland and Williams, 2003).

Many factors contribute to population movement. In sub-Saharan Africa, the most common factors are agriculture, droughts, war, conflict, economic vulnerability, and pastoral trade. Martens and Hall (2000) report that people move for a number of reasons, including environmental deterioration, economic necessity, conflicts and natural disasters. Kosinski and Prothero (1975) suggest that the decision-making process leading to population movement can best be understood in the light of '*push* and *pull*' forces. That is to say, when people's needs are not met in a particular environment, they move elsewhere. The '*push*' factor could be environmental degradation, population pressure on land, drought, famine, conflict, or lack of employment. When people are satisfied with their situation but believe that a move elsewhere will provide new and attractive opportunities, a '*pull*' factor is involved, which could be political, economic or social opportunities or improved living conditions. According to Martens and Hall (2000), the *push* and *pull* factors can operate simultaneously; for example, people can be pushed by environmental deterioration and scarce resources and

pulled by the economic opportunities offered by develop ent projects. Movements of people in a variety of forms and at a variety of scales play an important role in the malaria equation of parasites-vectors-people and contribute to the transmission of malaria. Changes in malaria transmission can come about by movement of a population from an area free from malaria or where malaria is low or rare, to high endemic areas, exposing the new non-immune immigrants to the disease. This may result in an increase in malaria incidence and severity (Prothero, 1977). Alternatively, a migrant population from an endemic area may move to a non-endemic area, importing the parasite to the native population, spreading infection and exposing non-immune people to the risk of infection (Prothero, 2001). Such importation is of epidemiological importance and of great concern in public health. Prothero (1977) categorises these migrant populations as either active transmitters or passive acquirers. Active transmitters harbour the parasite and transmit the disease when they move to areas of low or sporadic transmission, while passive acquirers are exposed to the disease through movement from one environment to another; thus they may have low–level immunity or may be non-immune, which increases their risk for diseases. The problems arising from these interactions are greater now than in the past (Prothero, 1994), therefore, increasing the need for more comprehensive knowledge and understanding of the interactions between population movements, disease transmission and diffusion.

Forced migration and displacement can have a significant impact on the distribution and burden of malaria. Recognition of the importance of these phenomena has increased over recent years. For example, during the Soviet invasion of Afghanistan and the arrival of 2.3 million Afghan refugees in Pakistan's north-west Frontier Province, the annual burden of malaria among the refugees rose tenfold from 11,200 cases in 1981 to 118,000 cases in 1991 (Rowland *et al.*, 2002).

The risk of refugees suffering from malaria after migration depends on their previous immunity and the transmission potential of the areas they traverse and

settle, including the infection status of other people in the same settlement. Boss *et al.* (1987) and Toole and Waldman (1990) indicate that refugees coming from a non-endemic area to an endemic area will be more vulnerable to local transmission than the host population, since they will lack natural immunity to native strains and are likely to suffer from malnutrition and stress. A study among the displaced Khmers living in camps reported a fall in annual parasite incidence of malaria from 1983 to 1985 and indicated that the decline in incidence was due to the evacuation of many camps away from forested areas (Meek, 1988).

With the refocusing of attention on malaria during the mid 1990s and the creation of international partnerships for malaria control (such as the Multinational Initiative for Malaria Control and RBM), awareness of the impact of malaria resulting from population movement has increased and has prompted concerns about malaria control interventions in complex emergencies (WHO, 2000).

1.5 FORCED MIGRATION AND REFUGEES

Armed conflict, civil disturbance and natural disasters often result in the large-scale displacement of civilians, both within countries and across international boundaries. In most cases, these displaced people have had to leave behind all but a few of their worldly possessions (UNHCR, 1999). In many parts of the world, such conditions continue to exist and proliferate, and this has led to a rapid increase in the number of victims who have been displaced. Many of these victims undergo physical and psycho-social trauma in the period prior to resettlement, as they have been fleeing wars and environmental problems. In many cases this reflects negatively on their physical and mental health.

1.5.1 Who is a refugee?

The term refugee has been defined in various ways. In 1951, the United Nations (UN) met and drafted the 1951 Convention which defined the status of refugees

as:

"Any person who owing to a well founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion is outside the country of his nationality and is unable, or owing to fear is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence, is unable, or having such fear is unwilling to return to it" (UNHCR, 1968).

This definition was used until 1969 when the Refugee Convention of the Organisation for African Unity (OAU) expanded the definition to include external forces as illustrated below:

"The term 'refugee' shall also apply to every person who, owing to external aggression, occupation, foreign domination or events seriously disturbing public order in either part or the whole of his country of origin or nationality, is compelled to leave his place of habitual residence in order to seek refuge in another place outside his country of origin or nationality" (OAU, 1974).

In evaluating bouh definitions, the 1984 Cartagena Declaration on Refugees, signed by Central American Ministers, broadened the definition of refugees to be used in their region and determined that:

"The definition or concept of a refugee to be recommended for use in the region is one which, in addition to containing the elements of the 1951 Convention and the 1967 Protocol, includes among refugees persons who have fled their country because their lives, safety or freedom have been threatened by generalized violence, foreign aggression, internal conflicts, massive violation of human rights or other circumstances which have seriously disturbed public order" (UNHCR, 1984).

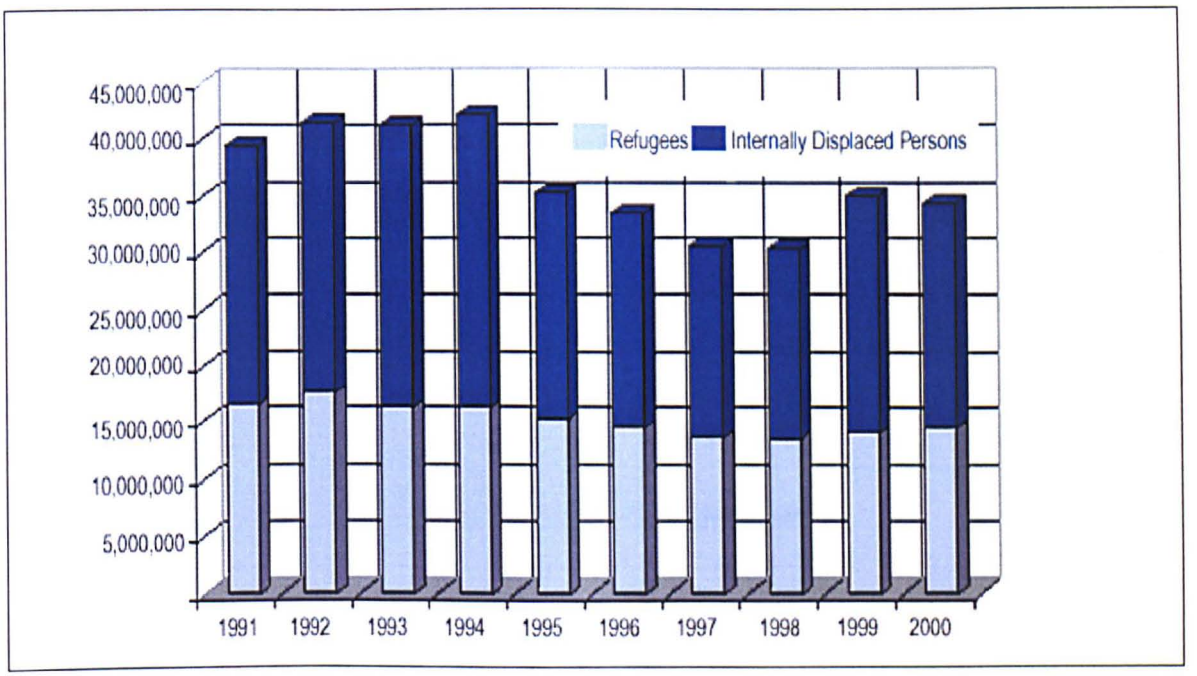
These definitions of refugee, according to the United States Committee for Refugees (USCR, 1988), exclude persons who leave their country of origin to seek economic betterment and persons or groups who may flee their homes due

to the above or other reasons, yet remain within the borders of their own country. The USCR committee argued that there are few, if any, international regulations covering these internally displaced populations, but it is estimated that more than half of all displaced persons worldwide are living within the borders of their home country.

1.5.2 Refugee statistics

According to the United States Committee for Refugees (USCR, 2002), the estimated refugee population at the end of 2001 was about 15 million worldwide. Many of these refugees had fled their homes because of war, persecution, and human rights abuses. Figure 1.6 below illustrates the number of refugees, including internally displaced persons worldwide from 1991-2000.

Figure 1.6: Number of refugees and internally displaced persons Worldwide, 1991–2000



Source: http://www.refugees.org/world/articles/50years_rr01_5.htm#50years

About two thirds of the refugee populations are found in two regions, which are: the Middle East with refugees estimated at 6,830,200, and Africa with refugees estimated at 3,002,000. Table 1.1 below illustrates the estimated number of refugees and asylum seekers worldwide as of December 2001.

Table 1.1: Number of refugees and asylum seekers worldwide December 2001

Region	Number of refugees
Africa	3,002,000
Europe	972,800
Americas and the Caribbean	597,000
East Asia and The Pacific	815,700
Middle East	6,830,200
South and Central Asia	2,702,800
Total	**14,920,500**

Source: http://www.refugees.org/downloads/wrs02/wrs02_table2.pdf

1.5.3 Refugees in Africa

In the last few years, wars and conflict in Africa have resulted in a large number of people being displaced and forced to become refugees. The world refugee survey (USCR, 2002) has indicated the relatively small number of African countries that have produced and hosted the majority of the world's refugees as of December 2001. These countries are shown in Table 1.2 below.

Table 1.2: Countries producing and hosting largest numbers of refugees in Africa as of December 2001

Countries producing the largest numbers of refugees in Africa		Countries hosting the largest number of refugees in Africa	
Country	**No**	**Country**	**No**
Sudan	439,000	Tanzania	498,000
Angola	409,000	Sudan	307,000
Burundi	376,000	Congo-Kinshasha	305,000
Congo-Kinshasa	349,000	Zambia	270,000
Eritrea	304,000	Kenya	243,000
Somalia	227,000	Guinea	190,000
Liberia	116,000	Uganda	174,000

Source: http://www.refugees.org/downloads/wrs02/wrs02_table2.pdf

Although most of the world's refugee population are produced by a very few countries, refugee flows have become widespread around the world, indicating pervasive instability. Sudan was reported as one of the largest producer of refugees in Africa as of December 2001 (see Table 1.2). On the other hand, Tanzania was reported as the leading refugee host country in Africa according to the World Refugee Survey (USCR, 2002).

1.6 COMPLEX EMERGENCIES

Over recent years many of the people who have been forced to become refugees have been caught up in situations which have been described as complex emergencies. The term "emergency" has been defined as a severe disruption of family life and community services that overwhelms the normal coping capacities of the affected people and society. UNICEF (1997) distinguishes three main

types of emergencies, namely: sudden disaster emergencies, slow onset emergencies and complex, conflict-related emergencies.

Complex emergencies have been defined as "*a humanitarian crisis in a country, region or society where there is total or considerable breakdown of authority resulting from internal or external conflict, and which requires an international response that goes beyond the mandate or capacity of any single agency and /or the ongoing United Nations country* programme" (IASC, 1994:2). Such complex emergencies, according to OCHA (1998) are typically characterized by:

- Extensive violence and loss of life, massive displacements of people, and widespread damage to societies and economies
- The need for large-scale, multi-faceted humanitarian assistance
- The hindrance or prevention of humanitarian assistance by political and military constraints
- Significant security risks for humanitarian relief workers in some areas

Many complex emergencies and/or natural disasters evolve from an acute phase where crude mortality among the refugees is above one death per 10,000 per day to a post emergency phase where mortality rates return to the level (<1/10,000) of the surrounding population (Meek *et al.*, 2000). The acute phase may last only a few weeks or months whereas the post emergency can last for many years.

During the acute phase of an emergency, before health services become properly established, emergency interventions, such as mass treatment for specific health problems in refugee populations: measles, diarrhoeal diseases, acute respiratory infections, malnutrition, and malaria, may be required (MSF, 1997). In addition, the need for treatment policies, drug supplies, equipment and qualified health staff with experience in complex emergencies is of importance. Interventions in the acute phase are aimed at reducing death and illness from preventable causes and starvation. Services provided often include: provision of

basic items such as food aid, shelter, water, sanitation, and medical health services (MSF, 1997; Sphere-Project, 2000). As security and access to the refugees improves during the post emergency phase, improved health provision becomes feasible. This is when basic needs have begun to be addressed and public health objectives should shift towards maintenance and consolidation of refugees' health status, sustainability of programmes and the encouragement of use of local resources (Hanquet, 1997).

A characteristic of complex, conflict related emergencies is that health systems are often severely compromised, and health policy formulation is disrupted. Health needs increase, along with morbidity and mortality rates, and humanitarian actors often enter the arena to provide essential services that the government is no longer willing or able to provide. Although some inter-agency co-ordination takes place, it is rare that a joint health policy and strategy framework is developed to guide the various agencies in their activities, with different agencies using different strategies and health models. In addition, health authorities do not have the capacity to monitor and guide the various activities, nor is there a single agency with the tools, resources and authority to take up this role. It is suggested that this lack of co-ordination and policy vision leads to inefficient use of limited human and financial resources, and results in less effective health services and increased morbidity and mortality (Bornemisza and Sondorp, 2002).

1.7 WHO CARES FOR REFUGEES?

When refugees move, they usually move in large groups, and as mentioned in the previous section, they are frequently in need of the provision of the means for basic survival such as food, shelter, safe water, sanitation, and health care. Such large scale movement implies huge logistical operations in responding to the emergency assistance required by refugees. The main actors involved in providing emergency assistance are UNHCR (in close cooperation with other UN

agencies), humanitarian NGOs such as Médecins Sans Frontières (MSF) and International Rescue Committee (IRC), host governments and local communities, and the refugees themselves (Zetter, 1996). The UNHCR is the lead agency in co-ordination and provision of refugee assistance and protection under the mandate of the host government.

In most refugee settings, there are often several competing NGOs with similar agendas. In addition, while some NGOs focus specifically on providing emergency relief aid, most of them generally focus on development. However, under emergency circumstance, the focus of some NGOs can shift from development to providing emergency humanitarian relief (Williams, 2001). Competition among the NGOs in providing services to affected communities in complex emergency often exists. Such competition can affect NGOs' efforts in coordinating relief services, and the focus of their interventions can be deviated affecting the delivery of services and thus the health of refugees.

The interventions of the host government during complex emergencies can also have an influence on the health of refugee populations. In the process of consolidating settlement processes of refugees, many host governments serve their interest by settling refugees in remote parts of the country with scarce resources, thus making provision of services difficult (Zetter, 1996). In addition, during the acute emergency phase, inputs from the host government are often received, but as the situation turns to the post emergency phase, intermittent change are often noticed as political influences may start to interfere with provision of humanitarian services.

In some instances, armed groups control the refugee camps and their populations. Guerrilla movements may benefit from the aid and may use the camps to legitimize their power base by exploiting the refugee population, diverting aid distributions to build up their economic base and using the camp as a source of recruitment of soldiers. This has happened in Pakistan, Honduras, Sudan and Thailand (MSF, 1997).

1.8 ESTABLISHMENT OF GUIDELINES FOR USE IN HUMANITARIAN EMERGENCIES

As humanitarian agencies have grown in size and prominence since the 1980s, there have been concerns amongst some agencies and individuals about the range of standards under which different agencies operate, and the potential negative effects of aid. Evaluators have consistently highlighted problems encountered in humanitarian operations, such as lack of professionalism, poor management, problematic funding policies and practice, absence of coordination, lack of humanitarian access and military targeting of civilian populations and relief workers (Dabelstein, 1996). These concerns have given rise to initiatives such as: the Providence principles (Minear and Weiss, 1993), the Code of Conduct for the International Red Cross and Red Crescent Movement, NGOs in Disaster Relief, Oxfam's Nutrition guidelines, UNHCR's Emergencies Handbook, and a series of further guidelines by MSF giving practical advice and benchmarks for health programming in humanitarian crises. All these are attempts to provide some basic principles that should guide agencies in humanitarian emergency situations. Although these attempts created some principles to help guide humanitarian agencies during interventions, it was the scale and intensity of the humanitarian crisis in Rwanda in 1994, which prompted the call for international guidelines for humanitarian agencies and led to the development of the Sphere Project (Borton, 1996).

The Sphere project is a consortium of the international humanitarian community set up to establish what is technically and normally possible for relief operations (Griekspoor and Collins, 2001). It serves as an organisational tool for self assessment and improvement, strengthening quality control, promoting human resource management, strengthening organisational principles, designing programme support structures, and building partnerships (Sphere-Project, 2000). The Sphere initiative was launched in 1997 by a group of humanitarian NGOs

and the Red Cross and Red Crescent movements, who developed a Humanitarian Charter and identified minimum standards to be attained in disaster assistance in each of the five sectors: water supply and sanitation, nutrition, food aid, medical services, shelter and site development. This process led to the publication of the first handbook in early 2000. The minimum standards take into account specific vulnerabilities, issues and potential gaps related to humanitarian aid, analysis, human resources, negative effect of aids, gender, participation and capacity building, as well as human rights. They also emphasize the importance of recognizing cooperation among all humanitarian actors in enhancing performance and accountability in disaster assistance efforts. The Sphere (http://www.sphereproject.org/handbook/index.htm) is based on two core beliefs:

- That possible steps need to be taken to alleviate human suffering arising out of calamity and conflict
- That those affected by disaster have a right to life with dignity and, therefore, a right to assistance

The issue of cooperation between humanitarian actors has been central to the philosophy of Sphere and to its approach in producing the handbook. The cornerstone of the handbook is the Humanitarian Charter, which is based on the principles and provision of international humanitarian law, international human rights laws, refugee law, and the code of conduct for the international Red Cross and Red Crescent Movement and NGOs in disaster relief. The Charter aims to promote NGOs' commitment to quality and accountability. Aimed at improving the effectiveness and accountability of disaster response, the Sphere Humanitarian Charter and the Minimum Standards in Disaster Response reasserts the right of populations affected by disaster, whether natural, man-made or due to conflict, to protection and assistance. It also reasserts the right of disaster-affected populations to life with dignity. Taken together, the Humanitarian Charter and the Minimum Standards in Disaster Response contribute to an operational framework for accountability in humanitarian assistance efforts. The Humanitarian Charter expresses agencies' commitment

to these principles and to achieving the Minimum Standards. This commitment is based on agencies' appreciation of their own ethical obligations, and reflects the rights and duties enshrined in international law in respect of which states and other parties have established obligations (Sphere-Project, 2000).

1.8.1 Sphere minimum standards in health services

The recommended minimum standards of health services by Sphere (see http://www.sphereproject.org/handbook/index.htm) are divided into three main sections. These include health systems and infrastructure, control of communicable diseases, and control of non-communicable diseases as indicated below:

1. Health systems and infrastructure
    - All people have access to health services that are prioritised to address the main causes of excess mortality and morbidity
    - Health services are designed to support existing health systems, structures and providers
    - People have access to health services that are coordinated across agencies and sectors to achieve maximum impact
    - Health services are based on relevant primary health care principles
    - People have access to clinical services that are standardized and follow accepted protocols and guidelines
    - The design and development of health services are guided by the ongoing coordinated collection, analysis and utilisation of relevant public health data

2. Control of communicable diseases
    - People have access to information and services that are designed to prevent the communicable diseases that contribute most significantly to excess morbidity and mortality
    - All children aged 6 months to 15 years have immunity against measles

- People have access to effective diagnosis and treatment for those infectious diseases that contribute most significantly to preventable excess morbidity and mortality
- Measures are taken to prepare for and respond to outbreaks of infectious diseases
- Outbreaks of communicable diseases are detected, investigated and controlled in a timely and effective manner
- People have access to the minimum package of services to prevent transmission of HIV/AIDS

3. Control of non-communicable diseases
   - People have access to appropriate services for the management of injuries
   - People have access to the Minimum Initial Service Package (MISP), which is not only a set of equipment and supplies, but a series of specific health activities, to respond to their reproductive health needs
   - People have access to social and mental health services to reduce mental health morbidity, disability, and social problems
   - For populations in which chronic diseases are responsible for a large proportion of mortality, people have access to essential therapies to prevent death

One of the countries in which sphere guidelines have been employed is Tanzania. A Sphere evaluation case study was conducted in five refugee camps in Tanzania. The aim of the study was to assess knowledge and attitudes of NGO staff towards the Sphere recommended minimum standard guidelines and determine if the guidelines had provided a common framework for humanitarian assistance. Findings revealed that although national and International NGO staff had good knowledge about the Sphere minimum standard guidelines, knowledge of the local field workers at the community level was low. Not all NGOs had incorporated the Sphere guidelines in their policies, proposals and practices.

Increased coordination had been noted among NGOs that had adopted the guidelines but none of these NGOs were able to meet the Sphere minimum standard guidelines. This was due to insufficient funds, inadequate resources and infrastructure, and limited understanding and interpretation of Sphere guidelines (Maina *et al.*, 2003).

1.9 REFUGEE EXPERIENCE

It is widely accepted that many complex emergencies evolve from an acute to a post emergency phase (see section 1.6). However, Desjarlais and colleagues (Desjarlais *et al.*, 1995) have suggested that from the perspective of the refugees themselves, there are several other phases that they experience during the process of forced migration. These include: pre-flight, flight, temporary settlement and resettlement. While each of these phases is accompanied by the need for the means for basic survival (food, shelter, safe water, sanitation and health care), each phase is also accompanied by a range and varying degrees of stress, which may impact the refugees' ability to maintain good health. A study by Kleijn and colleagues (Kleijn *et al.*, 2001) found that the most commonly reported traumatic event prior to flight was forced imprisonment and separation from others. But at this pre-flight period, individuals who later become refugees may also witness fighting and destruction and observe violent acts against loved ones, as well as experiencing famine, difficult economic conditions, familial conflicts, instability, forced isolations, lack of rights of freedom of expression, and human rights abuse. Such hardships may relate to the more frequently recognised factors of political persecution or armed conflict, but can also serve in their own right as major threats to well-being (Ager *et al.*, 1991). For example, in Sudan, most opposition groups are not allowed to voice their concerns about the government, and neither can they suggest changes or oppose the government during the on-going period of conflict and civil war. Assembling is forbidden and social gatherings are only allowed if permission has been granted and such events are closely monitored. Summerfield (1999) indicates that a key

element of modern political violence is exerting social control through the creation of states of terror, which penetrates the entire fabric of society and affects grassroots social relations, and states of well-being.

The flight period is the most emotional period for most refugees. Ager (1993) suggets that the flight period from one's original home is likely to prompt major emotional and cognitive turmoil. It is during this period that most refugees feel the shock of having to leave behind families, homes, possessions, friends, businesses and livelihoods. This stress is frequently exacerbated by the experience of extreme danger. At this phase many refugee experience violence, persecution, and financial insecurity, while others end up being victims of sexual harassment. According to Mollica and colleagues (Mollica *et al.*, 1987) and Agger (1994), it is during this phase that women are particularly vulnerable to sexual abuse. Swiss and Giller (1993) report that sexual violation is an endemic, yet, poorly visible facet of violent conflict.

In the settlement (acute) phase, refugees experience stresses of a different nature. They often struggle to settle and have problems in trying to adjust to the challenges of a new life and the methods by which humanitarian assistance is provided (Harrell-Bond, 1985). They are often forced to confront isolation, hostility, violence and racism in their new locations (Summerfield and Hume, 1993). Refugees may also experience stressful times in struggling to understand the different cultures of the communities and ethnic groups surrounding them in their new location, both between refugees within a camp, as well as, between the refugees and the local population. Stringham (1993) reports that differential rates and strategies of acculturation within families create major stresses. Furthermore, additional stressors that refugees frequently have to deal with in this phase include poor nutrition, socioeconomic disadvantages, poor physical health, overcrowding, collapse in their therapy management group, poor sanitation, inadequate health and basic services, insecurity and the outbreaks of disease.

However, the stressful pressures encountered by refugees at the acute phase of settlement in camps don't remain constant. There are changes over time as the refugees go through the process of adjustment and as the emergency evolves from the acute to the post emergency phase. The first few months are stressful to almost all refugees, but many problems ease as acculturation occurs and some language ability is acquired. Where the situation has stabilised, and where the possibility of return to their place of origin immediately or in the near future is remote, then in this post emergency phase refugees have to try to adjust and adapt to a new lifestyle in their new location. Some refugees find it difficult being totally dependent on relief services and such a situation can cause considerable stress (Harrell-Bond, 1986). Common refugees complaints in this phase include concerns about the attitude aid workers and their loss of status as individuals. Some refugees find it difficult to queue for food ratios, while in other situations there may be a struggle to compete with the local people for scarce resources. A camp which exists for a lengthy duration can lead to more substantial demands on natural resources, education, health facilities, transportation, social services and employment. In such circumstances, experience suggests that only very few are able to get appropriate jobs, while the majority lead a life of hopelessness (Harrell-Bond, 1985). It is also in this post emergency phase that disruption to normally accepted culture rules and culturally defined roles and behaviours can impact negatively on refugee life and cause particular stresses. In many cases displacement weakens culture and traditions. For example, in most cultures in Africa men are heads of household and breadwinners while women are usually socialised to take responsibility for child care, elder care, management of illnesses and household work (cleaning cooking, washing, acquiring water and wood, purchasing food etc). However, in refugee camps this is often not the case. Men are more likely to be unemployed, intermittently employed, or underemployed and their wives employed instead. For some families, this situation can be so contrary to cultural norms that it will cause stress between men and women in the household. On the other hand, some refugee men may not be willing to accept the idea of the wife working outside the home as most

men, especially Muslim men, portray this as a loss of protection for women. They may forbid their wives (or daughters) from accepting work and the lack of additional income may cause more hunger in the family. In addition, some refugees from cultures in which men and women work on separate professional levels might find it stressful to work in a low level service position under the supervision of women who hold other positions of authority.

Displacement also has an effect on children's upbringing, especially in a multi-cultural refugee camps. Most refugee children have three important non-material needs: identity, language and religion. In many refugee camps parents are not in the best situation to help their children through these processes, because they may be busy focusing on survival issues and may have their own losses to deal with, and adjustments to make. This can cause additional stress as they fear their children will be lost to a different lifestyle and adopt different cultural norms. Parents may also become depressed if their children don't use them as a source of experience and guidance, minimizing their traditional responsibilities as parents.

Marginalisation is one of the common effects of displacement following conflict and forced migration. The cultural status of displaced refugees is belittled when they are relocated to a new area where they may be regarded as strangers and denied opportunities and entitlements. They often lose economic power and live below the poverty line. In addition, many refugees cannot use their earlier acquired skills at their new location and human capital is lost or rendered inactive. Economic marginalisation is often accompanied by social and psychological marginalisation, expressed by a drop in social status, in the refugees' loss of confidence in society and by feelings of injustice and deepened vulnerability in themselves. The coercive displacement and victimization of refugees can depress the refugees' self image, particular since they are often perceived by the host communities as stigmatized and socially inferior.

One of the major factors affecting the life of refugees, even during the post emergency phase, is insecurity. In many cases refuges who have fled violence in their home countries often find themselves confronted with violence, be it political or ethnic, in the country of asylum. This is particularly true for refugees living in camps who are often confronted on a daily basis by a whole range of security threats coming both from within and outside the camp (Halperin, 2003).

As a consequence of all these changes, the first and second years in most refugee camps involves learning new roles and coming to grips with one's drastically changed statuses. A considerable degree of adjustment occurs simply because life must go on. During this process there are factors that either promote or hinder adjustment and contribute to mental health problems. These include: loneliness or isolation; inter-generational conflict; change of status, either occupational or vocational; host-refugee relationships; and culture shock. Usually after about four years from the time of settlement in refugee camps many refugees will have made a personal adjustment and have accepted their situation. However, delayed reaction to earlier traumas and reactions to the situations accepted often emerge at this period (JRS, 1996).

As the previous paragraphs have suggested, the phases identified by Desjarlais (1995), as being a part of the experience of many refugees, frequently result in a series of situations, which give rise of a variety of types and degrees of stress. Most refugees face a wide variety of stresses, which are influenced by the reason for migration, time spent during migration, the experiences encountered during transit, and the experiences in exile (personal security, housing, employment, social organisation, etc), as well as, the prospects for family reunification and hopes for return to their place of origin (or permanent resettlement). Social environment and cultural barriers will mediate the impact and physical expression of stress and the effect of such stresses are difficult to measure, and may vary significantly between individuals, as well as, between groups (Helman, 1998; Terheggen *et al.*, 2001).

1.10 MALARIA IN REFUGEE SETTINGS

Many forced population movements happen in those areas of the world where malaria is endemic (see Figure 1.1 for the distribution of malaria & Tables 1.1 and 1.2 for the data on distribution of refugees). In Africa, many refugees are displaced to areas where malaria constitutes a major health problem. In these situations malaria is frequently the primary cause of death among the refugees (Bloland and Williams, 2003). As mentioned in section 1.4, the risk that the refugees will suffer from malaria depends on their previous immunity and on the transmission potential in the areas they move through and settle in, including the infection status of the host community (Najera, 1996). Contracting malaria during residence in a refugee camp is to be expected in all malarious areas. Furthermore, malaria episodes might continue to occur, even in the absence of transmission in the camp, either as recrudescence of inadequately treated infections, relapses, or long incubating infections.

Refugee populations face many difficulties in trying to relocate themselves in new surroundings (van der Hoek *et al.*, 1997) and even in camp settings, they frequently face problems with respect to basic necessities such as water, food shelter and health care as earlier mentioned. In addition, the risk of malaria transmission is greatly increased in all environmental situations that favour human and vector contact, conditions that are present in most refugee camps (Najera, 1996). The placement of vulnerable refugees in camps or locations prone to vector breeding increases the risk of malaria transmission (Rowland and Nosten, 2001). For example, refugees whose camps are situated on the waterlogged margins of rivers or adjoining rice irrigation are unfortunate because such places are particularly prone to mosquito breeding and malaria. In contrast, camps situated only a kilometer away on dry wasteland or scrub have little or no malaria (Rowland, 1999; Rowland *et al.*, 1997).

Refugee camps are frequently densely populated, and characterized by poor sanitation and contaminated food and water. Overcrowding in the camps

increases the risk of human vector contact. Pits dug to provide latrines or to excavate earth for shelter construction trap standing water, which creates new breeding grounds for the mosquito. In addition, factors such as poor or no housing, movement into unused areas, low socioeconomic status, proximity of livestock, compromised immune status, malnutrition and a lack of adequate preventative and curative services all contribute to the increased risk of malaria among refugee populations (Bloland and Williams, 2003). Camp life is also often boring and purposeless (Belete *et al.*, 1977; Sumpter, 1980) creating apathy and compounding the long term problems of dependency. This can impact negatively on the health and well-being of refugees generally and affect their susceptibility to disease. In addition, malnutrition, which is common in most refugee camps, has also been associated with malaria morbidity and mortality (Shankar, 2000). Although the exact nature of the relationship between nutrition and malaria is not very clear, Greenwood (1987) reports that malaria can cause destruction of increased red blood cells and decrease production, thus complicating pre-existing nutritional anemias.

1.11 MALARIA CONTROL DURING COMPLEX EMERGENCIES

With the establishment of the RBM Complex Emergencies Network, the global efforts to reduce the burden of malaria have been expanded to address the needs of refugees caught up in complex emergencies in malaria endemic areas. Refugees usually remain vulnerable to malaria infection. Assistance may be required from the time they arrive the camp, until conditions favour a return home, which may take several years in chronic situations (Anon, 1997). Decisions about the most appropriate malaria control strategies to employ during complex emergencies, such as in refugee camps, are best made with an understanding of the epidemiological, entomological, clinical, behavioural and political factors, operating in the local context. However, because *P. falciparum* malaria can become life threatening within 48 hours, the minimum requirement for any malaria control programme includes effective case management (Bloland

and Williams, 2003). There is also need for coordination among the different actors providing service in the camp, accurate and timely assessment, effective planning, effective implementation and monitoring and evaluation.

As mentioned earlier (see section 1.6), the acute phase of complex emergency in refugee camps is often characterized by high mortality rates (Anon, 1997; Bloland and Williams, 2003; Meek *et al.*, 1999; Toole and Waldman, 1990; Williams, 2001). In addition, health services are not yet well established, and priority in the acute phase is to provide rapid basic life saving interventions within the first few days and bring diseases under control (RBM, 1998; WHO, 1999). Malaria control in this phase requires appropriate and effective case management (MSF, 1997; Rowland and Nosten, 2001; Sphere-Project, 2000). Interventions should be based on best evidence from available information and from rapid assessment of the situation.

When the situation stabilises in the post emergency phase and mortality rates reduce, interventions should shift from emergency relief to sustainable development. In this phase, the need for public health surveillance to control communicable diseases is important. A well designed surveillance allows for rapid identification of increases in cases of communicable diseases in an affected area, signaling the need for a specific response (Bloland and Williams, 2003). Without a good surveillance system it is impossible to track disease trends, recognize new disease threats, identify serious outbreaks or monitor control measures. For example, malaria surveillance is important to monitor trends, provide early warning of an outbreak and monitor the effectiveness of malaria control interventions. To have effective surveillance there is the need for a functional communication and logistical infrastructure that allows for timely information transfer between participating facilities and organisations. In addition, surveillance information should be summarised and returned to clinical services in an efficient manner so that it can be used to inform clinical management decisions (Bloland and Williams, 2003).

In the post emergency phase, malaria control programmes should be transformed to include sustainable preventive control efforts, such as decreasing human-vector contact through the construction of local huts for refugees, and increasing other preventative measure such as the use of insecticide treated mosquito nets (Meek *et al.*, 2000). Additional measures should include training health staff to improve their skills including the monitoring of disease trends and resistance patterns through an effective surveillance system (Sinyinza, 2004).

Malaria control programmes in complex emergencies also need to include strategies designed to target groups at risk. In most refugee settings, there are groups that are at increased risk of developing severe malaria because of factors such as, lack of access to effective treatment, malaria parasite resistance to commonly available drugs, lack of immunity to malaria and low immunity caused by infection and malnutrition. Such groups need more care and concern. There may also be groups that are more vulnerable because they are affected by social and political problems which impact on their ability to access treatment. Such vulnerable groups need special consideration when delivering health services.

1.11.1 Problems influencing effective case management of malaria in complex emergencies

The previous section outlined appropriate malaria control strategies for use in refugee camp settings but, as was highlighted in sections 1.6-1.9, the conditions experienced in many complex emergencies are likely to constrain the effective case management and control of malaria among refugees. In many refugee camps, conflicts can exist between the refugees and the host community, as well as, among the refugees themselves causing much insecurity. Most of these conflicts, for example, domestic violence, sexual abuse and harassment, and armed robbery, are due either to struggles over scarce resources, or are a result of political, social, or cultural factors. For example, insecurity may be the result of conflicts that already existed between groups of refugees during the pre-flight

phase or may result from battles between refugees and locals over scarce resources. Other areas of conflict can arise from violence due to forced marriage. Conflict and insecurity in the camps interferes with planning, supervision and implementation of programmes. Meek *et al.* (2000) report that such conflict leads to insecurity, which can make long-term planning impossible and cause major difficulties for health care delivery. MacArthur (2000) agrees that in many refugee settings such conflicts contribute to severe disruptions in health services, disease control programmes, and food distribution systems.

In addition to conflict within a camp, one of the most common problems faced in the delivery of malaria interventions is the organisational set up of the health system. Most displaced peoples' camps are overwhelmed with large influxes of refugees with the result that NGOs are faced by the challenge and complexity of providing sustainable health services for a large population in a short time. They often lack capacity, having insufficient qualified staff with adequate skills and experience to provide services in complex emergencies. In addition, their efforts to improve the services are often hindered by limited budget, and political tensions. Limited budgets prevent NGOs from expanding their health service to meet the demand of the refugees and to recruit adequately qualified staff. NGO activities in complex emergencies are not only affected by limited budgets, but also by delay in receiving funds, abrupt reduction of funds and decline in funding availability. Interventions are frequently also subject to influence and distortion by donor priorities and by wider political forces. All of these influences affect NGO efforts to implement activities as planned. As a result (and as the example in section 1.8.1 demonstrated), in most refugee camps, public health facilities are limited, under-staffed and overcrowded, equipment is limited, and drug supplies are often insufficient. In addition, budget constraints affect the NGOs' ability to effectively monitor and evaluate the quality of care that is being provided. In most complex emergency situations, the quality of health care, including the case management of malaria, is therefore often inadequate and characterised by

factors such as long waiting time, lack of drugs and lack of skilled staff (Reilley *et al.*, 2002).

In refugee camps, alternative sources of health care (such as private clinics, traditional healers and drug shops) are also often limited and in cases where particular treatment may have been preferred during the pre-flight period, absence of these treatment options can have an effect on the treatment and seeking behaviours of individuals.

Effective case management of malaria in complex emergencies is also faced by logistical problems. Getting supplies such as drugs to areas of complex emergencies can be difficult and is often exacerbated by insecurity, looting of stores, poor road infrastructure, and poor management of supplies.

Of particular concern in the case management of malaria in refugee settings is the issue of the selection of appropriate drugs for the treatment of malaria. The growing problem of drug resistance and the complex issues surrounding drug policy formulation were raised in section 1.3. As Bloland and Williams (2003) have pointed out, the drug policies of the source and host countries in many of the areas where there are large refugee populations may not accurately reflect the parasite resistance patterns in those areas. However, no firm guidelines exist regarding the selection of first-line antimalarial treatment in refugee camps. A recent joint report by WHO and UNICEF (WHO/UNICEF, 2003) suggests that in an emergency situation, where mortality is high, and where there is no readily available reliable resistance data, it may be necessary to use the most effective drugs such as artemisinin derivatives in the treatment of uncomplicated and severe malaria among the refugees whatever the national policies. For example, in Chad the first-line treatment for malaria is currently CQ, but in agreement with the Chad NMCP, MSF Belgium is using a combination of artesunate and amodiaquine as the first-line treatment for malaria in refugee camps in the south and east of Chad. The refugees in the south of Chad are from the Central African Republic, and those in the east of Chad are Sudanese from Darfur (Herp,

2004). When the emergency situation stabilises, then the national authorities should be consulted and the national policy on treatment of malaria adopted for use among the refugees. Alternatively, new decisions regarding drug choice can be made in agreement with the National Malaria Control Programme (NMCP) of the host country, taking into consideration information from experience during the emergency period.

The experiences and perceptions of the providers in the camp, and of the refugees regarding appropriate drugs for malaria treatment, will also play a role in effective case management. For example, where refugees may have been used to receiving CQ in their place of origin, they may be reluctant to switch to SP. Alternatively, if an ineffective first-line drug is being used in the camp, then this may discourage people from visiting the health centres.

Case management policy in a refugee camp may also affect decisions to seek treatment among the local population. Williams (2001) indicates that if members of the host community determine that better care and more effective treatment is being received by the displaced community, the host community might also demand health care services from the agencies. This can add further financial, staffing and logistical burdens to an already overstretched NGO.

Socio-cultural factors are known to influence perceptions of quality of care, treatment seeking behaviour, and the effective case management of malaria. In many complex emergencies, refugees find themselves surrounded by people from many different cultures and ethnicities, and refugees from one ethnic group may perceive that the services they receive from health care providers of a different ethnic group are inferior to the services that providers give to members of their own ethnic group. They may seek out providers from their own ethnic group and if there are none available, they may avoid health services altogether. In addition, longer term influences resulting from the prolonged mixing of cultures and ethnic groups may result in subtle changes in disease perceptions and behaviours. According to a report by the Kaiser family foundation (KFF, 1997),

culturally and linguistically appropriate health services are essential ingredients in quality health care. Cultural and linguistic factors are crucial contributors to the development and delivery of quality care to all people. These factors are especially important in any pursuit of the elimination of health disparities in ethnic and racial communities.

Mwenesi (1995) has emphasized the need to consider health beliefs and cultural attitudes to service when designing appropriate and acceptable services. Williams (2001) reports that understanding the larger socio-cultural context of both the displacement experience and the complex emergency facilitates the acceptance and effectiveness of public health interventions. However, in most complex emergencies, socio-cultural dimensions are not explored due to the lack of skills available to gather the information required (Bloland and Williams, 2003).

This lack of skills is frequently not restricted to socio-cultural research but also extends to other areas in which there is a need for operational research. In order to improve the delivery of malaria control in complex emergencies research is required to monitor and evaluate interventions and to expand understanding of the context in which those interventions are being implemented.

1.12 RATIONALE FOR THE STUDY

As the review in the previous sections has shown, malaria is a disease that flourishes in conditions of war and population displacement (Rowland, 2001). It has been estimated that as many as one third of malaria deaths in Africa occur in countries that have been affected by complex emergencies (Whyte, 2000). Recent publications by WHO (Meek *et al.*, 2000) and the National Research Council of the National Academies (Bloland and Williams, 2003) demonstrate that there is growing awareness of the public health importance of malaria control in complex emergencies, but, while studies on the epidemiological, entomological and clinical aspects of malaria control in complex emergencies have been undertaken, there are still very few data on the impact of refugees' behaviour on

the effectiveness of malaria control activities in such settings. Over the past decade there has been an increasing body of published literature (as demonstrated in the following chapter), which highlights the importance of considering socio-behavioural issues in designing and implementing effective malaria control programmes, especially those related to effective case management. However, little is known of the socio-behavioural factors influencing the effectiveness of malaria control activities in general, and effective case management in particular, in a post emergency phase refugee camp.

The health services in Kakuma refugee camp are run by an NGO, the International Rescue Committee (IRC), and data from their health information system (based on clinical diagnosis at the health clinics in the camp) suggested that malaria was a health problem among the refugees living in the camp (see data in section 3.8). To confirm the prevalence of malaria in the camp, the IRC conducted a clinic-based study in the camp during the rainy season in April 1999. 540 smears were collected over a period of one month from random patients who visited the facility with fever. The blood slides were examined under a microscope in the main camp hospital. Out of the 540 smears (180 smears from each of the five clinics), 373 tested positive for malaria. This gave a positivity rate of 69%. These data suggest that malaria was a health problem among the refugees in Kakuma camp in 1999. This was the only malaria prevalence survey conducted in the camp before this study.

Responsibility for the control of malaria within the camp lies with the IRC and their primary control strategy consists of case management of malaria. The results from the IRC survey, as well as from more recent health clinic data (see Tables 3.1-3.10), suggest that their strategy of case management is not particularly effective at controlling malaria among the refugees in Kakuma. The IRC were concerned about this issue and were eager to support an investigation into the reasons for the apparent failure of their malaria control strategy. To address both the concerns of the IRC and the overall paucity of knowledge on the socio-behavioural aspects of malaria control in a refugee setting, a project

was developed to investigate the treatment-seeking behaviour of refugees in the Kakuma refugee camp.

1.13 STUDY OBJECTIVES AND HYPOTHESIS

1.13.1 General aim

The general aim of the project was to determine the factors influencing effective case management of malaria in the Kakuma refugee camp in order to recommend strategies for improvement in malaria control.

1.13.2 Hypothesis

The hypothesis on which the research is based was that: the effective case management of malaria relies on prompt and effective diagnosis and rapid treatment with the relevant drugs. Prompt and effective treatment among refugees is constrained by the treatment-seeking behaviour of refugees as well as the quality of health care provided at health clinics. The treatment-seeking behaviour of refugees is affected by the disruption of their therapy management group, the effects of violence and trauma on refugees' perceptions of health and ill-health and their perceptions of the quality of care provided at the health clinics.

1.13.3 Specific Objectives

The specific objectives of the project were:

1. To investigate the effects of violence and trauma on refugees' perceptions of health and ill-health and determine the extent to which these psycho-social problems affect malaria treatment-seeking behaviour in the camp
2. To investigate the effect of displacement on the refugees' therapy management group and the extent to which this has affected their ability to seek prompt and appropriate treatment for malaria

3. To determine the health care providers' attitudes and practices in the management, prevention and control of malaria among the refugees
4. To assess the quality of malaria diagnosis and treatment of malaria at the health facilities
5. To assess the prevalence of malaria in the camp

1.14 OVERALL STUDY DESIGN

This doctoral study was carried out in Kakuma refugee camp, in Northwestern Kenya. The study employed a qualitative and quantitative methodology in taking a cross-sectional approach in determining factors influencing malaria treatment-seeking behaviours in Kakuma refugee camp. Specific psycho-social, cultural, economic and political factors, with reference to quality of malaria management in the camp, formulated the focus of the inquiry. Complementary methods of data collection within the camp were used to explore the proposed objectives and provide triangulation of findings. Methods included individual interviews, focus group discussions, observation, questionnaires, and the collection and testing of blood samples. Further details of the methods employed for each objective are included at the start of each of the results chapter.

Kakuma refugee camp in Kenya was selected because of the reported high burden of malaria among the refugees (IRC, 2000). The duration of fieldwork was about one year and eight months. A preliminary study was carried out over a period of eight months, from May to December 2001, and the main data collection from May 2002 to May 2003. The sample population included all refugees resident in the camp and the health care providers, most of whom were the refugees, involved in management, prevention and control of malaria in the formal outpatient health facilities and within the communities in the camp.

1.15 ETHICAL CONSIDERATIONS

Approval for the study was obtained from the Ethics Committee of the London School of Hygiene and Tropical Medicine, and concerned bodies in UNHCR and IRC head office in Nairobi and sub-office in Kakuma (Kenya). Before the study approval, the purpose and importance of the study was explained to the relevant bodies.

To ensure full participation of the refugees and health care providers, an initial meeting was held with the medical coordinator coordinating the health activities in the camp and key leaders from the community. The objectives of the study were explained, an outline of the study protocol was submitted and co-operation with study participants during the survey was sought. Issues pertaining to ethics and confidentiality were discussed and agreed upon. The principal investigator then paid an initial visit to all the health facilities to confirm visits for the fieldwork and to clarify answers or doubts raised by health care providers. Before each interview, discussion, and observation, the purpose of the study was explained to participants and informed consent sought. Confidentiality and privacy were maintained throughout data collection.

During the interviews with the psycho-socially affected participants and the non-affected participants who had experienced trauma, the principal investigator was aware of and sensitive to the fact that although informed consent was obtained, and emphasis put to thoroughly explain the purpose of the study, there was a possibility that individuals could recall their traumatic experiences at any time and this would cause them emotional discomfort. A plan was put in place to refer any individual that experienced emotional discomfort to the relevant services within the camp.

1.16 STRUCTURE OF THE THESIS

This study has been approached from epidemiological, anthropological and health service standpoints and has been divided into eight chapters. The following chapter provides a review of the literature on which the hypothesis is based. Literature on treatment-seeking behaviours, psycho-social issues and quality of health services relevant to refugee settings are very limited. Therefore, most of the review is related to relevant literature in non-refugee settings. Chapter Three provides the background and context of the study setting. Chapter Four presents the preliminary qualitative study conducted before the actual study. Chapter Five is a cross-sectional descriptive study that determines the effect of violence and trauma on peoples' perceptions of health and ill-health and investigates the extent to which these psycho-social problems affect malaria treatment-seeking behaviour in the refugee camp. It also investigates the effect of displacement on the refugees' social network and the extent to which this has affected their ability to seek appropriate treatment for malaria. Chapter Six presents the cross-sectional descriptive and observational study that assessed quality of malaria management at the health facilities in the camp and determined health care providers' attitudes and practices in the management and control of malaria. Chapter Seven describes the cross-sectional study conducted to assess the prevalence of malaria in the camp and Chapter Eight presents a general discussion of the results, provides recommendations for the future and draws the study to a conclusion.

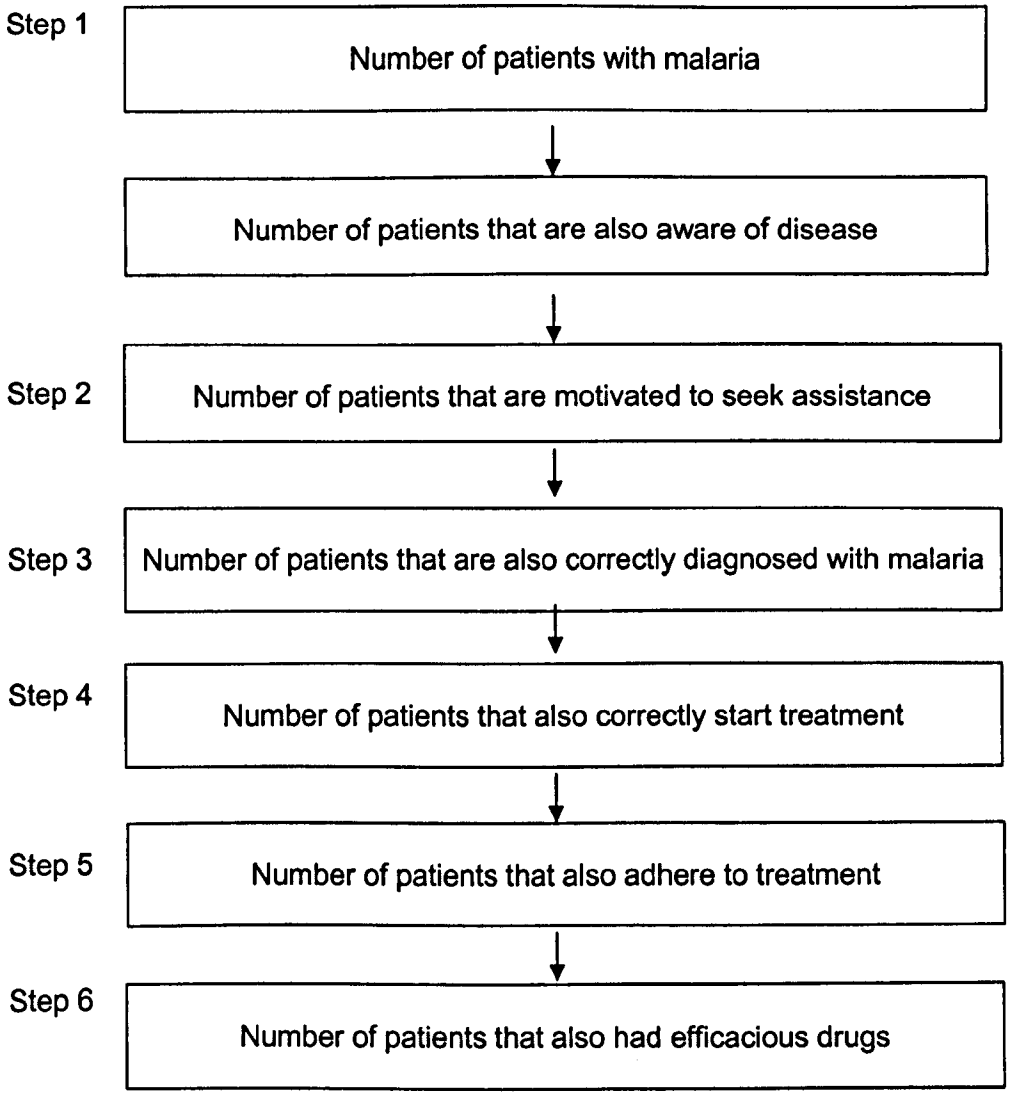
CHAPTER 2: CASE MANAGEMENT OF MALARIA

2.1 INTRODUCTION

Effective case management through the prompt diagnosis and effective treatment of malaria is one of the four approaches advocated by WHO to reduce the mortality and morbidity caused by malaria (WHO, 2000). The aim of this approach is to limit the duration of the disease, prevent progression from mild to severe malaria, prevent deaths from severe malaria, minimize the risk of selection and spread of resistant parasites and to reduce transmission in areas of high malaria transmission (WHO/AFRO, 2000).

In much of sub-Saharan Africa, the approach forms the basis of malaria control. A study in Tanzania (WHO, 1993) reported that, in practice, disease management at primary health care facilities was the basis for malaria control in the country, while Mumba *et al.* (2003) reported passive case detection and treatment as the most common type of malaria control strategy found in many developing countries. To analyse case management in malaria control programmes, a Piot model has been recommended (Mumba *et al.*, 2003). The basis of the model is a description of the different steps a person has to go through after becoming ill until being cured. For malaria, the steps include: awareness of the disease, motivation to be able to seek treatment, diagnostic process, appropriate treatment, adherence to the treatment regimen, and the efficacy of drugs. This has been illustrated in Figure 2.1 below.

Figure 2.1: Steps in the Piot model for malaria case management



Source: (Mumba *et al.*, 2003: 545)

At each step of this process, there is a chance that the patient may not proceed to the next one. Thus, when the model is applied to a population of patients, it can be expected that a proportion of the patients will be lost and only a limited number of patients will complete all steps successfully. It should also be noted, that an effective case management strategy requires appropriate treatment to be given at each level including home, peripheral health clinic and major health

centers or hospitals. This strategy is facilitated by the provision of standard treatment protocols that offer health education to ensure the adequacy of home treatment. In addition, they provide training and monitoring of clinical staff to ensure that treatment protocols are followed in the health facilities and effective drugs provided at all levels of delivery system (Comoro *et al.*, 2003). Effective tools for the diagnosis and treatment of malaria do exist, but, as the above model suggests, the effective case management of the disease results from a combination of both provider and patient behaviours. That is, prompt and effective treatment depends both on the treatment-seeking behaviours of the patient and the accuracy of the diagnostic and prescribing behaviours of the provider.

2.2 TREATMENT-SEEKING FOR MALARIA IN SUB-SAHARAN AFRICA

To assess the impact of treatment-seeking behaviour on effective case management, it is necessary to define what is meant by 'appropriate' treatment-seeking behaviour for the disease. RBM recommends that people with malaria start appropriate treatment within 24 hours of the onset of symptoms (WHO/UNICEF, 2003). Appropriate treatment-seeking behaviour can, therefore, be defined as accessing effective antimalarial drugs within 24 hours of the onset of malaria symptoms and completing an appropriate course of that drug. To examine the extent to which treatment-seeking for malaria in sub-Saharan Africa conforms to the RBM guidelines, the following section (2.2.1) provides an outline of what is currently known about treatment-seeking for malaria in sub-Saharan Africa. The majority of the available literature on treatment-seeking for malaria in sub-Saharan Africa derives from studies in highly endemic rural areas. There appear to be few studies in areas of low transmission and even less on treatment-seeking behaviour in refugee situations.

2.2.1 Patterns of treatment-seeking behaviour for malaria

Over the past few years many studies on treatment-seeking behaviour for malaria have shown that most cases in endemic areas of sub-Saharan Africa are first treated at home (Agyepong *et al.*, 1995; Fawole and Onadeko, 2001; Mwenesi *et al.*, 1995; Nyamongo, 2002; Tarimo *et al.*, 2000; Thera *et al.*, 2000). These results are hardly surprising since in any society, Western and non-Western, the family is the real site of primary health care (Helman, 1998), and it has been estimated that 70-90% of health care takes place in this sector (Kleinman, 1978). It is in the home that illness is initially perceived and defined; it is also where treatment is initiated by family members.

In view of the possibility of the rapid progression from mild to severe disease, the public health concern about the initial treatment of malaria in the home is the extent to which it affects the aim of providing appropriate antimalarial treatment within 24 hours of the onset of symptoms. Gathering data on this issue is a problem since, as recent reviews have found, studies of treatment-seeking behaviour frequently use vague terms such as 'home treatment' or 'pharmaceutical drugs' without reporting what therapies were actually used for a particular illness episode (McCombie, 1996; Williams and Jones, 2004).

Despite the lack of specificity in many studies, it is possible to say that the data suggest that the first treatments for febrile illness in much of sub-Saharan Africa usually include herbal remedies in the form of liquid, powder, salves, compresses and special bathing practices, hot compresses and special foods (Hausmann-Muela and Muela, 1998a; Oketch-Rabah *et al.*, 1998; Ryan, 1998), as well as frequent use of pharmaceuticals such as anti-pyretics and/or analgesics and antimalarial drugs (Agyepong *et al.*, 1995; Deming *et al.*, 1989; Kengeya-Kayondo *et al.*, 1994; Munguti, 1997; Mwenesi, 1993; Sommerfeld and von Arbin, 2001; Thera *et al.*, 2000). The sources of pharmaceutical drugs used in the home vary and include drugs bought from the local pharmacies, shops or itinerent vendors, as well as treatment with drugs left over from previous illness

episodes (Baume *et al.*, 2000; Deressa *et al.*, 2003; Fawole and Onadeko, 2001; Hamel *et al.*, 2001; Lubanga *et al.*, 1997; Nshakira *et al.*, 2002; Ongore and Nyabola, 1996). These studies also show that people with malaria commonly treat themselves with pharmaceutical drugs within 24 to 48 hours of the onset of febrile symptoms. However, few data are available on the proportion who actually treat themselves with an appropriate antimalarial. A recent study by Nshakira and colleagues in Uganda (Nshakira *et al.*, 2002) found that, of the children in their study, 72% had received a modern drug and 40% had been given the appropriate antimalarial (which at the time of the study was CQ) before they made their first visit to a health facility. Another recent study on self-treatment for malaria in Ethiopia found that 52.35% of the 630 participants had started treatment at home with an appropriate antimalarial within 2 days of the onset of symptoms (Deressa *et al.*, 2003). In her most recent review, McCombie (2002) has calculated that between a third and a half of all febrile illness are treated at home with an antimalarial. Many of the studies on treatment-seeking for malaria in sub-Saharan Africa report that although there is a tendency to start with home treatment, health facilities are commonly used if the first treatment is perceived not to have worked or if new and/or more serious symptoms appear (McCombie, 1996; Njama *et al.*, 2003; Williams and Jones, 2004). Nshakira and colleagues (Nshakira *et al.*, 2002) found in their Ugandan study that the median time taken to present at a health facility was 3.6 days after the onset of symptoms (and 72% of those had already received a pharmaceutical drug). Many other studies have found that the delay before seeking treatment at a health facility is often at least 3 days (McCombie, 1996). However, as mentioned above, many of those who do present at the health facilities are likely to have taken some form of modern drug and many may already have taken an antimalarial. Furthermore, use of a health facility appears not to prevent care seeking from other sources (such as continued use of herbal preparations or consultations with traditional healers) and many studies have shown simultaneous use of several strategies (Oketch-Rabah *et al.*, 1998; Sommerfeld and von Arbin, 2001; Thera *et al.*, 2000).

Whatever the source of antimalarial drugs (itinerant vendors, general shops, pharmacies or health facilities), several studies have found that failure to complete an appropriate course of treatment (correct dosage and timing) is common (Agyepong and Manderson, 1994; Krause *et al.*, 1998; McCombie, 1996; Thera *et al.*, 2000) . For many researchers, the focus of attention for this 'non-compliance' with appropriate and complete dosing has been on the patient and informal providers of care (Krause *et al.*, 1998; Slutsker *et al.*, 1994; Thera *et al.*, 2000). However, a recent study of the use of antimalarial drugs in Uganda suggests that only 34% of dosages prescribed in the District Medical Units complied with the national standard guidelines, while 37.8% of the patients followed the provider's recommendations (Nshakira *et al.*, 2002). The issue of the quality of care provided by health workers and its impact on effective case management is addressed in greater detail later in this chapter.

The data from the studies reviewed in this section suggests that, based on the current RBM guidelines, treatment-seeking for malaria among many populations in sub-Saharan Africa is inadequate. That is, while people actively seek treatment for illness frequently within 24 hours of the onset of a fever, fewer than 50% will receive an effective antimalarial during this time period and even fewer will complete an appropriate dose. Attempts to improve this situation rely on developing an understanding of why it happens. In addition, since the concern of this thesis is malaria management among refugees, the extent to which the findings from these studies can be applied to treatment-seeking behaviours among refugees needs to be considered.

Many of the studies reported above were undertaken in environments and contexts similar to those experienced by many of the refugees in sub-Saharan Africa in their place of origin. However, it is unclear to what extent the past experience of refugees is likely to have affected their patterns of treatment-seeking or if these behaviours can be translated into the refugee setting. In order to evaluate whether or not such patterns of treatment-seeking are likely to exist among refugees, as well as to understand why much of the treatment-seeking

behaviour for malaria in sub-Saharan Africa could be considered inappropriate (using the RBM guidelines), it is necessary to review what is known about the factors that shape and constrain treatment-seeking behaviours.

2.2.2 Decision-making and the effect of therapy management group

The studies on patterns of treatment-seeking behaviour show that people who make decisions about when and where to seek treatment for a particular constellation of symptoms are active seekers of care. Before investigating the factors that influence and constrain these decisions, it is worth looking at who is involved in the decision-making process.

Much research regarding illness and care seeking behaviours has clearly shown that decisions about ill health and when to seek medical help are part of a social process involving at least one other person apart from the sufferer (Calnan, 1988; Janzen, 1978; Kloos *et al.*, 1987). In his study of the quest for therapy in Lower Zaire, Janzen (1978) analysed in detail the ways in which kinship groups are implicated in diagnosis and treatment choice. He called those involved in the process the 'therapy managing group' and called attention to the influence of family support in the therapeutic process. He suggests that a therapy management group comes into being whenever an individual or set of individuals become ill or is beset by overwhelming problems. Various maternal and paternal kinsmen, and occasionally their friends and associates, rally for the purpose of sighting information, lending normal support, making decisions and arranging details of therapeutic consultation (Janzen, 1978). Therapy management groups vary in size and composition. Walker *et al*, (1977) refer to the size of a group as the number of people with whom an individual maintains some social contact regarding treatment decisions when sick. In general, the larger a person's therapy management group, the more support they receive such as health information. This is basically because there are more people available to provide support that may be needed regarding disease treatment. Strength of ties also plays a role in the therapy management group. Shumakee and Bronwell (1984)

refer to strength of ties in a therapy management group as a combination of characteristics likely to be intercorrelated in terms of the amount of time, the emotional intensity, the intimacy, and the reciprocal services which characterizes the tie. This goes hand in hand with the density of a management group, which according to Walker *et al.* (1977) is the extent to which the members of the therapy management group know and contact each other. A small dense support group of predominantly strong ties might indeed be more effective in giving support than a large group of weak density. Homogeneity of membership is also very important in a therapy management group. Walker and his colleagues (Walker *et al.*, 1977) define homogeneity of membership in a group as the extent to which group members share social characteristics such as age, sex, ethnicity and social class, and attitudinal and behavioural characteristics such as social values and life styles. For a group to be very understanding, it has to be homogenous. Important as well is the dispersion of membership within a therapy group. Walker *et al.*, (1977) refer to dispersion of a membership in a group as the ease with which members of the therapy management group can make face to face contact. This also includes the geographical distances between group members, and the availability of transportation incase they need to meet as soon. These factors play an important role in strengthening an effective therapy management group.

Several studies of treatment-seeking for malaria have found that decisions regarding whom to consult and when, frequently involve people other than simply the person who is ill. That is, they often involve some sort of therapy management group. For example, when a child becomes ill with a fever, decisions to seek treatment outside the home (particularly if payment will be required) are frequently not the responsibility of the mother alone but also require discussion and agreement with others such as the father of the child, the in-laws or other close relatives (Alilio *et al.*, 1998; Janzen, 1978; Molyneux *et al.*, 2002; Muela *et al.*, 2000; Tanner and Vlassoff, 1998). However, there is evidence to suggest that different groups of people are involved in the management therapy

group depending on how 'malaria' is perceived. Studies have found that uncomplicated malaria in endemic areas of sub-Saharan Africa is often viewed as a mild 'normal' illness (Agyepong and Manderson, 1994; Kengeya-Kayondo *et al.*, 1994; Munguti, 1997; Ruebush *et al.*, 1995), and that treatment decisions are made by individuals themselves, or for children, by mothers and close relatives. In contrast, severe malaria with convulsions is seen as a different disease, a personalistic illness that requires the involvement of a broader therapy management group (Hausmann-Muela *et al.*, 1998). The literature reviewed suggests that, even for mild disease, the decision to seek treatment for malaria is rarely the decision of the affected individual alone. However, these studies have all been undertaken in stable settings and it remains unclear the extent to which treatment-seeking for malaria is affected by breakdown in therapy management groups.

2.3 FACTORS AFFECTING TREATMENT-SEEKING FOR MALARIA

2.3.1 Awareness of the disease

Regardless of where the locus of decision-making resides, as the Piot model suggests, and as the studies reviewed in section 2.2.1 have shown, there are several steps in the treatment-seeking process. To understand the factors influencing these steps, it is necessary to disaggregate the stages of the process, to understand the iterative dynamic of the process and to place it within the context in which it occurs. Awareness of the disease is composed of two stages, firstly the recognition of a change in health status (either in the individual or in those for whom they have responsibility) and secondly the labelling of that change, the naming of the illness.

Over the past 10 years or so, many studies have been published that suggest that in most endemic areas of sub-Saharan Africa, symptoms such as fever, headache and generalized body ache are widely recognised as signs indicating a significant change in health status that require therapeutic intervention

(Agyepong and Manderson, 1994; Mwenesi, 1994; Nyamongo, 2002; Tarimo *et al.*, 2000; Thera *et al.*, 2000; Williams *et al.*, 1999). These symptoms, which correspond closely with the complex symptoms and are used to define the biomedical notion of uncomplicated malaria, were frequently given the label 'malaria' (Agyepong *et al.*, 1995; Deressa *et al.*, 2003; Kengeya-Kayondo *et al.*, 1994; Molyneux *et al.*, 2002; Mwenesi, 1994; Nyamongo, 2002; Ruebush *et al.*, 1995; Tarimo *et al.*, 2000; Thera *et al.*, 2000). In some studies (Hausmann-Muela and Muela, 1998a; Winch *et al.*, 1996) the term 'malaria' was linked to perceptions of a specific aetiology for the disease, but in many cases the term was used to describe all minor febrile illnesses with similar symptoms, regardless of their cause. That is, the naming or labelling of the disease was based as much on perceptions of symptoms and possible cures as on beliefs about a specific aetiology (Ager *et al.*, 1996; Hausmann-Muela and Muela, 1998a; McCombie, 1996; McCombie, 2002; Williams and Jones, 2004).

Giving a name or label to a constellation of symptoms is important since it frequently opens specific pathways to effective care, but the renaming of a disease as a result of response to treatment is as common among lay persons as it is among medical practitioners (McCombie, 2002). The results of many studies on the influence of beliefs about malaria on treatment-seeking for the disease suggest that while the identification and labelling of malaria does open up specific pathways to care, the treatments selected are often based more on prior treatment experiences and a realistic appraisal of available options than on an understanding of the aetiology of the disease (Ager *et al.*, 1996; Agyepong and Manderson, 1994; Klaver, 1993; Molyneux *et al.*, 2002; Oberlander and Elverdan, 2000; Oketch-Rabah *et al.*, 1998).

2.3.2 Effect of trauma on disease awareness

The studies reviewed in section 2.3.1 show that the symptoms of malaria are widely recognised and the label 'malaria' is extensively used in many populations in sub-Saharan Africa. However, it is unclear the extent to which the traumatic

experiences that many refugees undergo before and during their displacement affect their ability to recognize a change in health status (either in themselves or in those they are responsible for) or how these experiences may influence the labelling of that change and the naming of the illness.

The concept that war and traumatic events can have a negative effect on people's emotional, mental and social well-being existed for centuries, but over the past 150 years, since the development of psychiatry as a discipline, it has become a medical rather than a spiritual or religious problem (Tarrier *et al.*, 2000).

Attention to the psychological consequences of armed conflict has received particular concern since the Vietnam war and in 1980 a "new" disorder, Post Traumatic Stress Disorder (PTSD) officially entered the psychiatric nomenclature (Young, 1995). At the same time, humanitarian agencies involved in assisting refugees have taken more interest in the psychological and social impact of violent conflict, and since the mid 1980s relief and aid organisations have seen the provision of psychological assistance to refugees as part of their agendas. As a consequence, within refugee settings, PTSD has become a commonly used term to talk about the effects of traumatic events such as displacement, bombings, torture, rape and other physical attacks. However, several researchers have argued that PTSD is not the only trauma related disorder. After traumatic events, unexplained somatic symptoms, depression, sleep disturbance and other symptoms are not uncommon, and PTSD is just one of many mental health problems that can arise as the result of trauma (Friedman, 1996; Newman and Kaloupek, 1996; Ursano, 2002).

Despite these critiques, many refugees are diagnosed with PTSD and other trauma related disorders. PTSD vary widely within any given refugee population, with prevalence rates ranging from 4% to 86% for PTSD and 5% to 31% for depression (Hollifield *et al.*, 2002). Few studies have assessed distress

over time, but some have documented that distress is often chronic. For example, Mollica *et al.* (2001) assessed psychological distress in a sample of Bosnian refugees to determine if the distress associated with being a refugee is chronic. They found in their follow-up study that 45% of the study participants who originally were diagnosed with depression, PTSD, or both continued having the problem three years later, and an additional 16% were diagnosed with PTSD during the study period. Porter and Haslam (2001), in their meta-analysis, demonstrated that across 14 different studies, the general stress of war had a significant impact on war victims. However, displaced persons were often more disturbed than non-displaced controls even when the controls had experienced considerable war stress. Porter and Haslam (2001) indicated that these results are in agreement with studies in refugee settings that have reported that living in institutional refugee camps is more disruptive than living temporarily with family, friends, or in private accommodation.

2.3.2.1 How stress and trauma affect awareness

Different people respond with different degrees of stress to different stressors (Kessler *et al.*, 1996). However, there are at least four factors which determine the degree to which one will feel stressed:

- Control: a person feels stressed to the extent to which they perceive they are not in control of themselves or the stressor
- Predictability: a person feels stressed to the extent to which they are unable to predict the behaviour or occurrence of the stressor
- Expectation: a person feels stressed to the extent to which they perceive their circumstances are not improving and will not improve (give up hope in life)
- Support: a person feels stressed to the extent to which they lack support systems, including family, friends, colleagues, persons in authority, official bodies, and the law

Because of the severity of the traumatic event, people who have experienced trauma many times feel loss of control. They experience cognitive effects that include impaired concentration, impaired decision-making ability, memory impairment and confusion (Ursano, 2002). In addition, in people with PTSD, memories of the trauma reoccur unexpectedly, and episodes called "flashbacks" intrude into their current lives. This happens in sudden, vivid memories that are accompanied by painful emotions that take over the victim's attention. This re-experience, or "flashback," of the trauma is a recollection. It may be so strong that individuals almost feel like they are actually experiencing the trauma again or seeing it unfold before their eyes, and in nightmares. All these symptoms make them loose control over their thoughts (Helman, 1998).

Several studies have tried to understand how memories of trauma affect behaviour. Lindsay (1994) argues that traumatic stress induces interferes with the integration of the traumatic experience of an ongoing stream of conscious experience, thought and action. This state of dissociation results in an amnesia for the traumatic event. However, according to Kihlstrom and Schacter (1995), this functional amnesia affects only explicit memory, or conscious recollection. A complete mental representation of the event remains available in storage, and is expressed implicitly through dreams, and behaviour. By explicit memory, Kihlstrom and Schacter, (1995) refers to conscious recollection, as when a person recalls or recognises an event from the past, while by implicit memory, they refer to the influence of past events on current experience, thought, or action, even though these events may not be accessible to conscious recollection. Supporting Kihlstrom & Schacter' notion on explicit and implicit memories is van der Kolk (1994) who argues that traumatic stress interferes with the consolidation of an explicit memory, but has no effect on implicit sensory, motor, or affective representations of the traumatic event. Furthermore, by virtue of high levels of adrenaline and other stress hormones, such implicit representations are deeply imprinted in memory, and can intrude on consciousness in the form of annoying sensations, images, feelings, and motor

activities. Similarly, Herman (1992) suggested that traumatic memories lack verbal narrative and context, and exist only as a vivid sensations and images.

Several studies have suggested that health may be influenced directly by physiological, behavioural and psychological processes in specific ways (Cardozo *et al.*, 2000; Helman, 1998). Many ill people report a noticeable worsening of their physical symptoms under stress and trauma. This may be because stress or trauma has a wide variety of psychological effects on the body, and how emotions and the physical body relate is still not very clear. However, reduction of stress or trauma and improvement of coping skills may help control certain physical symptoms in some types of illnesses.

Psychological mechanisms have been implicated as one of the factors influencing health and recognition abilities. First, thinking about oneself and one's world may place individuals at risk of various forms of psychopathology, including depression (Beck *et al.*, 1979) and anxiety (Schwarzer and Wicklund, 1991). Second, under stress, cognitive or social factors may heighten an individual's perception of himself or herself as sick, either by increasing awareness of bodily sensations that might otherwise go unrecognised (Myrtek and Brugner, 1996) or by prompting individuals to attribute normal symptoms or bodily sensations to evidence of pathology requiring medical intervention (Mechanic, 1972). Pre-existing attitudes about illness can also affect adjustment to it. When the thoughts and emotions of people change, their physical symptoms also shift. Even when their physical symptoms remain the same, the patient's attitude about them can undergo a transformation. Reduction of stress and improvement of coping skills may help control certain physical symptoms in some types of chronic or serious illnesses (Conway, 1995). Pre-existing attitudes about illness can also affect adjustment to it. Even when the physical symptoms remain the same, however, the patient's attitude about them can undergo a transformation. For example, the symptoms might be easier to accommodate to and this might occupy less of the person's awareness and the person might see

their illness in a new, more accepting light. If the ill person has less of a conviction that illness negatively impacts their lives, their overall existence may be significantly better, even if their symptoms don't improve.

As the above studies suggest, a common feature of stress across cultures is its expression through somatisation, that is, through physical symptoms such as vague aches and pains, headaches, sweating, palpitations, dizziness and weight loss (Kleinman, 1980). However, while many cultures share the characteristic of somatisation, numerous studies have shown that distress and depression are not expressed in the same way in all cultures or communities (Kleinman *et al.*, 1978; Lin *et al.*, 1985; Swartz *et al.*, 1998). All cultures have specific 'languages of distress' where specific physical symptoms are widely recognised as culturally acceptable ways of expressing underlying emotional distress (Helman, 1998). The literature reviewed above suggests that the physical symptoms that they report to express their distress are likely to be culturally specific. The extent to which these symptoms overlap with the signs and symptoms of malaria may have important implications for the recognition and labelling of malaria and the subsequent consequences for treatment-seeking behaviour of traumatised refugees.

2.3.3 Access and availability

The studies reviewed in section 2.3.1 showed that while awareness of malaria is an important first step driving the treatment-seeking process, belief in the causation of the disease is frequently only one of the factors which play a role in determining patterns of resort to care. Many studies also suggest that treatment-seeking for malaria is not always a linear process. Patients do not always proceed from one option to the next in a sequential manner and it is not uncommon for more than one provider to be consulted, and more than one treatment regime to be followed at any one time (Agyepong and Manderson, 1994; Ahorlu *et al.*, 1997; Molyneux *et al.*, 2002; Oberlander and Elverdan, 2000; Oketch-Rabah *et al.*, 1998). Data from several studies suggest that pragmatism

is often more important that logical consistency or adherence to a theoretical paradigm in searching for a cure (Hausmann-Muela *et al.*, 1998a; Oberlander and Elverdan, 2000).

A feature of this pragmatism is to maximize treatment variety in the hope of finding at least one treatment that will help stop the illness (Ryan, 1998). Miguel and colleagues (Miguel *et al.*, 1998) argue that the choice of these medicines tends to be based on previous experience with drugs proven to be most effective. Numerous studies have shown that the search for an effective antimalarial is one of the primary factors affecting peoples' choice of provider for malaria treatment in sub-Saharan Africa. For example, one of the most commonly cited reasons for not using public health facilities as the first provider of treatment for malaria is the frequent lack of drugs and/or equipment available at those facilities (Nyamongo, 2002; Oketch-Rabah *et al.*, 1998; Ruebush *et al.*, 1995; Williams *et al.*, 1999). On the other hand, many people report using local shops and drug sellers as a first choice because they have drugs in stock, they are easily accessible and drugs can sometimes be obtained on credit or charges negotiated (Agyepong and Manderson, 1994; Baume, 1998; Baume *et al.*, 2000; Igun, 1987; Molyneux *et al.*, 2002; Ongore and Nyabola, 1996). Apart from the frequent lack of drugs, another commonly reported reason for not using public health facilities is their inaccessibility. Inaccessibility can either be in terms of physical distance or it can be related to restricted opening hours. It can also be due to frequently long queues which result in long waiting times for patients (Adongo and Hudelson, 1995; Ahorlu *et al.*, 1997; Baume *et al.*, 2000; Gilson *et al.*, 1994; Munguti, 1997; Oketch-Rabah *et al.*, 1998; Ruebush *et al.*, 1995; Tarimo *et al.*, 2000). While the accessability and availability of drugs and services has been found to have an impact on treatment-seeking behaviour, a further important consideration is that of cost. As Ryan (1998) has reported, in seeking treatment for illness people seek to minimize the cost of care by frequently chosing treatments that are less expensive and easier to administer.

2.3.4 Cost

Cost has a strong influence on the choice and decision to seek treatment and has been looked at from different dimensions. Several studies have discussed the issue of both direct and indirect costs (Asenso-Okyere and Dzator, 1997; Attanayake *et al.*, 2000; Jayawardene, 1993; Sauerborn *et al.*, 1991). Jayawardene (1993) referred to direct costs as those which involve chemotherapy and transport, and indirect costs as loss of time and work days, and indebtedness resulting from expenditure and loss of income. Asenso-Okyere and Dzator (1997) analysed both direct and indirect costs from the perspective of individuals, household and society. They reported that direct costs include cash payment for travelling to seek treatment, cash payment for treatment, and cash payment for preventive measures taken by individuals, households, governments and non-government organisations.

Direct costs relate to the value of time lost to malaria through morbidity and mortality. They further indicated that when the disease is severe, the patient cannot carry out normal productive activities. Therefore, some time is lost to production and these include travel time to the health care facility, time spent at the facility by an individual waiting for a turn to obtain service, or time taken by family members as the patient's care taker.

A commonly cited reason for not using public health facilities in the treatment of malaria is because of the costs involved in the process. As mentioned above, these include considerations of both the direct and indirect costs. Many countries in sub-Saharan Africa have, over the past few years, introduced the concept of 'cost-sharing' into their health systems. Although in several countries antimalarial drugs for children under-five are supposed to be free in the public health system, in reality people are often charged informally for a visit to the health facility. The cost of treatment and of loss of income due to taking time off work to travel and wait in a queue have all been frequently cited as reasons why public health facilities are rarely the first choice for malaria treatment in much of sub-Saharan

Africa (Adongo and Hudelson, 1995; Ahorlu *et al.*, 1997; Hausmann-Muela *et al.*, 1998; Ndyomugyenyi and Magnussen, 2000; Ortega and Binka, 1994; Williams *et al.*, 1999; Williams and Calnan, 1991).

2.3.5 Perception of quality of services

The availability and affordability of primary health care in and of itself does not guarantee its utilisation (Chabot and Bremmers, 1988; Larsen and Rootman, 1976). A final major factor that influences choice of care is the perception of the quality of care offered by the health care provider. Household surveys (Amonoo-Lartson *et al.*, 1985; Donabedian, 1968) have revealed that perceived low quality of health care is one of the main reasons as to why people do not attend primary health care services for illness. Pepperall and colleagues (Pepperall *et al.*, 1995) report that the skills of health personnel and their reputation are important factors in the use of health facilities. In their study, lack of skills featured among peoples' complaints with regard to health services, alongside complaints about staff attitude and lack of drugs.

Cheesbrough (1998) reports that delays in seeking modern treatment can be related to poor quality of care such as lack of laboratory tests to ascertain diagnosis and for monitoring treatment response in view of the evolution of drug resistance. The literature on factors affecting treatment seeking for malaria has shown that while health workers are often thought to know the most appropriate treatment and give the best advice (Agyepong and Manderson, 1994; Baume *et al.*, 2000; Tarimo *et al.*, 2000) they are also frequently said to be rude and dismissive (Gilson *et al.*, 1994; Ruebush *et al.*, 1995; Williams *et al.*, 1999). By contrast, private providers are frequently said to be friendly in offering support (Adongo and Hudelson, 1995; Agyepong and Manderson, 1994; Klaver, 1993). Studies of provider behaviour suggest that patients' concerns may be justified. Several studies have found that providers in the public sector are frequently rude to their patients, often spend little time diagnosing illness and give few or no

instructions on drug dosage (Agyepong *et al.*, 1995; Baume *et al.*, 2000; Durrheim *et al.*, 1999; Gilson *et al.*, 1994).

These studies indicate that while provider behaviour may have an effect on effective case management through influencing treatment-seeking behaviour, it may also have more direct consequences for effective case management through the quality of diagnostic and prescribing practices of the provider.

2.4 QUALITY IN HEALTH CARE

During the last few decades, concern for quality in health care has been growing. Silimperi *et al.* (2002) report that the concern has been triggered in part by the growth in local autonomy and democratization, decentralization of health systems and health sector reform. Quality in health care is becoming a national and international policy issue that should be included as a component for clinical governance (Marshall, 2000). But what do we mean by quality in health care? Donabedian (1980;654) defines quality in health care as: "A kind of care which is expected to maximize an inclusive measure of patient welfare, after one has taken account of the balance of expected gains and losses that attend the process of care in all its part". In 1990, the Institute of Medicine (IOM) in the United States defined quality in health care as the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge (Lohr, 1990).

In using this definition, the IOM narrowed the goal from improving total patient welfare to improving health outcomes but, at the same time, moved the focus from patients to individuals and populations. It thus allowed quality of care to incorporate promotion and prevention and not just cure and rehabilitation as defined by Donabedian (Palmer, 1997; Palmer and Miller, 2001).

Several researchers have defined quality in health care according to their own understanding. Brook (1991) defines quality in health care as the component of

the differences between efficacy and effectiveness that can be attributed to care providers, taking account of the environment in which they work, while Ovretveit (1990) defines quality in health care as meeting customer requirements at the lowest cost through three elements, mainly:

- Customer quality, which relates to whether the service gives customers what they want, as measured by customer satisfaction and complaints
- Professional quality, which relates to whether the service meets customer needs as defined by professionals and whether the professional procedures and standards that are believed to produce the required outcomes are observed
- Process quality, which is the design and operation of the service process to use resources in the most efficient way to meet customer requirements

Taking much broader stances are Roemer and Montoya-Aquilar (1988) who defined quality of health care as the proper performance of interventions that are known to be safe, affordable to the society in question, and that have the ability to produce an impact on mortality, morbidity, disability and malnutrition.

These examples imply that the concept of quality of health care can be approached from several different perspectives: that of the consumer, that of the provider, and/or that of the society in which the care is delivered. Anderson (1989) suggests that employers define health care quality in terms of value obtained for their health care investment; for patients, quality means feeling better, and for the hospitals, quality means care that they can get paid for. Conscious of such differences in perspective is Rodriguez and Weber (1988) who emphasized that quality is socially constructed. It may depend on who is assessing it and what values and consensus are used in evaluation, and by what implicit or explicit standards or gauges it is being objectively or subjectively evaluated.

2.4.1 Quality assurance in health care

Quality Assurance (QA) is a management system, which builds quality assessment, monitoring and improvement into working practices of a health service unit. It is increasingly being considered as an integral function in all health service delivery organisations. It has been part of health care for the past 100 years.

Quality Assurance was introduced into modern medicine by a British nurse, Florence Nightingale, who assessed the quality of care in military hospitals during the Crimean War (Brown *et al.*, 1995). It was not until in the 1980s when Quality Assurance expanded to primary health care in the United States and Europe and later to the developing countries. Quality assessment, on the other hand, is the process of determining the level of quality of health services.

Concern for quality health care has existed for decades. But an honest concern about quality, however genuine, is not the same as methodical assessment based on reliable evidence (Maxwell, 1984). Internationally, we can find examples in North America, the Caribbean, Asia and Africa (Nicholas *et al.*, 1991). Assumptions behind these activities help to improve effectiveness, efficiency and cost containment. Like quality in health care, quality assurance has been defined in various ways. Brown *et al. (*1995*)* and Offei (1995) used the following three descriptions to define quality of a programme: It is oriented towards meeting the needs and expectations of the patient and the community. It focuses on the work and activities of health care providers and on the processes of health care delivery. It uses data to analyse the processes and it encourages a multi-disciplinary team approach. Ruelas and Frenk (1989) however, define quality assurance as a systematic process for closing the gap between actual performance and the desirable outcomes, while Palmer (1983) defines QA as a cyclical activity using standards of measurement. Berwick (1991), on the other hand, defines QA as a systematic managerial transformation designed to address the needs and opportunities of all organisations as they try

to cope with increasing change, complexity and tension within their environments. All these definitions of QA share several characteristics, each referring to a systematic ongoing process that is oriented toward improving performance and using data in the process.

Quality assurance (QA) has been identified as the main tool for quality improvement in developing countries. Recent experience in applying quality management to health care systems suggests that four tenets should be adhered to in an ideal quality assurance programme (Nicholas *et al.*, 1991). The first tenet states that QA is oriented toward meeting the needs and expectations of the patient and the community. The second tenet states that QA focuses on systems and processes. The third tenet states that QA uses data to analyse service delivery processes and the fourth tenet states that QA encourages a team approach to problem solving and quality improvement.

It is important to note that the definition of QA can be extremely broad and can include all programme management activities. In practice, the scope of QA effort depends on the needs and capacities of the health service organisation. However, if an organisation desires a comprehensive approach, a QA initiative can be developed as a component of a general management improvement effort (Brown *et al.*, 1995). In practice, QA is a cyclical, iterative process that must be applied flexibly to meet the needs of specific programmes.

2.4.2 Measuring quality in health care

The standard framework for measuring quality of care provision has been based on three measures of quality: structure, process and outcome (Donabedian, 1980). Donabedian argues that quality requires an appropriate structure that develops the proper processes and hopefully results in desired outcomes. In two of his studies (Donabedian, 1980; Donabedian, 1988), Donabedian reports that structure measures the characteristics of the health system, including the personnel and facilities that provide health care and how they are organised. In

other words, structure refers to the attributes of the settings in which care occurs. This includes material resources, human resources and organisational structure.

Several researchers have used structure measure in measuring quality of care. Structural measures are relatively inexpensive to obtain and are readily available (De Geynt, 1995). However, some criticism has been encountered with regard to this measure. Nordyke (2000) argues that although structural measure is necessary, it is not a sufficient condition for better health outcomes. To have a valid dimension of quality, there must be evidence that variation in structural measures can lead to changes in patients' outcome (Brook, 1996; Brook *et al.*, 1996).

Donabedian (1980) refers to process measures as the factors of the encounter between the health care provider and the patient and what it contributes to what is actually done in giving and receiving care. This includes the patient's activities in seeking care and carrying out instructions as well as the practitioner's activities in making a diagnosis, and recommending or implementing treatment.

Process measures have been considered a preferable tool in measuring quality of care and can be used to provide feedback for quality improvement initiatives (Rubin *et al.*, 2001). Because many factors can influence patient outcomes, process measures have the potential to identify for clinicians which processes they followed or didn't follow that had the potential to affect patient outcomes. Process measures provide information that is actionable, i.e. what is being done well and what needs improvement (Donabedian, 1980). Process measures require less risk adjustment for patient illness than do most outcome measures.

Mant (2001) reveals the intrinsic advantage of process measures as being more sensitive to differences in the quality of care and easier to interpret than outcome measures. However, for quality of care based on process measures to be valid, there must be a strong relationship between process and outcome measures (Brook, 1996; Brook *et al.*, 2000; Rubin *et al.*, 2001; Siu *et al.*, 1992). These links

between process and outcome measures can come from previously published evidence or may be demonstrated for the group whose quality of care is being evaluated. But prior evidence supporting the relationship might be weak or non-existent for many processes even when they are truly linked to outcomes (Rubin *et al.*, 2001). In least developing countries, process measures have been reported as difficult to obtain due to deficiency in information systems (De Geynt, 1995; Duran-Arenas *et al.*, 1998), scarceness of medical records (Peabody *et al.*, 1994) and lack of information technology resources to integrate medical records from different sources (Munoz, 2002).

Donabedian (1980) reports that outcome measures the subsequent health status of the patient and donates the effects of care on the health status of patients and populations, while Mant (2001) indicates that outcome measurement reflects all aspects of the processes of care and not simply those that are measurable or measured. He further reports that attributes such as technical expertise and operators' skills, while likely to be important determinants of outcome in some situations, cannot easily be captured as performance indicators. The outcomes dimension of quality includes a set of results from the delivery of health services such as the clinical and functional status, quality of life and satisfaction with care (Batalden *et al.*, 1994; McGlynn, 1995). But the difficulty here in using outcome as measures of quality is that it depends on spurious relationships that don't reflect the level of care received by the patient (Brook *et al.*, 1996).

2.4.3 Quality of care from patient's perspective

As has been shown from the literature reviewed in section 2.3.5, quality of care from a patient's perspective is very important because satisfied patients often are more likely to comply with treatment and to continue using primary health care services. Most patients perceive quality of care as meeting their perceived needs on time (Brown *et al.*, 1995). Rahmqvist (2001) reports that quality of care from the patient's perspective is an important aspect in the development of health services. Patient satisfaction plays an important role in maintaining relationships

between patients and health care providers (Marquis *et al.*, 1983), compliance with medical regimens (Wartman *et al.*, 1983), and continued use of medical services (Thomas and Amos, 1984). Patient satisfaction is felt to be of paramount importance with respect to quality assurance and the expected outcomes of care. However, the relevance of patient satisfaction studies with respect to quality management and improvement in the health care sector is often questioned because of conceptual and operational problems such as reliability and validity of the patient's report, and ambiguity of the patient satisfaction concept (Donabedian, 1992). There is increasing acceptance that the views of consumers provide useful information about key aspects of health service delivery and the enthusiasm for measuring patient satisfaction as one way of doing this has been growing steadily (Draper *et al.*, 2001). A study on mothers' perspectives on the quality of postpartum care in Central Shanghai, China (Lomoro *et al.*, 2002) pointed to the importance of consumer feedback in the fact that it highlighted areas of postpartum services for improvement and the ways to reduce barriers that exist in the provision of care.

2.4.4 Quality of care from health care provider's perspective

From the provider's perspective, quality of care means being skilful, having the resources and meeting the conditions necessary to improve the health status of the patient (Brook, 1991). Providers tend to focus more on technical competence, effectiveness and safety. Studies have reported that gaps between the desired and actual performance of providers limits the quality of outpatient care in developing countries (Donabedian, 1980; Franco *et al.*, 2002). Identifying such gaps requires knowledge of what the providers are supposed to do, as well as the factors that affect the performance of those activities. Donabedian (1980) suggests that provider behaviour is linked to structure and process and poor performance is not always linked to individual competence but may also have much to do with the context in which the performance takes place. That is, performance is influenced not only by competence, but also by motivation and

organisational factors. To close the gap, it has been suggested that health care providers need and expect effective and efficient technical, administrative and support services to provide high quality care (Brown *et al.*, 1995).

2.4.5 The state of quality of care in developing countries

The literature reviewed in section 2.3.5 suggests that the quality of care for malaria in sub-Saharan Africa is insufficient. However, quality of care in developing countries has for long been viewed with low interest. It is only recently that developing countries are becoming aware of its importance. Reerink and Sauerborn (1996) reported that assessing and improving quality of health care was, until early 1996, a low priority, both for policy makers in developing countries, and for technical agencies. The reasons they stated for neglect of quality of care included: a perceived priority of extending coverage at the expense of quality; the view that quality is difficult to assess in the absence of reliable documentation and health information systems; and the perception that improving quality is tantamount to increasing inputs, thus costly and not affordable for many countries.

Many studies have been carried out that show how primary health care services in developing countries are delivered with evidence of low quality of care. Among them is a study by Amonoo-Lartson and colleagues (Amonoo-Lartson *et al.*, 1985), that assessed the process of providing maternal and child health care in Ghana. The study compared actual (observed) performance levels with expected levels for a number of diagnostic, therapeutic and counselling tasks and found significant performance gaps, especially in the area of physical examination and in the counselling of patients/clients. A further study in Ghana (Ofori-Adjei and Arhinful, 1996) found that one year after clinical training in the appropriate case management of malaria the practical management of malaria by medical assistants had deteriorated significantly. Similarly, Sauerborn and colleagues (Sauerborn *et al.*, 1989) analysed maternal and child health services in Burkina Faso and reported screening for risk factors in both under-five clinics

and antenatal clinics as below standard. The study also found that communication in both curative and preventive clinics was poor. It is, therefore, not surprising that community satisfaction with primary health services is low, especially in the domain of interpersonal skills of health center staff. Other studies in malaria endemic countries have indicated limited ability of rural medical doctors to differentiate malaria episodes from other febrile illnesses without microscopic examination (Font *et al.*, 2001; Greenwood, 1997; Olaleye *et al.*, 1998).

2.5 QUALITY IN MALARIA DIAGNOSIS

The effective case management of malaria strongly depends on the correct diagnosis of the disease. The recommended method for the diagnosis of malaria is through laboratory confirmation of parasites in a peripheral blood smear. However, in much of sub-Saharan Africa, the vast majority of malaria diagnosis is made on the clinical presentation of disease symptoms and this is because of lack of necessary equipments and technical skills to carry out laboratory diagnosis appropriately.

2.5.1 Laboratory diagnosis

Malaria is a febrile illness caused by the presence of malaria parasites in the red blood cells of human beings. A person suffering from malaria usually gets fever but not all fevers are due to malaria (WHO, 2002). Presence of the parasite can be determined by demonstration of organisms in blood smears (Petithory *et al.*, 1997), and this is through examination of the peripheral blood. The examination process includes proper specimen preparation, proper staining procedures and proper examination and analysis of the stained slide by a skilled technician in malaria microscopy (Coleman *et al.*, 2002).

Microscopy of Giemsa stained thick films by a skilled microscopist has remained the standard laboratory method for the diagnosis of malaria (Craig and Sharp,

1997; Makler *et al.*, 1998; Warhurst and Williams, 1996). However, microscopy cannot be considered as the 'gold standard' for malaria diagnosis because low-level parasitaemias and mixed infections are frequently not detected. Interpretations of results are, in most cases, inaccurate and procedures for the preparation of slides and enumeration of parasites are inconsistent (Craig and Sharp, 1997; Font *et al.*, 2001; Warhurst and Williams, 1996). In such cases, no parasites can be found in peripheral blood smears from patients with malaria, even in severe infections. This may be explained by partial antimalarial treatment or by sequestration of parasitized cells in deep vascular beds. In these cases, parasites, or malarial pigment may be found in the bone marrow aspirates. Presence of malarial pigment in circulating neutrophils and monocytes may also suggest the possibility of malaria. The low sensitivity of field microscopy in his study indicates that the technique will only identify individuals with relatively high parasite levels.

While the most widely used and currently cheapest method for detecting parasites in the blood is light microscopic examination of appropriately stained blood films, there are several new technologies, such as rapid diagnostic tests (or dipsticks) and molecular tests which can be used to detect the parasites or their antigens. Kolaczinski and colleagues (Kolaczinski *et al.*, 2004) suggested OptiMAL 48 rapid antigen test, which they indicated is adequate for acute and postemergency situations when the alternative is just clinical diagnosis. However, these are frequently unavailable or are currently too expensive to be commonly used in much of sub-Saharan Africa. Light microscopy is the most commonly used because it is long established, cheap and offers many advantages. WHO/USAID (WHO/USAID, 1999) reports that microscopy is sensitive, and when used by skilled and careful technicians it detects low parasite densities, it is informative because when parasites are found they can be characterized in terms of their species, it is a recognised technique that can be shared with other disease control programmes, and it can be subject to quality control. However, microscopy also has disadvantages. It is labour-intensive and

time-consuming and depends absolutely on good techniques, reagents, microscopes and well trained and supervised technicians, conditions that rarely exist in developing countries. The technical requirements and trained personnel for microscopy are often not available and when this is the case, microscopy becomes unreliable and a potential waste of resources (Ivers, 2003).

In laboratory tests for malaria parasites using microscopy, thick and thin blood smears are usually prepared. Equipment required for collecting blood are pricking needles, spirit, cotton, slides, pen/pencils and record forms (WHO/USAID, 1999). The smear is prepared from blood collected by venipuncture, finger prick or ear lobe stab. It can also be collected from other parts of the body according to the condition of a person. For example, in obstetric practice, cord blood and placental impression smears can be used (Kakkilaya, 2002). The blood slides containing the smear have to be clearly labelled with labels that are resistant to smudging and the effects of fixing, staining and cleaning blood films with inorganic solvents. The label should contain at minimum, the patient's name or code number (Houwen, 2000).

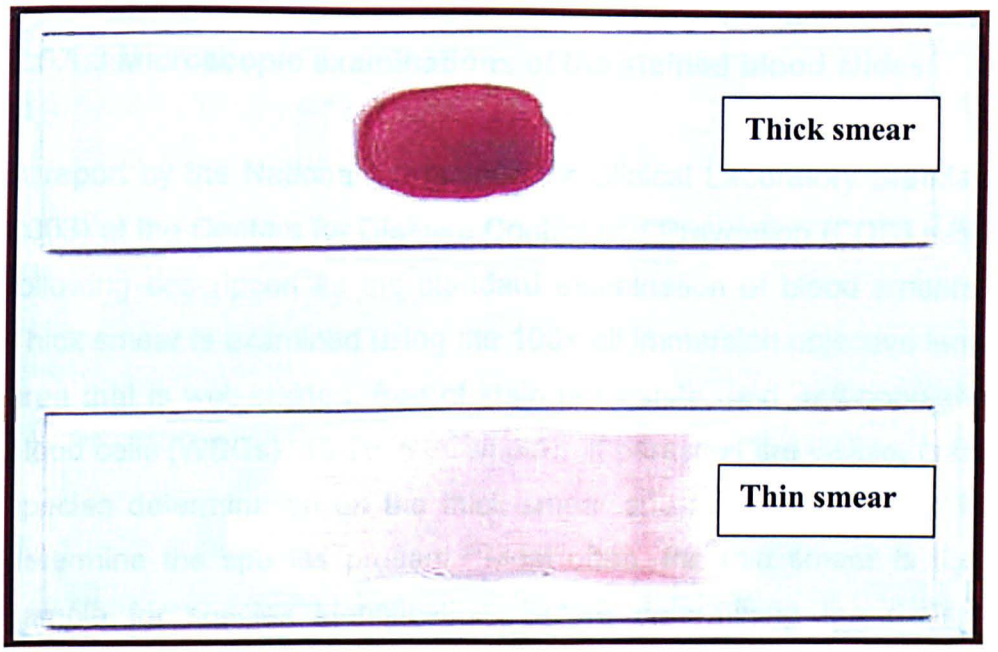
The thick smears are used to identify the parasites and thin smears to identify the species. Diagnosing the malaria parasite on a thin film can be difficult and time-consuming when the parasitaemia is low (Petithory *et al.*, 1997). Numerous concentration techniques exist but the most frequently used is still the thick blood film. It can improve efficiency in diagnosis but it takes time for smears to dry and in the process, flaking and unsticking of smears sometimes occur, with loss of parasites, and often the organisms present may be distorted in appearance (Houwen, 2000). Although thick films are sensitive in detecting low levels of parasitemia, it can be difficult to interpret without experience because of the lysis of the red blood cells during the staining process (Ivers, 2003).

2.5.1.1 Preparation of thick and thin blood smears

To prepare a proper blood smear for microscopic diagnosis of malaria, the following procedures have been recommended by (WHO, 2001) as the standard preparation of thick and thin smears. Place 3 drops of blood, obtained from a finger prick where applicable, in a blood slide 1 cm from the edge of the slide and another drop of blood 1 cm from the first drop of blood. Use another edge of another clean slide as a spreader to make a thick smear by joining the 3 drops of blood and spreading it in an area of 10mm in diameter. Make thin smear by bringing in contact the spreader with the drop of blood at an angle of 30-45 degrees from the horizontal and pushing the spreader steadily drawing the blood behind until the smear is formed and allow to dry. Thick smear is dried for 30 minutes fixing it in methanol and thin smear is dried for 10 minutes and faced in methanol.

According to the standard guidelines of preparation of blood smear by WHO (WHO, 2001), a good quality thick smear is one that is placed 10mm away from the edge of a slide, round in shape with a diameter of 10mm, thickness containing 10 layers of Red Blood Cells (RBC) and 10-12 White Blood Counts (WBCs), and should be visible per oil immersion of microscope. A thin smear, on the other hand, is regarded of good quality if it is uniformly spread over the slide, thin enough so that newsprint can be read through the smear, it is tongue shaped, and consists of a single layer of RBCs (WHO, 2001). An example of a good prepared thick and thin smear is presented in Figure 2.2 below.

Figure 2.2: Prepared thick and thin blood smear



Source: http://www.rph.wa.gov.au/labs/haem/malaria/diagnosis.html

2.5.1.2 Staining technique

Although there are a variety of stains such as Field's, Giemsa's, Wright's and Leishman's, Giemsa stains remains the standard stain most commonly used worldwide (Warhurst and Williams, 1996). The process of staining of blood films using Giemsa staining is indicated below.

In staining thick smears, immerse thoroughly dried slides in a jar or keep the slides in a horizontal position, stain with diluted 3% solution of Giemsa stain for 30-45 minutes, wash the slide with the same buffer gently and put the slide to dry in a tilted or upright position (Houwen, 2000).

For thin smears, air dry thin films, fix in methanol for 1 minute, wash in tap water and flood the slide with Giemsa diluted 1 in 10 ration of buffered distilled water pH 7.2. The diluted stain must be freshly prepared each time. Stain for 30-45

minutes, run tap water onto the slide to float off the stain and to prevent deposition of precipitate on to the film, then dry vertically (Houwen, 2000).

2.5.1.3 Microscopic examinations of the stained blood slides

A report by the National Committee for Clinical Laboratory Standards (NCCLS, 2003) at the Centers for Disease Control and Prevention (CDC) has reported the following description as the standard examination of blood smears for malaria. Thick smear is examined using the 100× oil immersion objective lens. Select an area that is well-stained, free of stain precipitate, and well-populated with white blood cells (WBCs) (10-20 WBCs/field). If parasites are visible, make a tentative species determination on the thick smear and then examine the thin smear to determine the species present. Most often, the thin smear is the appropriate sample for species identification. Before determining the results of a slide examination using the microscope, WHO (2001) recommends that at least 100 fields, each containing approximately 20 WBCs, be screened before calling a thick smear negative. Assuming an average WBC count of 8,000 per micro-liter of blood, this gives a threshold of sensitivity of 4 parasites per micro-liter of blood. In non-immune patients, symptomatic malaria can occur at lower parasite densities, and screening more fields (e.g., 200, 300, or even the whole smear) might be warranted, depending on the clinical context and the availability of laboratory personnel and time. NCCLS standards recommend examination of at least 300 fields using the 100× oil immersion objective.

Thin smears are useful for species identification of parasites already detected on thick smears, screening for parasites if adequate thick smears are not available, and a rapid screen while the thick smear is still drying. Screen at low magnification (10× or 20× objective lens) if this has not been done on the thick smears. Carefully examine the smear using the 100× oil immersion objective lens. NCCLS standards recommend examination of at least 300 fields using the 100× oil immersion objective. The blood films need to be checked more than

once. This is important for their consistency and quality in terms of minimum requirements.

Several studies have indicated the difficulties in reaching accurate malaria diagnosis in the absence of diagnostic facilities (Coleman *et al.*, 2002; Genton *et al.*, 1994; Krause *et al.*, 1998; Lubanga *et al.*, 1997; O'Dempsey *et al.*, 1993). For example, a study in Western Kenya found out that existing laboratories in rural health centers were almost non-functional due to lack of reagents and necessary equipments (Kakai, 2001) Other studies have mentioned lack of skilled microscopists (Kakai, 2001; WHO/USAID, 1999), limited supplies, inadequate maintenance of microscopes and reagents and inadequate quality control in most regions where malaria is endemic, especially in the periphery of the health care system (Coleman *et al.*, 2002). Recognizing the limitations of microscopic diagnosis for malaria parasites and taking into consideration the few clinical laboratories in most endemic malaria regions, diagnosis of malaria through clinical signs and symptoms remains the most common diagnosis of the disease in sub- Saharan Africa.

2.5.2 Clinical diagnosis of malaria

Clinical diagnosis is a widely used approach in the diagnosis of malaria. In most endemic countries in sub-Saharan Africa, especially in rural areas where laboratory support does not exist, malaria diagnosis depends solely on clinical diagnosis. The advantages of this approach are that it is quick and affordable. That is why it is widely used in most endemic countries. WHO/USAID (1999) states that clinical diagnosis for malaria is inexpensive to perform and requires no special equipment or supplies. In terms of disadvantages, however, the symptoms of malaria are non-specific and overlap with those of other febrile illnesses, which can make clinical diagnosis unreliable.

Among the signs and symptoms of malaria, the most common is fever, which is usually accompanied by chills, headache, general body pain, nausea and

vomiting. Most of the communities in endemic areas are familiar with these symptoms that are associated with malaria and they frequently self-diagnose based on these features. However, if left untreated, particularly among non-immune individuals, severe malaria with symptoms such as convulsion, severe anaemia, drowsiness and coma can develop and lead to death (WHO/USAID, 1999).

Clinical diagnosis of malaria is based on physical examination, as well as on histories of these signs and symptoms. In areas of high endemicity, treatment guidelines recommend treating all febrile illness among non-immunes with antimalarials (Barat *et al.*, 1999). While this approach is cheap, accurate diagnosis requires high technical skills.

A recent review of the clinical algorithms used in the clinical diagnosis of malaria suggests that symptoms and signs of uncomplicated malaria overlap with several other febrile illnesses to such an extent that experienced physicians have difficulties in diagnosing malaria. In most endemic countries, patients with acute febrile illness receive anti-malaria drugs from providers with little clinical training who prescribe anti-malaria drugs for every patient with fever. This, according to Chandramohan *et al.* (2002), gives a sensitivity of their diagnosis close to 100% while the specificity is likely to be very low. These viewpoints are supported by reports that the ability of rural medical aids or doctors to diagnose malaria in the absence of microscopy is limited (Font *et al.*, 2001).

Substantial over diagnosis was detected in some areas as well as low diagnostic accuracy. A study in the Gambia (Olaleye *et al.*, 1998) indicated that the diagnosis of malaria in children using clinical skills alone had sensitivities of 86% and specificity of 61%, while Rooth and Bjorkman (1992) reported that diagnosis of malaria by rural medical aids in Tanzania had a specificity of only

13% and in Niger a specificity of 21% (Olivar *et al.*, 1991). Treatment on the basis of clinical features alone is acceptable in highly endemic areas where the majority of the fevers are likely to be due to malaria. However, applying the criteria designed for the clinical diagnosis of malaria in high endemic setting may lead to considerable over diagnosis of malaria in areas of low transmission. Studies in sub-Saharan Africa (Font *et al.*, 2001; Gilson, 1993; Krause *et al.*, 1998; Nsimba *et al.*, 2002) have indicated among others, low malaria diagnostic accuracy as having an effect on the quality of antimalarial drug prescriptions and malaria treatment. An additional concern in refugee settings is the overlap between the somatic symptoms of psychological distress (see section 2.3.2) and those of non-psychological diseases (in particular, malaria) thus increasing the chances of misdiagnosis (Goldberg *et al.*, 1980).

CHAPTER 3: STUDY SETTING

3.1 COUNTRY PROFILE (KENYA)

Kenya has a population of about 32 million with an annual growth rate of about 1.15% (UNICEF, 2003). It has an area of approximately 582,646 sq km. It has a cosmopolitan culture that comprises traditional pastoralists, rural farmers, and urban residents. Its capital city is Nairobi.

The country has a very diverse population that includes most of the major languages of Africa. The main national languages spoken are English and Swahili, but there are also 42 ethnic languages. Kenya's African population is divided into three linguistic groups: Bantu, Nilotic and Cushitic. The major religion in Kenya is Christianity, followed by Islam and other religions. Kenya's economy is seen as strong enough to promote growth in Africa but it is stagnating due to poor management and uneven commitment to reform.

Kenya is located across the equator on the East coast of Africa. It shares borders with five other nations: Uganda to the west, Tanzania to the south, Ethiopia to the north, Sudan to the northwest and Somalia to the east. Part of Kenya's East Coast touches the Indian Ocean where the port of Mombasa serves as the main gateway to the sea. The topography of Kenya appears diverse, ranging from sea level to over 5,000 meters on the summit of Mount Kenya. It creates different climatic and ecological conditions and comprises two distinct physical regions, the lowlands and the highlands. The northern three-fifths of Kenyan land is arid, semi-desert, to desert. The south is temperate, dominated by a high, mountainous central plateau, which levels out to a series of highlands and plains to the east and west. Below is the map of Africa

indicating the location of Kenya (See direction of error in Figure 3.1 below).

Figure 3.1: Map of Africa showing location of study country

Source: http://www.nsrc.org/AFRICA/africa.html

Kenya is divided by the equator into two almost equal parts. The region north of the equator is hot and receives comparatively little rain. The Southern region falls into three meteorological zones: the coast which is humid, with an average annual temperature ranging from about 76 degree Fahrenheit in June and July

to about 82 degree Fahrenheit in February, March and April; the highlands which are relatively temperate; and the Lake Victoria region which is tropical.

Kenya is a republic which won its independence from British colonial rule in 1963 and now is a unitary State. It has a multi-party political system whose hallmark is parliamentary democracy. The core of the system is a National Assembly or Parliament. Kenya comprises seven provinces. The provinces are further divided into districts, one of which is Turkana district where Kakuma refugee camp, the area of study, is located. The map of Kenya, including the study area location, is presented in Figure 3.2 below.

Figure 3.2: Map of Kenya showing location of study site

Source: http://www.lib.utexas.edu/maps/africa/kenya_pol88.jpg

3.2 REFUGEE POPULATION IN KENYA

Kenya has been a signatory to the 1951 Convention and 1967 protocol related to the status of Refugees since 1966 and 1981. It is also a signatory to the OAU Convention on Refugees. Kenya's refugee population includes Somalis, Sudanese, Ethiopians, Ugandans, and a smaller group made up of various nationalities. Refugee numbers have been reduced from 420,000 in 1992 to 187,000 as of June 1998. The decrease is mainly due to the repatriation of

more than 155,000 refugees to Somalia and the return of over 70,000 Ethiopians. A total of 1,500 refugees of various nationalities were repatriated and another 4,500 benefited from the third country resettlement between January and June 1999. Despite the repatriation and resettlement process, the flow of people seeking refuge in Kenya has continued. Towards the end of 2000, Kenya hosted 230,000 refugees. An estimated 160,000 were from Somalia, more than 55,000 from Sudan and about 8,000 from Ethiopia, about 5,000 from Uganda and nearly 5,000 from other countries.

Kenyan authorities required most refugees to live in three designated camps near the village of Dadaab in the country's remote east, and in a camp in Northwest Kenya known as Kakuma, which is the study site of this doctoral study.

3.3 KENYA'S HEALTH CARE SYSTEM

Kenya recognizes that good health is prerequisite to the socio-economic development of the country. According to the Kenyan health policy framework (1994) and development plan (1997/2001), the government's policy objective in the health sector is to have affordable, effective and accessible health services that promote well-being, and improve and sustain the health status of all Kenyans. Therefore, health policies and strategies are aimed at reducing the incidence of disease and improving the health status of Kenyans as indicated above by increasing life expectancy, reduction in mortality rates, and improvement in the nutritional well-being of the population in general with special emphasis on children under-five years.

According to Kimalu (2001), Kenya inherited a three -tier health system during its independence in 1963 in which the central government provided services at district, provincial and national levels. (Font *et al.*, 2001) Missionaries provided health services at sub-district levels and the local government provided services in urban areas. This system operated until 1970, when the government

established a system of comprehensive rural health services in which the health centers became the crucial points from which preventive, promotive and limited curative services were delivered. But in the current system, alongside government services, missionaries and NGOs provide health services at delivery points that range from dispensaries to hospitals. The government's health care delivery system is pyramidal with the national referral facilities at two main hospitals which are Kenyatta National Hospital and Eldorat Teaching Hospital. These are followed by provincial, district and sub-district hospitals with health centers and dispensaries at the base. As public sector services encompass preventive, promotive, curative and rehabilitative services, non-governmental organisations (NGOs) and private providers concentrate on curative services with limited provision of preventive services.

3.3.1 Health facilities

The health facilities in Kenya comprise hospitals, health centers, health dispensaries and mobile clinics. Kimalu (2001) indicates that the number of health institutions in Kenya increased from 861 in 1967 to 2,131 in 1990 and again increased to 4,235 in 1999. The number of beds and cots in health facilities increased fourfold from 11,344 in 1963 to 52,186 in 1998. Most of the beds are in hospitals, with a few in health centers and nursing or maternity homes.

3.3.2 Health personnel

The Kenyan government have continued to train and staff health institutions with appropriate medical personnel. According to the report by Kimalu (2001), Kenya had 710 doctors, 26 dentists and 148 pharmacists in 1965. The number of medical personnel increased to 3,971 doctors, 685 dentists and 1,447 pharmacists by 1996. This increase is not yet sufficient to meet the needs for professional medical staff in Kenya.

3.3.3 Health reforms

Kenya's health reform includes decentralization of health delivery system through restructuring and strengthening of the Ministry's district level management capacity, cost sharing programmes and endorsement of primary health care principles Kimalu (2001).

3.3.4 Health financing

Health services and programmes in Kenya are financed by three main sources that include the government, the private sector and non-governmental organisations. The Kenyan Human Development report (UNDP, 1999) indicates that the health expenditure by the government is about 60% of what is required to provide minimum health services. This implies that health care delivery in Kenya is under-funded.

3.3.5 Health indicators

The Kenya Demographic Health Survey (MOH-Kenya, 1998) indicates that the infant mortality rate in Kenya has gone up from 51 per 1,000 live births in 1992 to 74 in per 1,000 live births in 1998. The under-five-mortality rate has shot up from 74 in 1992 to 90 in 1995 and 112 in 1998. The underlying factors according to Kimalu (2001) could be attributed to deterioration in the quality and quantity of health services in the country, and increased incidence of HIV/AIDS from 629 in 1992 to 1,506 in 1997 and National prevalence during the same period increased from 7.4% to 11.8% with the urban rate being higher than the rural rate (UNDP, 1999).

3.4 MALARIA IN KENYA

Malaria is a common and major public health problem in Kenya and is responsible for 30% of all new cases attending to the outpatient health facilities, of which 19% result in admission. The case fatality rates due to malaria ranges between 3.5-8.5%. Almost every person in Kenya is exposed to the risk of malaria infection and 70% of the population lives in malaria endemic areas of Kenya. Malaria is endemic in most parts of Kenya and is influenced by altitudes, which determine average temperatures and rainfall patterns. Transmission is unstable and sporadic and influenced by rainfall. Malaria in Kenya affects everybody and the most vulnerable group are children under-five, pregnant women, non-immune and semi-immune individuals. The vector responsible for malaria transmission in Kenya is *Anopheles gambiae*. The most common species is *Plasmodium falciparum*, while the less common species is *Plasmodium vivax* (Doherty *et al.*, 1999) Malaria epidemics in Kenya have become periodic since the 1980s. They have been characterized by transmission upsurges in the highlands in the Western and later semi-arid north eastern part of Kenya after the El Niño rains. It has been reported that epidemics of malaria in Kenya are usually due to El Niño rains and climatic changes (WHO, 1999).

3.5 DIVISION OF MALARIA CONTROL - KENYA

Division of Malaria Control (DOMC) was until October 2000 known as the National Malaria Control Programme (NMCP). The NMCP was created by the government of Kenya in 1994. NMCP was elevated to the status of a division to broaden the fight against malaria by the Kenyan government (MOH-Kenya, 2000). The DOMC is now directly under the department of preventive and promotive health services of the ministry of health. The DOMC has the overall responsibility for planning, and coordination of inputs and activities for malaria control at all levels. These include:

- Playing a lead role in defining and dissemination of the national malaria strategy and set annual milestones for the implementation of the national malaria strategy

- Responsibility for providing relevant links within the ministry and liaison with other ministries, development partners, UN agencies and NGOs to coordinate actions and inputs

- Developing a critical mass of resource persons at the provincial and district levels for capacity building for the implementation of the national malaria strategy

- Acting as the primary source of technical advice for the provincial and the district levels. Information for this task is generated through the various technical working groups. The technical working groups are constituted by the Ministry of Health to advise the DOMC and coordinate partners in specific components of the strategy

- Identifying areas for technical support and soliciting expertise available through RBM via WHO/AFRO to support capacity building work
- Participating in research, monitoring and evaluation of malaria activities

3.5.1 The national malaria strategy

There are four key strategic approaches to malaria control in Kenya (MOH-Kenya, 2000):

- Case management; guaranteeing people's access to quick and effective treatment
- Providing malaria prevention and treatment to pregnant women
- Ensuring the use of insecticide treated nets (ITNS) and other vector control measures by the at risk communities
- Improving malaria epidemic preparedness and response

3.5.2 Antimalarial drug policy in Kenya

The first-line treatment of malaria in Kenya for along time was CQ. As noted in the literature reviewed in Chapter one, (section 1.3), it was in 1978 that CQ resistance was first detected, and in 1989 CQ resistance was acknowledged by the NMCP at the MOH after eight descriptions of parasitological failure had been reported. Nevertheless, CQ was still retained as the first-line treatment of uncomplicated malaria until October 1997 when the draft guidelines of changing policy of the first-line treatment from CQ to SP were issued and a committee was formed to consider the implications of implementing this policy. It was not until August 1998 that the guidelines were officially launched. By the time of the launch of the revised national guidelines, more than 20 independent studies on CQ failure across the country had been recorded (Shretta *et al.*, 2000).

3.5.3 How antimalarial treatment policy was being implemented in Kenya

Despite the change in policy of the first-line treatment for malaria from CQ to SP in 1998, the mechanisms of communicating research evidence to those directly involved in wider health sector policy development and implementation was not very effective (Shretta *et al.*, 2000). The committee formed to oversee the implementation of the policy had little dialogue with the various stakeholders: executive board, the pharmacies board, provincial medical officers (PMOs), and providers of the proprietary forms of antimalarial drugs in Kenya. The implication of not including these stakeholders led to further delays in implementation of the new policy, especially at the district level. This is a likely reason why Kakuma health management continued to use CQ, even if the policy for the first-line treatment had been changed from CQ to SP. Furthermore, when SP was introduced, it was only available on prescription and could only be dispensed by qualified clinical staff. In addition, supplies of SP drugs were inadequate and not available at the lowest levels of the formal health sector (Kimalu, 2001; Shretta *et al.*, 2000). This encouraged the use of CQ, despite the change in antimalarial treatment policy in the country.

Towards the end of 1999, effective changes were made in the MOH and SP could be made available by recognised medical and paramedical staff without prescription. However, one sector that had not yet been addresses was the informal sector (e.g. drug shops), which are the major source of antimalarial drugs in the community as indicated by (Mwenesi, 1994). It was not until 2001 that SP became widely available in Kenya.

3.6 DISTRICT PROFILE (TURKANA)

Kakuma refugee camp is situated in Turkana district, which is the largest district in Kenya but with the smallest population (270,000). The district is located primarily in northwest Kenya and around Lake Turkana. Its geographical position and low population has led to its marginalisation, this being manifested in the lack of infrastructure, governmental development and relief activities. The Turkana area is semi-arid with a hot climate throughout the year. It rarely rains.

The Turkana people (the host) are the largest Nilotic group in East Africa. The majority have no education leading to high rate of illiteracy in the area. Most of Turkanas, both men and women, are pastoralists, who spend their days searching for adequate grazing and water for their livestock. They live a life of subsistence, herding cattle, goats and camels and survive primarily on milk, meat and blood. They engage in raiding, murder and stealing from other tribes. They live in small temporary huts built from grass or cartons, which in most cases are used by the whole family.

The Turkana live in extended family settings and, as is common in several ethnic groups in Africa, Turkana men marry several wives. Turkana women usually wear huge quantities of beads around their necks, along with an aluminum or brass neck ring (*alagam*). The Turkanas are skilled at carving wooden water troughs and containers. They mostly move on foot or use camels as their means of transport. Turkana district has experienced little rain in the last three to four years, which has led to severe famine, exacerbating the

already existing tension between the refugees and their hosts. Materially, the people of Turkana are undoubtedly less well off than the refugees of Kakuma camp. This situation leads to friction between the refugees and the indigenous population of the area.

Health-wise, the common diseases among the Turkanas are malaria, diarrhoea, RTI, brucellosis, tuberculosis and skin disease. In the past, malaria in Turkana district was not as common as it is in the last few years (Mwambu, 1986). The burden of malaria among the Turkanas is said to have increased and is now similar to that among the refugees in Kakuma. The refugees have been blamed for bringing malaria with them (Mwambu, 1986). This is not the first blame of its kind. In Southeast Asia, population movement across the Thai-Cambodian border is believed to have contributed greatly to the expansion of multiple drug resistance. Thus migrants were investigated actively for malaria parasites and treated if positive (Singhasivanon, 1999).

3.7 STUDY AREA (KAKUMA REFUGEE CAMP)

Kakuma refugee camp, situated in the Northwestern region of Kenya was established in 1992. It is a home to approximately 87,360 refugees from nine countries: Sudan, Somalia, Ethiopia, Liberia, Democratic Republic of Congo, Uganda, Rwanda, Burundi and Eritrea. It is located about 120 kilometers south of the Sudan/Kenya border and 95 kilometers south of Lokichokio. The area is extremely hot and the vegetation is sparse.

The camp was established following the influx of 20,000 Sudanese asylum seekers from southern Sudan who were fleeing the escalating civil war in their country in 1992. Having been established since 1992, Kakuma camp currently can be considered to be in a care and maintenance phase, rather than an emergency phase. However, new refugees still continue to arrive at the camp and it is estimated that about 400 refugees, mostly from Sudan, arrive in Kakuma every month (UNHCR, 1999). In addition, about 12,000 Somali Bantu

refugees have been moved from a camp in Kenya called Dadaab to Kakuma early 2003 (IRC, 2003). This has led to the increase of the refugee population in Kakuma camp.

The approximately 87,300 population in Kakuma camp comprises nine different nationalities and more than 40 different ethnic groups. In addition to the refugees, the area where Kakuma camp is established is the home to local Kenyan Turkanas. Persistent drought in the semi-arid area has caused a significant number of Turkanas to move closer to Kakuma, thus placing greater pressure on the health infrastructure.

Kakuma camp is situated in a marginal, drought-prone land that can barely support the refugees to carry out the agriculture activities which could make them self-reliant. Food supply is inadequate and irregular and there is an acute shortage of water. Kenya has no policy of local settlement and, in Kakuma, the refugees are almost 100% dependent on international humanitarian assistance for food and other basic supplies.

Refugees are not permitted to herd livestock, an activity that is monopolised by the local Turkana people. Freedom of movement is restricted outside the district. Employment options are extremely limited. Qualified refugees are integrated by aid agencies and the UN bodies working in the camp to provide service for their people in different available activities (working as teachers, health workers, watchmen, cooks, etc.) and they are paid only small monthly cash incentives. Refugee women in the camp who are interested in developing their skills undergo community development and are trained in income-generating activities such as tailoring, basket making, tie dying and soap making to promote self reliance. Men are involved in firewood trading, tailoring and shoe-making. Others are involved in businesses such as food and clothes selling, operation of phone calls, etc.

3.7.1 Administration, management and camp setting

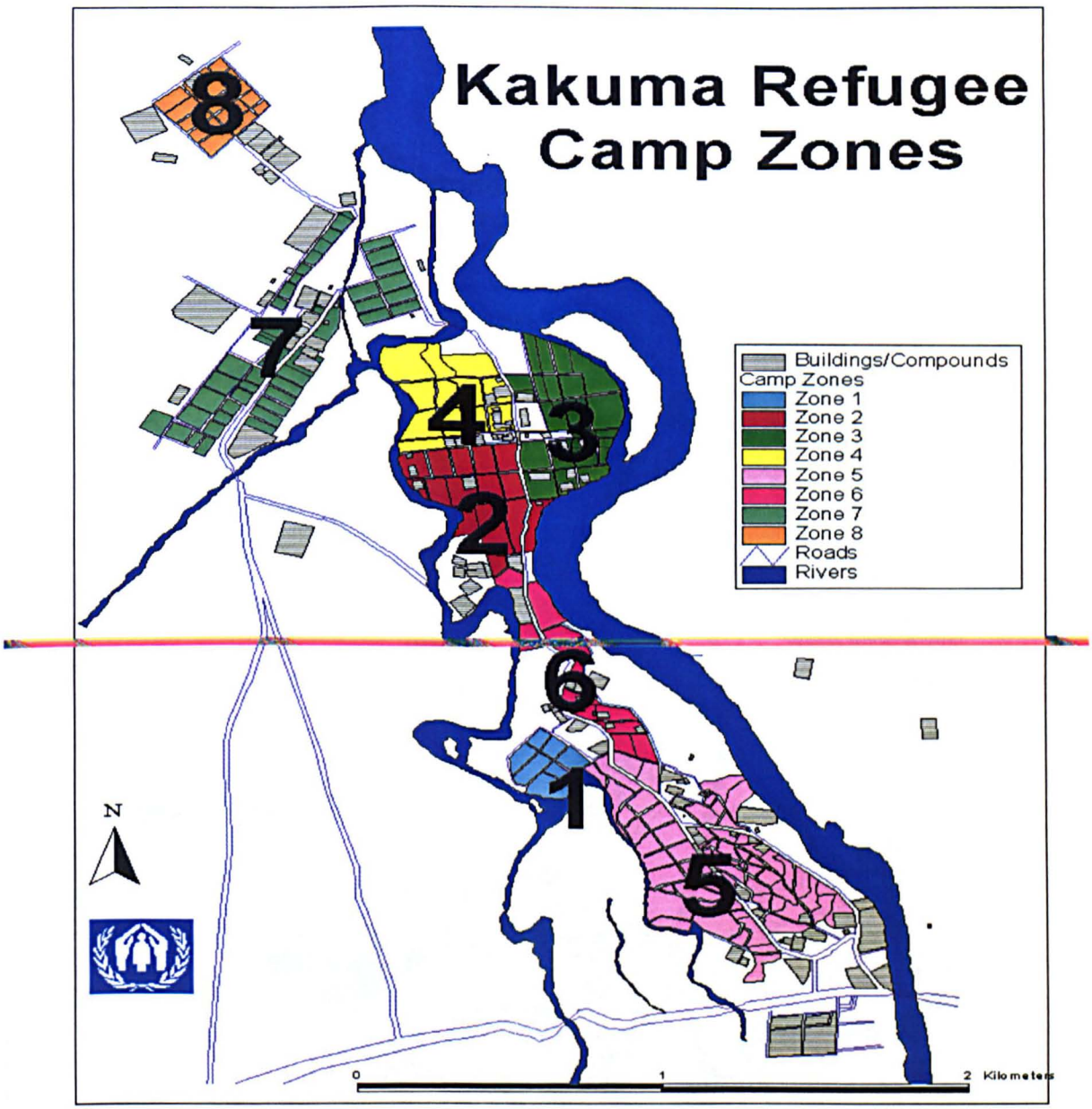
Kakuma refugee camp operates under the administration of UNHCR, in collaboration with the host government through its agency known as the National Refugee Secretariat (NRS), in the ministry of home affairs. UNHCR works closely with NRS and other agencies to coordinate assistance provided to the refugees. The UNHCR is the leading agency in the camp that plays the role of programme co-ordination, protection, monitoring, inter-camp transfers, inter-clan mediation, and documentation for resettlement and repatriation in collaboration with NGOs.

Although the camp is under the administration of UNHCR, it is being managed by an NGO called the Lutheran World Federation, Department of World Service (LWF/DWS). LWF/DWS was invited in 1992 by UNHCR to help establish Kakuma refugee camp. Since then, LWF/DWS still manages most of the activities in the camp, which include: Management of the reception center and new arrivals, storage and distribution of non-food items and other project supplies, such as firewood, shelter materials, construction materials, and water equipment, management of education programmes in the camp and management of community and social services such as sports, youth, women and cultural activities, and promotion of gender issues.

Since 1992, the camp has expanded to more than four times its original size and has been divided into three phases: Kakuma 1, Kakuma II, and Kakuma III (See Figure 3.2). In 1998, Kakuma II was opened, primarily to accommodate Somali refugees who were transferred from other camps within the country. In 1999, Kakuma III was opened to accommodate the continuous flow of refugees from Sudan and Somalia. The three phases of the camp are further sub-divided into zones, groups and blocks, and refugees are settled according to nationalities and ethnic groups.

Each nationality in the camp has a chairperson who liaises between NGOs and the refugees. The chairpersons are elected by the community to represent them. Each nationality also has a community center where activities are carried out and meetings held. At the periphery of the camp, there is a small river referred to as a 'laga' by the locals in the area. Below (Figure 3.3) is a map of Kakuma indicating the 8 administrative zones. Household structures within the camp are mainly tukuls (houses made of mud and roofed with grass or zinc) and tents.

Figure 3.3: Administrative map of Kakuma showing the division of the eight zones within the camp

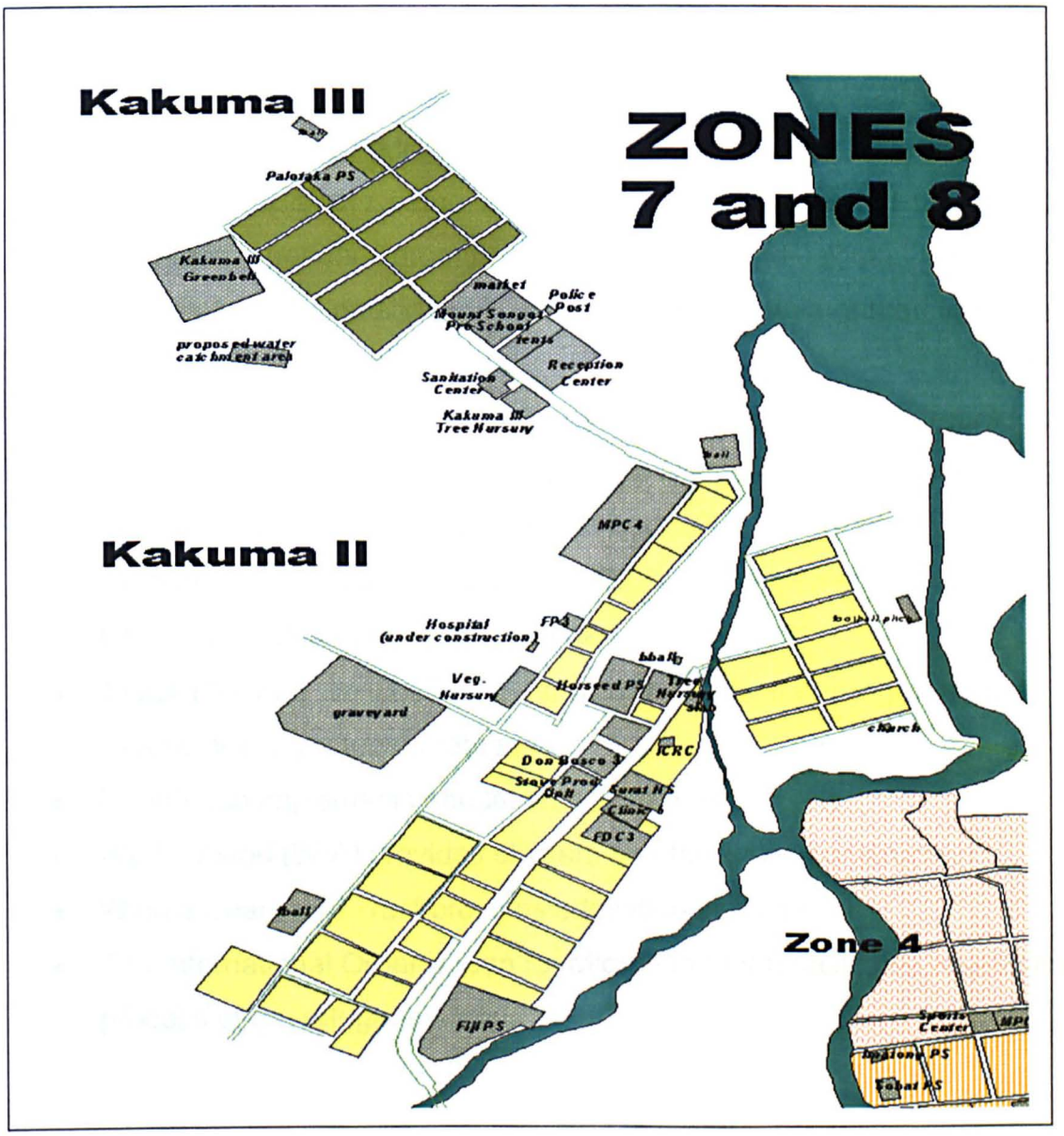


Source: Kakuma Refugee Camp GIS Project, Kenya (UNHCR, 2003)

Kakuma I was the first established section of the camp. It's the biggest section of the camp and covers zone 1 to 6. It has a population estimated at 55,062. Kakuma II is an extended section of the camp and is relatively small, and

located just next to Kakuma I. Its population is estimated at 6,225. Kakuma III however is an extended section of the camp that is located quite further from Kakuma I and II and covers zone 8. Its population is estimated at 26,073. The map indicated in Figure 3.4 below illustrates the extended section of the camp that covers Kakuma II and III.

Figure 3.4: Map showing the extended section of the camp (Kakuma II and III)



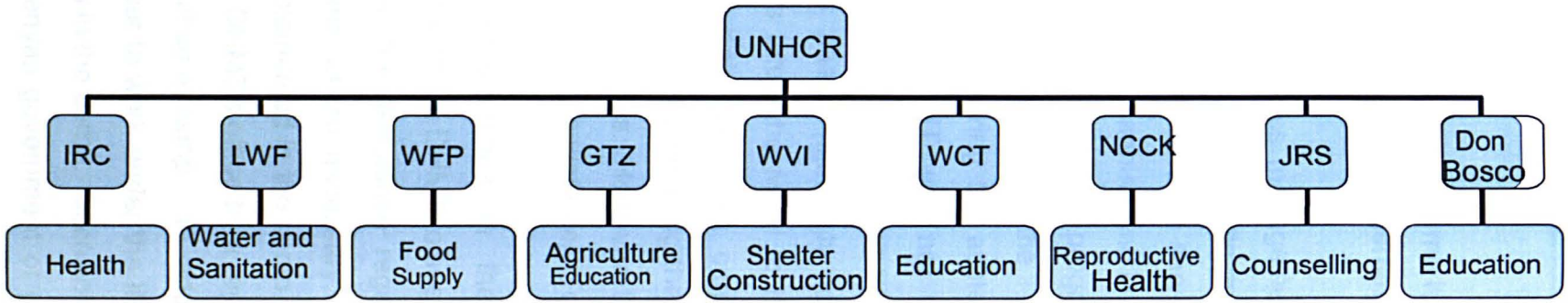
Source: Kakuma Refugee Camp GIS Project, UNHCR, Kenya (UNHCR, 2003)

3.7.2 Activities carried out by the implementing partners (NGOs)

In Kakuma refugee camp, there are nine international supporting agencies carrying out several complementary activities within the camp under the UNHCR-Kenya country programme. The agencies and their main responsibilities comprise of:

- International Rescue Committee (IRC) implements the following programmes: health activities, adult education, community-based rehabilitation programmes, and film aid educational programmes
- World Food Programme (WFP) supplies food
- Lutheran World Federation (LWF) is responsible for the general management of the camp and provides services related to water and sanitation, gender promotion, education, and youth and culture programmes. In addition, it is also involved in issues related to provision of security in the camp
- National Council of Churches Kenya (NCCK) provides basic reproductive services and spiritual counseling to the refugees in the camp, but they have withdrawn their activities due to budgetary problems.
- German Technical Cooperation (GTZ) implements agriculture and environmental education programmes
- Jesuit Refugee Services (JRS) provides counseling programmes to the psycho-socially affected refugees
- Don Bosco implements education programmes
- World Vision (WVI) provides shelters and facilitates construction
- Windle Charitable Trust provides education services
- The International Organisation for Migration (IOM) facilitates resettlement process of the refugees abroad

Figure 3.5: Organisational chart of NGOs in Kakuma refugee camp



3.7.3 Interaction between the Kakuma health care services management and the district health management team

Kakuma health care services management is made up of the UNHCR health coordinator and the IRC health coordinator, as well as the hospital administrator, IRC head of preventive and curative services, managers of the sub-health units and JRS manager. In the planning and implementation of health care services in the camp, including malaria control programmes, Kakuma health care services management collaborates with the DHMT, which includes a DOMC representative. Initially, during the acute phase when Kakuma refugee camp was established, the DHMT was not very involved in the monitoring and supervision of the health care services in the camp. But as the camp moved to the postemergency phase (although not really the case in terms of relief services) four years later, the MOH in the country signed a memorandum of understanding with Kakuma health care services management requiring all health activities in the camp, including the malaria control programmes, to follow the national health guidelines. However, the MOH did not have systems in place to see to it that the guidelines were being closely followed.

Regarding health programmes in the camp, the health care services management liaises with the DHMT to seek approval for their health programmes as well as to seek for assistance regarding implementation of health care services in the camp where necessary. The DHMT supervises and monitors health activities implemented in the camp, mainly through monthly health reports that are sent to the DHMT's office by a representative of the health care services management in Kakuma camp. In addition, the DHMT has seconded one Clinical Health officer to work under the IRC and assist in implementation of the health programmes in the camp. Occasionally, when there are donations in cash or kind from the Kenyan government or governments of other countries for the health services in the camp, they are channelled through the DHMT, under the

MOH to the health care services management in the camp. Representatives of Kakuma health care services management are also occasionally invited to attend meetings organized by the DHMT on health issues regarding the district.

3.7.4 Population in Kakuma camp

The total population within Kakuma camp is estimated at 87,360 (UNHCR, 2002b), of which, children under-five account for 15,053 (17.4% of total population). The Sudanese make up the majority (72%) of the camp population, followed by Somalis (15%) and other ethnic groups mentioned above. The camp, being only 120 kilometers from the Sudanese border, is the primary immediate source of assistance to many Sudanese from Eastern Equatoria, Southern-Sudan. Females in the camp account for 36,153 (41%) of the total population. Males are the majority and account for 51,207 (59%), most of whom are the unaccompanied boys (referred to as the lost boys) who were separated from their parents due to the civil war in Sudan. The population in the camp comprises four major religions: Catholics, Protestants (most of whom are Sudanese and Ugandans); Christian Orthodox (most of whom are Ethiopians and Eritrean) and Muslims (most of whom are Somalis). Each ethnic group speaks their own dialect so there are several and mixed languages spoken in the camp.

Students, including school children, account for 35% of total population. The literacy rate among Sudanese males is higher than in any other ethnic group in the camp. In contrast, Sudanese women have very high illiteracy rate due to the traditions and culture that discourage the education of women. The total number of students in Kakuma is 28,000, of which 5,590 are in the preschool section (age 3-6). Out of this 5,590 preschool population, 2,780 are girls. Primary school students account for 20,240, of which 7,118 are girls. Secondary school students account for 2,508, with some dropouts, leaving a total number of 2,053 of which 197 are females (LWF, 2001). Large numbers of students are unaccompanied,

making it difficult for them to pursue further education.

3.7.5 The security situation in Kakuma camp

The security situation in Kakuma can be described as poor and unstable. According to UNHCR, it has worsened since 2001, leading to reports of weekly murders and bringing the humanitarian services to a halt on several occasions. (UNHCR, 2002). Hostile interactions exist between the refugees and their hosts, especially among the Sudanese (Dinka) refugees and the Turkana (Host) who have similar value systems with regard to cattle keeping. Among these two communities, cattle ownership is a way of life, a means of trading and paying dowries and a manifestation of a person's worth. But the refugees are forbidden from keeping cattle in the camp. This has eroded both their material wealth and their sense of identity and worth.

The refugee settlement camps are clustered in an enclave within the indigenous communities of the Turkana nomads of Kenya, who live in poverty and deprivation and are sometimes armed with rifles. These indigenous pastoralists often wander through the refugee resettlements in search of pasture but at the same time they have been known to loot the refugee possessions. This encroachment usually leads to clashes involving death and looting. In addition, tensions erupt sporadically with the host community due to the competition over the scarce resources provided to the refugees. The latest reported clash in the camp broke out early May 2003 between the Turkana (host) and the Sudanese, leaving 11 people dead (UNHCR, 2002). Frequent clashes between the refugees and the host community have led the UNHCR and the NGOs in the camp to impose restrictions on movement within the refugee camps, which inhibits provision of essential services to the refugees.

Lack of security experienced by the refugees makes them unable to move freely within the camp during night hours, in turn making access to the emergency unit

in the hospital dangerous. Although IRC has two ambulances that assist in the movement of patients to the emergency unit in the hospital at night, not all patients have access to it. This is due to lack of adequate communication facilities (high frequency radio) in the camp that would enable refugees to call for an ambulance at night during emergencies. What usually happens in case of an emergency at night is that the refugee living far from the hospital usually go to the nearby police post (only six police post exist in the camp: three in Kakuma I, one in Kakuma II, and two in Kakuma III) and use the police radio to inform the clinical health worker on duty about the sick person. After a brief enquiry into the situation of the sick person, and when felt it's an emergency, an ambulance is sent to bring the sick person to the hospital. However, those who don't have a police post within the catchments area have to wait till morning, and carry the sick person to the hospital. Alternatively, they may try other means of first-aid (call a health worker, traditional healer if around in the area).

Violent clashes between ethnic groups of the same nationalities are also common in the camp. For example in 1997, fighting between the Sudanese Dinkas and Sudanese Nuers led to a number of deaths and more than 100 injuries. The fight was the result of the political background and long existing conflict during the pre-flight period. Likewise, in January 2003, there was much tension and several clashes between the different Somali clans and sub-clans. The tension and clashes were related, not only to political and cultural reasons, but also to social problems caused by jealousy towards the Somali Bantu who were to be resettled in the USA.

Apart from clashes between the refugees and the host community and among the refugees themselves, there are bandits along the roads to the camp, which makes travelling to and from the camp by road very insecure. This affects supplies to the camp. A number of incidents of armed robbery have occurred on the main road between Kakuma, Lodwar and Lokichokio (neighbouring districts),

resulting in loss of life. Ethnic clashes also occur, often leading to killing. In addition, the location of the camp near the warring countries favours proliferation of arms/weapons. This has worsened the security situation in the camp, as many refugees are well armed.

Domestic and sexual violence against females remains a big problem in the camp. Despite numerous programmes in the camp to address sexual violence, reported cases of rape have increased. Most of the rapes occur when females go out looking for firewood as the firewood distributed in the camp is insufficient. Female Genital Mutilation (FGM) is also forcefully practiced among some refugee nationalities, especially among the Somalis. On the other hand, Sudanese, girls and women are known to be abducted for the purpose of forced marriage as part of the Sudanese culture, and in the process, many of the girls and women get injured. Most of this domestic and sexual violence cases adds to stress and trauma among girls and women in the camp, many of whom end up being diagnosed with PTSD.

The security situation in the camp is under the control of the district officer in the area, the UNHCR, and LWF. These bodies are working in close cooperation with the local authorities to ensure improved security. Conflict resolution and peace initiative programmes between the refugees and the host community have been established. One of the NGOs (LWF) in the camp has been assigned the task of coordinating security patrols and surveillance activity in the whole camp, involving the Kenyan police. Conflict mitigation within the camp is a central theme in many of the LWF programmes and a system has been put in place to have a continuous night security patrol by armed police within the camp.

3.7.6 Employment and relations between employees and employers

About 30% of households in Kakuma have a person who is employed by an NGO implementing activities in the camp (UNHCR, 2002b). The government of

Kenya does not allow local integration of the refugees and they also do not allow refugees in the camp to be employed on the same terms as Kenyan nationals. Refugee front-line health care providers employed by NGOs in the camp are paid limited incentives in local currency that varies between, an equivalent of, 20 and 50 US dollars per month. On the other hand, national Kenyan front-line health care providers are paid incentives that vary between, an equivalent of, 60 and 150 US dollars per month. This difference in payment has caused problems for the relationship between the refugee employees and their NGO employers. The refugee employees blame the NGO employers for discriminating against them. They also perceive that they are being exploited by the NGO employers who use the refugee resources to lead a good life in the camp, while they (refugees) are left to suffer and endure the harsh living conditions of the camp.

The relationship between the refugee and Kenyan employees is poor as earlier stated in this chapter. The difference in incentives paid to the refugees and Kenyan employees often causes much tension and hatred between the two employees. Likewise, the limited incentives paid to the refugees are usually opposed by the local employees and local community that desires to see more Turkana (Kenyans) employed. This causes much tension among the local and refugee employees, especially among the qualified refugees, who feel they are being exploited because of their status as powerless refugees.

3.7.7 Collaboration among NGOs

The provision of services to the refugee community is a multi-sectoral affair that requires centrally controlled co-ordination as well as parallel consultation. One of the major challenges faced by the NGOs in offering services to the refugees in Kakuma is the fragmentation of services. Each NGO appears to be confined to its own programme and deals with it in a vertical manner. Integration often proves difficult as each agency considers itself an implementing partner to

UNHCR. Although UNHCR tries to co-ordinate more closely the activities of the various NGOs at play, its effort to strengthen collaboration among the NGOs appears inadequate.

3.7.8 Funding

The main donors financing humanitarian assistances in Kakuma camp are the US government, through the bureau of Population, Refugees, and Migration (PRM); United States Agency for International Development (USAID) and the Office of United States Foreign Disaster Assistance (OFDA). Although some NGOs receive direct donations, most of the donations are usually channelled through the Kenyan government to UNHCR, where it is then passed on to the respective NGOs.

3.7.9 Self-reliance

There are several barriers to increasing self-reliance in Kakuma camp, which necessitate continued large scale donor commitment to refugee aid. The location of the camp in a dry and semi-arid area does not favour agricultural production. In addition, rains have not been consistent and between 1999 and 2001, Kenya experienced its worst drought in almost 40 years. Turkana district was the worst affected by the drought. Insufficient access to land and the locally unreliable rainfall mean that most refugees cannot cultivate, except for a minority who can cultivate vegetables within the camp boundary using waste water from the camp taps. Other self-reliant activity carried out by some few refugee women are income generating activities such as production of various garments and embroidered articles, baskets, mats, and soap.

3.7.10 Humanitarian relief services

Kakuma was established as a temporary camp with the aim of providing acute emergency humanitarian relief services for the refugees, mainly, food, water, shelter and health care services. Unexpectedly, it is now in its 12th year

postemergency phase, and the refugees are still dependent on international assistance. Although some of the NGOs have struggled to shift their programmes towards developmental activities, most of them still provide emergency humanitarian assistance. Almost all NGOS are faced by limited budgets. Despite the increases in population, donor fatigue is manifested by stagnant and reduced funding levels, and the continued failures to meet minimum international humanitarian standards of service provision.

3.7.10.1 Food

In Kakuma, food distribution is inadequate. The refugees are still dependent on World Food Programme (WFP) for food, with the exception of a few who are engaged in business or who have relatives abroad sending them money on a frequent basis. The food distributed to the refugees is mostly maize, wheat flour, oil, beans, pulses or lentils. Complementary foods are occasionally given and these are usually potatoes and cabbages. The minimum food ration recommended by WHO per an average person per day is 2100 calorie standard (Sphere-Project, 2000). In 2002, the average ration per person per day in Kakuma camp was 1746 calories, and for the first five months of 2003, the average was 1988 calories (WFP, 2003). Although refugees rarely receive enough food to meet the 2100 calorie/day standard, there was a marked increase in food distributed to refugees in 2002-2003 compared to the previous years when food rations sometimes could decrease to 1,500 calories per person per day. The increase in the food ration over the last year is a result of the allocation of more funds toward the basic needs of the refugees by UNHCR. The majority of the refugees have no access to jobs and money, so that food is their only asset. Refugees often sell some of the food ration to supplement their diet by purchasing food not supplied in the general ration such as meat, other vegetables and groundnuts.

Given the food situation in Kakuma, the refugee population can be distinguished by categorising them into three categories:

- Those who have relatives abroad who regularly send them some money. The money helps them supplement their diet and gives them the possibility of starting a business
- Those who, besides the food rations, receive incentives because of their involvement with NGO programmes. These groups can also afford to supplement their diet and at least lead a life in the camp
- The overall majority of the camp population who are fully dependent on food rations in the camp. These are the poorest members of the refugee community. They experience reduction in food security, which further impoverish them, resulting in high rates of malnutrition. Some of these refugees resort to theft, banditry, possession of additional ration cards illegally, and fraud, all as a coping mechanism.

3.7.10.2 Water supply

The supply of water in the camp is the responsibility of an NGO called LWF/DWS. This NGO operates and maintains the camp water-system, which consists of more than 10 active bore holes, three booster stations, 18 reservoir tanks, all linked with an extensive piping system which supplies water to the camp population through tap stands located within 500 meters of each group settlement in the camp. There are more than 500 taps serving the refugee population in Kakuma. Although some refugees access less than 10 liters of water per average person per day, an amount below the minimum standard of 15-20 liters per average person per day (Sphere, 2000), supply of safe water to the refugees in the camp has greatly improved in recent years. The increase in water supply, as in food ration, is due to allocation of more funds towards the basic needs of the refugees by UNHCR.

3.7.10.3 Housing

Most of the houses in Kakuma camp are sub-standard. They are poorly constructed and are mostly one room houses, made from mud with a small triangular wall of about 20 cm. The houses are roofed with worn-out UNHCR

tarpaulin and grasses, while others are surrounded by bits of plastic filling, with lots of openings. During the rainy season, most of the houses leak and some even collapse. The few standard houses in Kakuma are those built in 2002 to accommodate Somali Bantu refugee who were transferred from Dadaab camp situated in the eastern part of Kenya to Kakuma.

3.7.10.4 Health and health care system

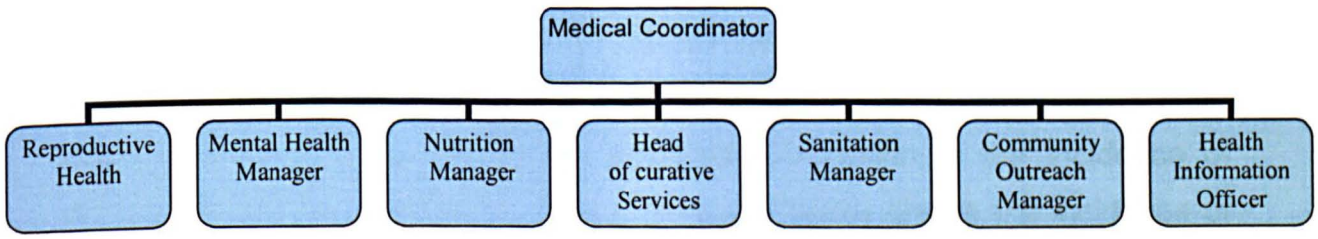
Upon the establishment of Kakuma refugee camp in 1992, the International Rescue Committee (IRC), a humanitarian agency, immediately initiated a Primary Health Care (PHC) programme at the request of the United Nations operations Lifeline Sudan, UNHCR, and the Kenyan Government. The health system in the camp has been developed around the concept of Primary Health Care, with facilities and programmes designed to provide preventive and curative health care in close proximity to all refugees.

The established health facilities in the camp consist of a 90 bed hospital, which situated in Kakuma I. The hospital comprise of: a minor operating theatre, an out-patient department (OPD), male and female inpatient wards for acute contagious diseases, a tuberculosis ward, a laboratory, a pharmacy and a supplementary-feeding center in the hospital. In addition to the hospital, there is a mental health department and five community-based outpatient health facilities, referred to as clinics. Three of the clinics are based in Kakuma 1, and one each in Kakuma 2 and 3. The clinic in Kakuma 3 has been expanded because of the large population in the area. The five clinics provide curative outpatient services, preventive health care services, ante and post-natal care, as well as the EPI programme, family planning services, and nutrition programmes. They are also centers for a community outreach programme focusing on preventive health care and education, and a community based mental health programme that provides a clinic for case management where patients are assessed and treated and where psychological support is provided through group and individual counselling. Available human resources in the general health sectors consist of 25 national and international staff, and about

500 refugee staff, distributed within the hospital, the outpatient health facilities and the community outreach programme. The host communities have one hospital (Kakuma mission) that is well equipped and serves as a referral in the area.

The overall health programme in the camp is coordinated by a medical coordinator who does most of the administrative work. The outpatient health facilities fall under the management of the head of the curative services. Figure 3.6 below indicates the managerial organogram of the health system in the camp.

Figure 3.6: Managerial organogram of primary health care programme in the camp



3.7.10.4.1 Treatment outlets for febrile illness in the camp

Three treatment outlets are available for treatment of febrile illness in the camp. These are (i) the health facilities (hospital and clinics) which have essential drugs such as analgesics, SP, quinine, Septrim and CQ; (ii) shops which sell legal (aspirin, paracetamol) and illegal drugs such as antibiotic and antimalarial injectables (quinine, penicillin), and (iii) traditional herbalists that sell traditional medicine believed to treat febrile illness.

3.8 A REVIEW OF MALARIA INCIDENCE IN KAKUMA CAMP

In this section, malaria incidence among the refugees in Kakuma camp is reviewed. The magnitude of morbidity and mortality arising due to malaria is quantified. In order to examine the extent of the problem of malaria in the camp, it is necessary to summarise the reports and records reviewed in the health facilities in Kakuma refugee camp, which are the responsibility of IRC and JRS. IRC is responsible for the primary health care programme in the camp, while JRS does some counseling for refugees with mental health problems.

3.8.1 Malaria disease-morbidity

Malaria, diarrhoea and respiratory tract infection (RTI) have been reported as the major health problems and common diseases among the refugees in Kakuma camp. Of these communicable diseases, malaria is the most common endemic disease in the camp, with estimates by presumptive' clinical diagnosis ranging from 25% to 56% in both the general and under-five total populations in the camp (IRC, 2000). Despite the camp being situated in an arid area, malaria incidence is very high, and there is seasonal variation in the incidence of reported malaria in the camp. Table 3.1 to 3.6 below shows the incidence of disease per month, obtained through presumptive' clinical diagnosis, in the general and under-five populations from the year 2001 to 2003 with malaria presenting high incidence.

Table 3.1: Incidence of disease in the general population, January to April 2003

Disease	*Jan*	*Cases per 1,000 /month*	*Feb*	*Cases Per 1,000 /month*	*Mar*	*Cases per 1,000 /month*	*April*	*Cases per 1,000 /month*
Malaria	5,615	67	6,840	*82	4,487	53	5,083	60
*RTI	4,046	49	4,102	49	4,196	50	4,399	52
Diarrhoea	2,094	25	1,740	20	1,326	16	1,979	24
Measles	1	0	2	0	0	0	0	0
Meningitis	0	0	0	0	0	0	0	0
*STDs	476	6	660	8	576	7	726	9
Others	7,297	87	7,657	92	4,058	48	7,645	90
Total	**19,529**	**234**	**21,001**	**251**	**14,643**	**174**	**19,832**	**235**

Source: IRC health facility records (IRC, 2003)

*Note: The sharp increase in malaria morbidity rate in February was due to increase in the number of refugees as the Somali Bantus were moved from Dadaab camp in eastern Kenya, to Kakuma. early February 2003

*RTI: Respiratory Tract Infections

*STDs: Sexually transmitted Diseases

Table 3.2: Incidence of disease among the under-five population, January to April 2003

Disease	*Jan*	*Cases Per 1.000 /month*	*Feb*	*Cases Per 1.000 /month*	*Mar*	*Cases Per 1.000 /month*	*April*	*Cases Per 1.000 /month*
Malaria	2,347	178	2,399	181	1,976	148	2,222	161
*RTI	2,151	142	2,155	162	2,382	179	2,507	182
Diarrhoea	1,343	102	1,008	76	795	60	1,244	90
Measles	0	0	1	0	0	0	0	0
Meningitis	0	0	0	0	0	0	0	0
*STDs	0	0	0	0	0	0	0	0
Others	2,232	80	1,777	134	1,177	88	1,197	87
Total	**8,073**	**502**	**7,340**	**576**	**6,330**	**475**	**7,170**	**520**

Source: IRC health facility records (IRC, 2003)
*RTI: Respiratory Tract Infections
*STDs: Sexually transmitted Diseases

Table 3.3: Incidence of disease in the general population January to June 2002

Disease	*Jan*	*Cases per 1,000 /month*	*Feb*	*Cases per 1,000 /month*	*Mar*	*Cases per 1,000 /month*	*April*	*Cases per 1,000 /month*	*May*	*Cases per 1,000 /month*	*June*	*Cases per 1,000 /month*
Malaria	5,334	62	5,463	64	4,855	57	4,741	55	7,802	91	6,713	104
Pneumonia	816	10	849	10	869	10	696	8	997	12	538	6
Diarrhoea	1,564	18	1,909	22	2,125	25	3,130	36	2,541	29	1,673	20
Measles	0	0	2	0	0	0	0	0	1	0	0	0
Meningitis	0	0	0	0	0	0	0	0	0	0	0	0
*STDs	293	3	333	4	449	5	307	4	786	9	734	9
*RTI	4,113	48	4,734	55	3,839	45	3,122	37	5,572	65	4,680	55
Others	694	8	6,459	76	6,413	75	6,256	73	6,216	73	5,282	62
Total	**12,814**	**150**	**19,749**	**231**	**18,550**	**217**	**18,252**	**213**	**23,915**	**280**	**19,620**	**256**

Source: IRC health facility records (IRC, 2002)
*STDs: Sexually Transmitted Diseases
*RTI: Respiratory Tract Infection

Table 3.4: Incidence of disease among the under-five population January to June 2002

Disease	*Jan*	*Case per 1,000 / month*	*Feb*	*Case per 1,000 /month*	*March*	*Cases per 1,000 /month*	*April*	*Cases per 1,000 /month*	*May*	*Cases per 1,000 /month*	*June*	*Cases Per 1,000 /month*
Malaria	2,393	196	2,698	213	2,069	159	1,867	143	3,471	333	2,776	267
Pneumonia	508	42	614	48	671	52	453	35	673	65	274	26
Diarrhoea	824	68	954	75	1,190	91	1,910	147	1,752	169	983	95
Measles	0	0	2	0	0	0	0	0	1	0	0	0
Meningitis	0	0	0	0	0	0	0	0	0	0	0	0
*STDs	0	0	0	0	2	0	0	0	15	1	15	1
*RTI	2,193	179	2,454	194	1,840	141	1,524	117	1,930	185	2,391	230
Others	1,828	150	1,400	110	1,432	110	1,710	131	1,927	185	1,290	124
Total	**7,746**	**634**	**8,122**	**640**	**7,204**	**554**	**7,464**	**573**	**9,769**	**939**	**7,729**	**743**

Source: IRC health facility records (IRC, 2002)
*STDs: Sexually Transmitted Diseases
*RTI: Respiratory Tract Infection

Table 3.5: Incidence of disease in the general population
July to December 2002

Diseases	*Jul*	*Cases per 1,000 /month*	*Aug*	*Cases per 1,000 /month*	*Sep*	*Cases per 1,000 /month*	*Oct*	*Cases per 1,000 /month*	*Nov*	*Cases per 1,000 /month*	*Dec*	*Case per 1,000 /month*
Malaria	5,062	77	5,218	79	5,955	68	4,665	62	5,717	70	3,980	48
Pneumonia	841	13	682	10	570	6	262	4	754	9	393	5
Diarrhoea	1,287	20	1,321	20	1,526	23	1,911	26	2,027	24	1,406	18
Measles	0	0	0	0	0	0	0	0	1	0	3	0
Meningitis	0	0	0	0	0	0	0	0	0	0	0	0
*STDs	383	6	495	7	582	7	444	6	366	4	310	4
*RTI	3,265	50	3,722	56	4,089	47	3,581	48	3,672	45	2,817	34
Others	5,504	84	6,713	101	7,211	82	6,652	89	10,591	129	6,193	75
Total	**16,342**	**250**	**18,356**	**277**	**20,487**	**233**	**17,515**	**234**	**17,515**	**213**	**14,896**	**181**

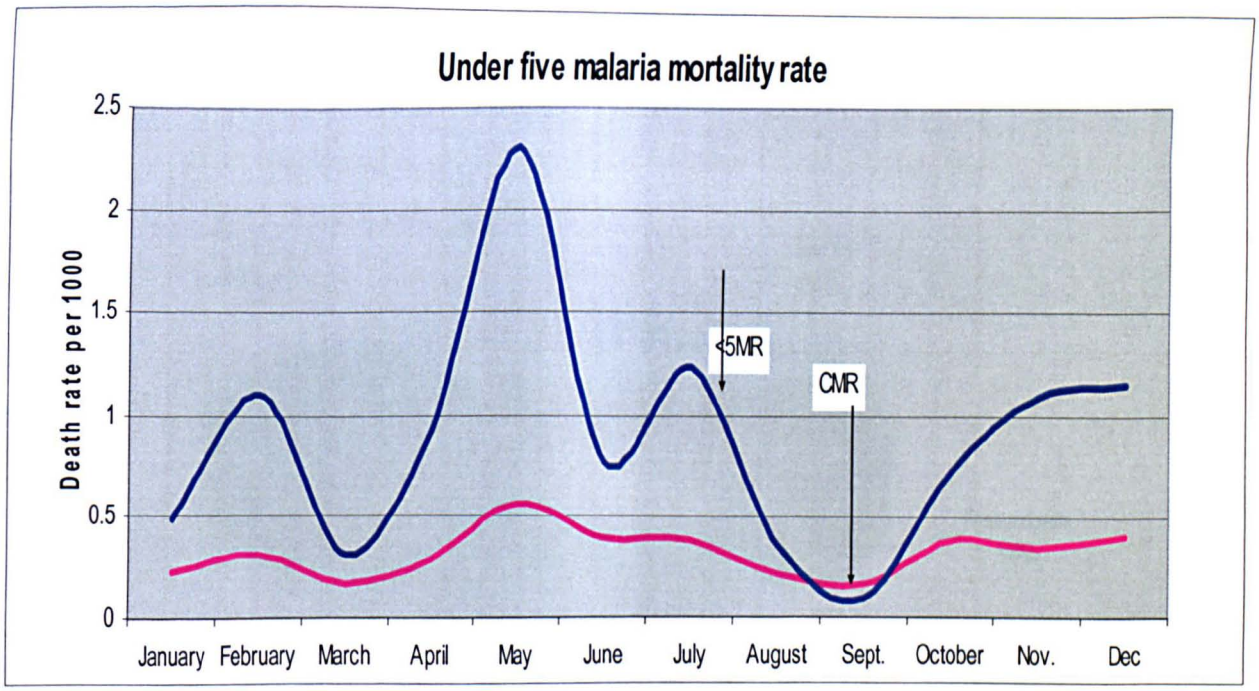
Source: IRC health facility records (IRC, 2002)
*STDs: Sexually Transmitted Diseases
*RTI: Respiratory Tract Infection

Table 3.6: Incidence of disease among the under-five population, July to December 2002

Disease	*Jul*	*Cases per 1,000 /month*	*Aug*	*Cases per 1,000 /month*	*Sept*	*Cases per 1,000 /month*	*Oct*	*Cases per 1,000 /month*	*Nov*	*Cases per 1,000 /month*	*Dec*	*Cases per 1,000 /month*
Malaria	1,615	153	1,859	167	2,045	151	1,784	129	2,214	141	1,568	100
Pneumonia	368	35	298	27	250	18	121	9	510	33	224	14
Diarrhoea	625	60	862	78	1,168	86	1,142	82	1,340	86	860	55
Measles	0	0	0	0	0	0	0	0	1	0	2	0
Meningitis	0	0	0	0	0	0	0	0	0	0	0	0
*STDs	0	0	0	0	0	0	0	0	0	0	0	0
*RTI	1,633	155	1,877	168	1,986	146	1,734	125	1,939	124	1,370	88
Others	1,262	120	1,446	130	1,646	121	1,629	117	2,429	155	1,806	115
Total	**5,503**	**522**	**6,342**	**569**	**7,095**	**523**	**6,410**	**462**	**8,433**	**539**	**5,830**	**372**

Source: IRC health facility records (IRC, 2002)
*STDs: Sexually Transmitted Diseases
*RTI: Respiratory Tract Infection

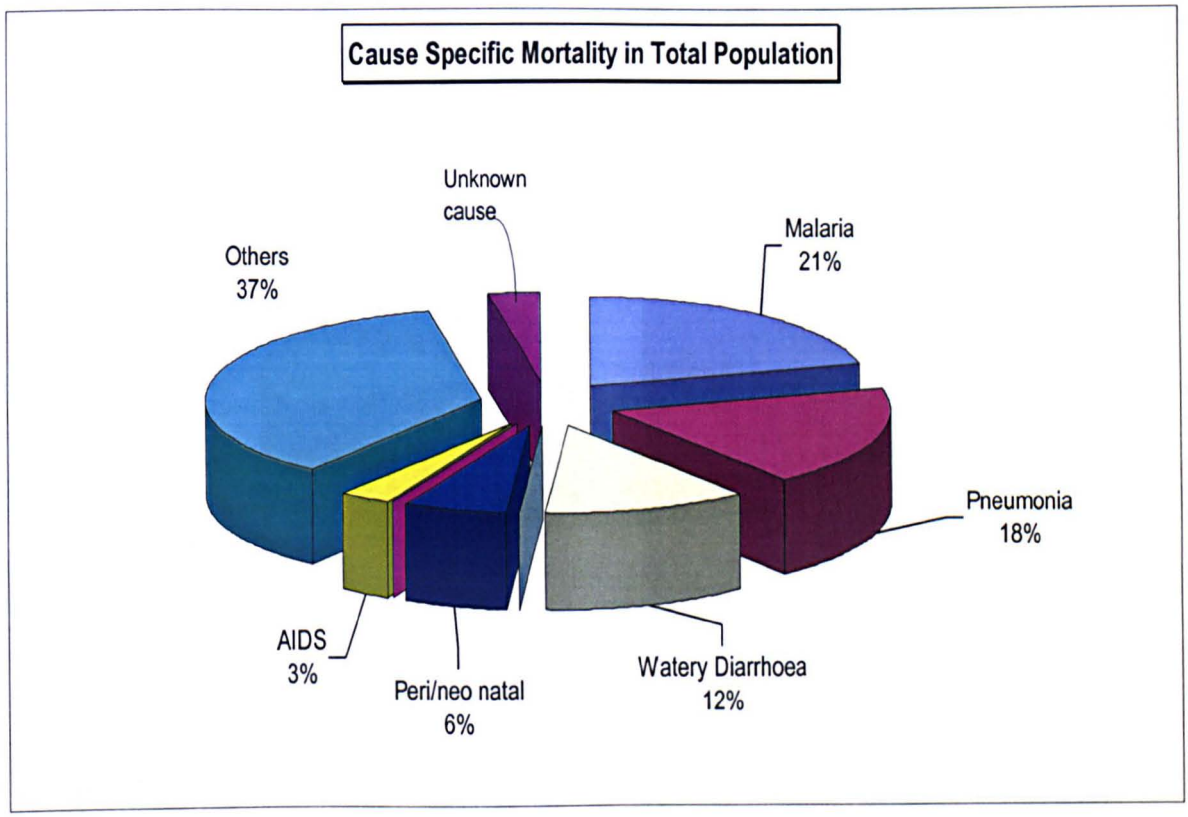
Figure 3.7: Mortality rates recorded at the health facilities Kakuma, 2002



Source: IRC health facility records (IRC, 2002)

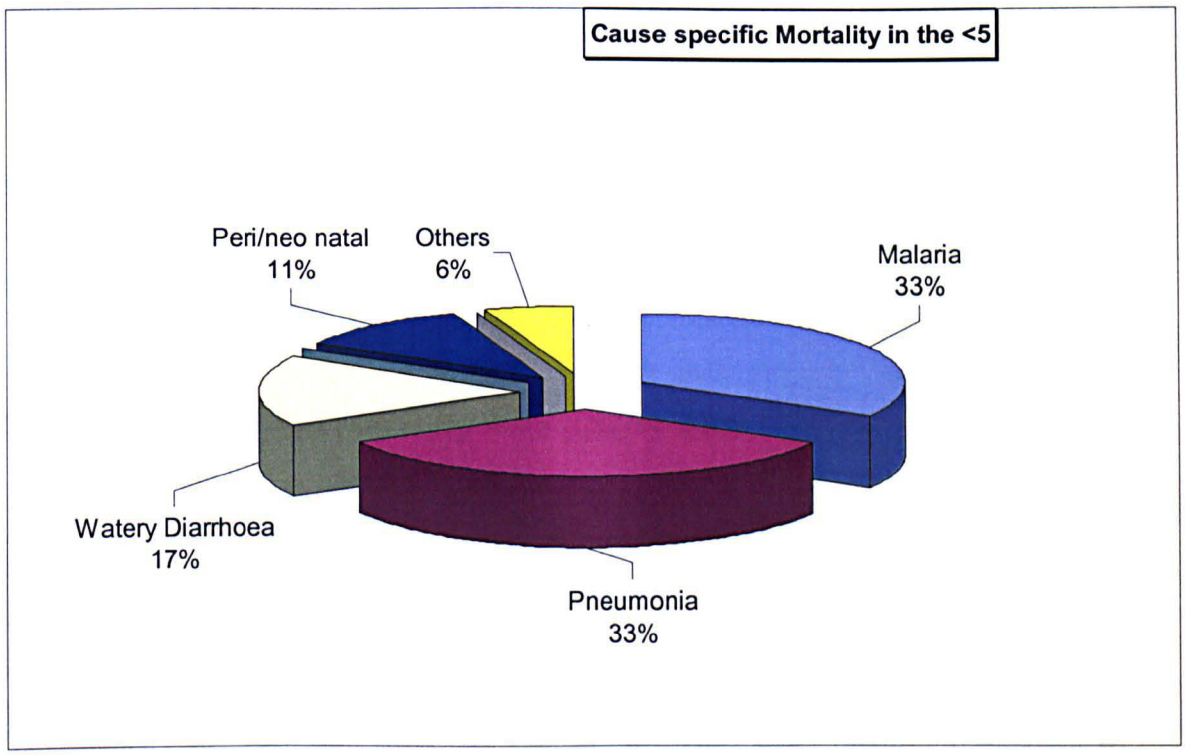
Figure 3.7 above shows a relatively high mortality rate, especially in children under-five, in the rainy season which is between the months of April and June 2002. The common causes for mortality in both the total population and the under-five in the camp are malaria, diarrhoeal diseases and respiratory tract infections. The cause- specific mortality in the total and under-five population has been illustrated in the Tables 3.9 and 3.10 below.

Figure 3.8: Cause specific mortality in total population, Kakuma, 2002



Source: IRC monthly report (IRC, 2002)

Figure 3.9: Cause specific mortality in the under fives, Kakuma, 2002



Source: IRC monthly report (IRC, 2002)

3.8.2 Mortality rates recorded at the health facilities in the camp - 2001

Tables 3.7 to 3.9 below illustrate crude mortality rates and cause-specific mortality of the general population of the camp and that of the under-five population specifically in the camp from January to December 2001. These data on mortality were obtained from the IRC health facility records.

Table 3.7: Crude Mortality Rate (CMR), 2001

Month	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
Number of deaths	21	9	14	25	12	24	8	16	22	20	25	23
Death rate/1000[1]	0.3	0.1	0.2	0.3	0.2	0.3	0.1	0.2	0.3	0.2	0.3	0.3

Female / Male ratio: 8:15 (1:1.9) Source: IRC health facility records (IRC, 2001)

Table 3.8: Under-five Mortality Rate (CMR), 2001

Month	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
Number of deaths	7	3	7	13	7	9	3	6	8	9	9	8
Death rate/1000[1]	0.8	0.3	0.7	1.3	0.6	0.8	0.3	0.5	0.6	0.6	0.6	0.5

Female: Male ratio: 3:5 (1:1.6) Source: IRC health facility records (IRC, 2001)

Note: [1] The calculations conducted by IRC have been based on per 1,000 people (IRC, 2001).

As noted in Chapter One (see section 1.6), a common way for defining a public health emergency is by using epidemiological terms. When the CMR exceeds 1/10,000 population per day, the situation is termed as an emergency. This is a common situation in the acute phase of an emergency. When the CMR drops below 1/10,000 population per day, the situation is no longer considered acute and these lower rates are commonly found in the post emergency phase of a complex emergency (Meek *et al.*, 2000; Williams, 2001).

Table 3.9: Cause-specific mortality in the total population, January to December 2001

Diseases	Jan No.%	Feb No.%	Mar No.%	Apr No.%	May No.%	Jun No.%	Jul No.%	Aug No.%	Sep No.%	Oct No.%	Nov No.%	Dec No.%
Malaria	4(19)	0	0	2 (8)	0	2(8.3)	0	2(12.5)	3(14)	2(10)	2(8)	3(13)
Pneumonia	2(9.5)	0	1(7)	4 (16)	1(8)	1(4.2)	0	2(12.5)	2(9)	3(15)	1(4)	2(9)
Watery diarrhoea	2(9.5)	1(11)	1(7)	2 (8)	2(17)	0	2(25)	0	2(9)	3(15)	2(8)	2(9)
Bloody diarrhoea	0	0	0	0	0	0	0	0	0	0	0	0
Measles	1(4.8)	0	0	0	0	9	0	0	1(4.5)	1(5)	0	1(4)
Meningitis	1(4.8)	0	0	1 (4)	0	0	0	1(6)	0	0	0	0
Cholera	0	0	0	0	0	0	0	0	0	0	0	0
Maternal death	0	0	1(7)	0	0	0	0	1(6)	0	0	1(4)	0
Peri/neonatal	2(9.5)	2 (22)	4(29)	3 (12)	1(8)	8(33.3)	1(12.5)	3(19)	4(18)	2(10)	3(12)	4(17)
Malnutrition	1(4.8)	0	0	0	0	1(4.2)	0	0	1(4.5)	1(5)	2(8)	0
*Others	8(38)	6(67)	7(50)	13 (52)	8(67)	12(50)	5(62.5)	7(44)	9(41)	8(40)	14(56)	11(48)
Total	**21(100)**	**9(100)**	**14(100)**	**25(100)**	**12(100)**	**24(100)**	**8(100)**	**16(100)**	**22(100)**	**20(100)**	**25(100)**	**23(100)**

*Others include: HIV related, alcohol intoxication, and cardiomyopathy, and died at home (unknown cause)
Source: IRC health facility records (IRC, 2001)

Table 3.10: Cause-specific mortality among the under-five population January to December 2001

Diseases	Jan No.%	Feb No.%	Mar No.%	Apr No.%	May No.%	Jun No.%	Jul No.%	Aug No.%	Sep No.%	Oct No.%	Nov No.%	Dec No.%
Malaria	2(29)	0	0	1(8)	0	1(11.1)	0	1(17)	2(25)	1(11.1)	2(22.2)	1(12.5)
Pneumonia	1(14)	0	1(14)	3 (25)	1(14)	1(11.1)	0	1(17)	1(12.5)	2(22.2)	0	1(12.5)
Watery diarrhoea	1(14)	1(33)	0	2 (17)	2(29)	1(11.1)	2(66.6)	0	1(12.5)	0	1(11.1)	2(25)
Bloody diarrhoea	0	0	0	0	0	0	0	0	0	0	0	0
Measles	0	0	0	0	0	0	0	0	0	0	0	0
Meningitis	0	0	0	1 (8)	0	0	0	0	0	0	0	0
Cholera	0	0	0	0	0	0	0	0	0	0	0	0
Maternal death	0	0	0	0	0	0	0	0	0	0	0	0
Peri/neonatal	1(14)	2(67)	4(57)	3 (25)	1(14)	4(44.4)	1(33.3)	3(49)	1(12.5)	2(22.2)	2(22.2)	2(25)
Malnutrition	0	0	0	0	0	1(11.1)	0	0	0	1(11.1)	0	0
Others	2(29)	0	2(29)	3 (25)	3(43)	1(11.1)	0	1(17)	3(37.5)	3(33.3)	4(44.4)	2(25)
Total	**7(100)**	**3(100)**	**7(100)**	**13(100)**	**7(100)**	**9(100)**	**3(100)**	**6(100)**	**8(100)**	**9(100)**	**9(100)**	**8(100)**

* No Number of deaths (% of the total number of deaths) Source: IRC health facility records (IRC, 2001)

CHAPTER 4: PRELIMINARY STUDY

4.1 INTRODUCTION

An initial study was designed to provide preliminary information on knowledge about malaria, and the factors influencing malaria treatment-seeking behaviours among the refugees in Kakuma camp. This preliminary study provided lessons learned in the design of the main study

4.1.1 Specific Objectives

To determine the extent to which different refugee households perceive malaria as a major health problem, their knowledge on its cause and symptoms, their recognition of complications, and behaviour in seeking treatment when malaria and its complications are suspected

To determine the social, cultural, political and economic factors influencing treatment-seeking behaviour for malaria in the refugee camp

To determine the average delays in seeking appropriate treatment and whether reliance on self-treatment (self-treatment here is referred to treatment at home using a variety of sources such as drug retailers, neighbours, traditional healers etc.) and other related factors that contribute to delays in receiving appropriate treatment

4.2 METHODOLOGY AND STUDY DESIGN

This chapter presents the methods and results of the preliminary research, which was undertaken through focus group discussions, general observations and

interviews over a period of 8 months from May-December 2001. The researcher spent the first month of the research explaining the purpose and importance of the study and seeking research clearance approval from the concerned bodies in the UNHCR and IRC head offices in Nairobi and sub-office in Kakuma, as noted in the previous chapter.

The second month of the study was spent identifying, selecting and training research assistants. The selection process included meeting with IRC health workers and key community members who assisted the researcher in identifying local candidates among the refugees with experience in research, surveys and assessments. The candidates, most of whom were health workers, were interviewed by the researcher and the best nine were selected and trained for one week on research methodology, including data collection techniques. Being refugees themselves and living and working in the camp, most of the selected research assistants had good rapport with study participants. A topic guide was developed for the discussions and piloted to a group of 7 refugees from different nationalities in the camp. The topic guide was then modified to align more strongly with the desired objectives. In the third month of the research, study participants were selected by the research team using purposive sampling methods directed to each of the nationalities residing in the camp.

In addition, a group of adult Sudanese youth (youth here was defined according to the Sudanese context) aged between 15 and 24 years was included in the study. This was an important sampling decision as young people under 25 years old represent about one third of the total population in the camp, most of them having arrived in the camp unaccompanied by adults.

The accommodation of the refugees in the camp is arranged according to nationality and ethnicity by GTZ, in collaboration with UNHCR. This arrangement facilitated the identification, selection and involvement of the different nationalities and ethnic groups in the study. Data were collected over a period of three month and preliminary analysis was conducted in the last

month of the study period. The study involved youth and adult participants only and the participants were refugees who had been in the camp for not less than two years.

The researcher had a break of one month during the study period following insecurity in the camp and she spent the one month period within the camp, training the community health workers on health education techniques as a measure to strengthen the IRC health education outreach programme. Eighteen focus group discussions (FGD) were conducted. Each FGD was composed of 8-15 participants and was carried out by a team of 4 people. This included a facilitator, who was the principal investigator, a note taker, an observer and a translator. Since the study included different nationalities, more than 6 different translators were needed in the study but for each FGD, the most appropriate translators were used for direct translation. Before the FGDs, the study team underwent one week training on their specific roles and on FGD methodology. Each FGD lasted up to 2 hours.

Before each discussion, the aim of the study was explained to the participants, privacy and confidentiality was assured and consent sought verbally. It was clearly explained to them that they could withdraw at any time if they wished. Each nationality in the camp has its specific community centres, and the focus group discussions were held in those community centres accordingly.

The piloted topic guide (see appendix 6) was employed for the discussions. Each session started with a general discussion of the situation in the camp and problems faced by the participants. After each discussed topic, a summary of opinions was made by the facilitator, which was agreed upon by all the participants before moving to the next question.

Data collected were analysed by developing categories consistent with those articulated in the topic guide. Quotations were selected for the purpose of

illustrating expressed opinions when reporting the results as provided in the next section.

4.3 RESULTS FROM THE PRELIMINARY STUDY

4.3.1 Characteristics of the preliminary study population

The preliminary study comprised of 202 participants (refugees) who were divided into 18 groups. The groups and number of study participants are illustrated in Table 4.1 below. For each nationality, except the Somalis, there was one FGD with women and one FGD with men. For the Somalis, there was one male and female group of Somali Bantus and an additional group of Somali Mogadishu women. While among the Sudanese, there was one additional FGD with the youth, unaccompanied 'lost boys' who ran from the war and were separated from their families.

Table 4.1: Groups and number of study participants

Group	No of women	No of men	Youth (males)	Total
Sudanese	13	12	15	40
Ethiopian	11	9	0	20
Somali Mogadishu	14	0	0	14
Somali Bantu	15	12	0	27
Congolese	11	9	0	20
Ugandan	11	10	0	21
Burundian	12	8	0	20
Rwandan	11	8	0	19
Eritrean	12	9	0	21
Total	110	77	15	202

Participants' ages ranged between 15 and 54. Most of them had formal basic education. Among the Sudanese participants, one third of the males and females were educated to the intermediate or secondary level and about two thirds to the primary level. Only two males were educated to the University level and less than a third had no formal basic education. Over half of the male and female participants from Eritrea and almost all male participants from Burundi were educated to the primary level, while only about three male participants from Eritrea were educated to the intermediate level. This was not the case with participants from Ethiopia who were either not educated at all or educated to the intermediate level.

With regards to the Somalis, the majority of participants had no formal education and less than one quarter of the male participants was educated to the primary level. Most the participants from Congo, Rwanda and Uganda, regardless of gender, were educated to the primary level and very few male participants were educated to the intermediate or secondary level.

Regarding participants' marital status, the majority from Sudan, Uganda, Somali, Ethiopia and Eritrea were single, separated, divorced, or widowed. Very few participants were married and lived together. But most of the participants from Congo, Rwanda and Burundi were married.

Almost all participants from Eritrea, Rwanda, Burundi and Congo were jobless, although a few were NGO employees. However, over half of the Sudanese participants were locally employed within the camp and one third of them were students. Half of the participants from Ethiopia and one third from Somali were self employed or business people, the rest were jobless.

Concerning religion, almost all of the participants from Sudan, Uganda, Congo, Burundi and Rwanda were Christians (Catholics, Protestants, etc), while almost all participants from Somali were Moslems. The majority of the participants from Ethiopia and Eritrea were Orthodox (Christian).

The majority of participants, most of who were the Sudanese, had been in the camp for 6-9 years, while participants from other nationalities had been in the camp for 2-5 years. Almost half of the participants from all nationalities and ethnic groups were heads of households and only a few were dependents.

4.3.2 Participants' perception of malaria illness

Following the introductory discussion, the groups talked about how they perceived and defined malaria illness and what local terms they used to describe malaria. The majority of participants from all groups, with the exception of a few Somalis, perceived malaria as a serious illness of great burden and associated it mostly with fever or 'hot body'. The common local term used by almost all the groups in the camp, with the exception of a few Somalis, to describe malaria or febrile illnesses is the same biomedical word 'malaria'. Some of the participants from the different groups pronounced it as 'malariya'.

'Malaria' is the term commonly used in the place of origin of the Sudanese refugees. Since the Sudanese constitute the majority of the total population in the camp, they appear to have influenced the other nationalities to adopt the word 'malaria'. On the other hand, the majority of the Sudanese participants mentioned that each ethnic group in Sudan also has a local term used to describe febrile illnesses. However, Sudan contains more than 100 ethnic groups, and in the 1950s they adopted the word 'malaria' from the British. Since then, 'malaria' been used as a common term to describe febrile illnesses among all the ethnic groups. A few Somalis associated both diarrhoea and fever with malaria and the local term they use to describe malaria is 'Homa wa Ishala'.

4.3.3 Malaria in the refugees' original area of settlement

Participants from all groups were asked if malaria was a problem back home in their original area of settlement. Almost all participants from the different

nationalities, with the exception of a few Somalis and Burundians, agreed that malaria was a major health problem in their original area of settlement. They mentioned that malaria in the camp differed from the one back home, mostly in terms of severity and response to treatment. They described malaria in Kakuma as very 'sharp' and 'poisonous'. In illustrating the severity of malaria in Kakuma, one of the Somali women from a high malaria endemic area, had this to say:

"No, no, no, this is not malaria. It should be another disease. It comes in a way that you feel it in your bones and goes to your head and can make you mad. You hear many women in the camp here aborting at the early stage. This is because of the malaria. People die here because of the malaria. Back home, there is nothing of this kind". (Somali Bantu woman)

Most of the participants from all groups, the majority being the Sudanese, mentioned that because of the severity, malaria in Kakuma camp caused typhoid, jaundice, and abortion. As a result, they reported experiencing frequent attacks of malaria compared to the attacks they experienced back home. They indicated using a variety of treatment for malaria in their area of origins that comprised of official and non official sources such as public health facilities, drug stores, and traditional medicines. Most of them indicated having used the same malaria drugs, (most CQ) given to them in the camp, back home in their place of origin and said the drugs were very safe and effective in treatment of malaria. Their concern was why the same drugs didn't have the same rate of effectiveness in Kakuma camp. Some few participants thought the drugs in the camp were not the original drugs. Others thought the drugs must have been expired. In highlighting the difference between the effectiveness of malaria drugs back home compared to the ones in the camp, one of the Sudanese women from one of the malaria endemic areas of south Sudan had this to say:

"In my country, we use CQ for treating malaria and after 3-5 days of treatment, a person recovers immediately. But here, it is just too much. We take CQ as if we are taking food and still continue to suffer from the malaria. Can't you people discover what it is about this so called malaria"? (Sudanese woman)

In contrast, some of the Somali Bantus and Somali Mogadishu reported that back home in their area of settlement, there are areas with no or low prevalent malaria but in agricultural areas, malaria is of high burden. A few participants from Somali Mogadishu and Somali Bantu said they come from areas with less malaria, and as a result, they are suffering from malaria in the camp. The remaining Somali's admitted having malaria back home, which to them was not as poisonous as the one in the camp. Meanwhile Burundians had mixed opinions. A few of them who stayed near the lake back home experienced a severe malaria burden, saying it was almost related to the one in Kakuma camp. But the majority of the Burundians said malaria is not very common in towns where they have lived so they never experienced malaria before like what they are experiencing in Kakuma. One of the women from the malaria non-endemic area of Burundi had this to say:

"Now I can understand when people complain of malaria because I now know what it means to have malaria. Before, I used to wonder why many people complain about malaria, which I believed was never a serious disease". (Burundian woman)

4.3.4 Malaria as a common health problem in Kakuma camp

When asked about the common diseases in the camp, the majority of participants from all the different nationalities involved in the study-mentioned malaria, respiratory diseases and diarrhoea as the most common diseases with high prevalence and burden. Malaria was mentioned by all groups as the leading disease and a major health problem in the camp followed by diarrhoea and respiratory diseases. In expressing their views about malaria as a problem in the camp, one of the Ethiopian men had this to say:

"Health workers in the camp keep on talking about 'AIDS' prevention and not much or almost none about malaria prevention, forgetting that malaria in the camp is a major health burden here, even more than AIDS".(Ethiopian man)

A few female participants from Sudan, Somali, Ethiopian and Burundi mentioned diarrhoea as the leading major health problem followed by malaria and respiratory tract infection (RTI) and a minority of women from Uganda and Eritrea mentioned RTI as the leading major health problem in the camp, especially in children followed by diarrhoea and malaria.

4.3.5 Perception about malaria and its complication

Perception about malaria cause, signs and symptoms, complications and prevention, showed some variation among the different nationalities. However, in general, study participants from all the nationalities involved had at least some knowledge about malaria. Tables 4.2-4.9 below summarise knowledge of the participants about malaria and its complications. The lists in each box are from the most frequently mentioned (top) to least frequently mentioned (bottom) causes, signs and symptoms, complications and methods of prevention.

Table 4.2: Sudanese' perceptions of malaria and its complications

Group	Malaria causes	Malaria signs and symptoms	Malaria complications	Suggestions for malaria prevention
Sudanese women (13)	-Hot weather -Worries & stress -Hunger -Mosquito -Dirty & unboiled water -Poor sanitation -Evil spirit	-Headache -Fever -Body weakness -Vomiting -Bad dreams -Shivering -Lost of appetite -Mouth sores -Don't know	-Madness -Jaundice -Abortion -Body weakness -Rolling eyes -Lack of sleep -Death -Don't know	-Provide effective malaria drug -Provide mosquito nets -Provide insecticides -Improve diet -Move camp to a cool area -Adequate water -Improve sanitation
Sudanese men (12)	-Worries/stress -Mosquito -Hot weather -Doing heavy work -Don't know	-Fever -Body pain -Headache -Nausea and vomiting -Palpitation -Bitter mouth taste -Shivering	-Mental problem -Typhoid -Jaundice -Depression -Lost of weight -Diarrhoea	-Provide bed nets -Provide well balanced diet -Improve health facility treatment -Move the camp to a productive location
Sudanese youth (15)	-Poor diet and hunger -Stress -Hot weather -Mosquito -Walking in standing water -Row food -Poor sanitation -Weather change -Blood transfusion -Don't know	-Headache -Body weakness -Vomiting -Convulsion -Lost of appetite -Feeling cold -Shivering -Lost of energy	-Jaundice -Yellow fever -Typhoid -Frequent coughing -Lack of blood in the body -Madness -Sleepless nights	-Provide balanced diet -Provide local medicine -Clear bush & dirt -Provide insecticides -Provide malaria prophylactic -Screen blood before transfusion

Table 4.3: Somalis' perceptions of malaria and its complications

Group	Malaria causes	Malaria signs and symptoms	Malaria complications	Suggestions for malaria prevention
Somali Mogadishu women (14)	-Stress and frustrations -Hot weather -Lack of enough food -Poor shelter -Poor water and sanitation system -Mosquito -Don't know	-Typhoid -Headache -Fever -Vomiting -Diarrhoea -Joint pain -Coughing -Back pain -Dizziness -Don't know	-Mental disorder -Anaemia -Abortion -Convulsion -Stomach extension -Death -Dizziness -Rolling eyes -Don't know	-Provide balanced diet -Provide mosquito nets -Improve health facility services -Provide effective malaria drugs -Provide mosquito insecticides -Improve shelters -Provide adequate water -Improve sanitation -Don't know
Somali Bantu women (15)	-Hot/dusty weather -Poor diet -Hunger -Stress/worries -Mosquito -Poor sanitation -Dirty water -Bewitches -Don't know	-Fever -Diarrhoea -Headache -Body rash -Joint pain -Stress -Sleepless night -Neck pain -Cough	-Typhoid -Jaundice -Death -Mental disorder -Stomach extension -Don't know	-Need for more food -Move the camp to a cool productive area -Use of mosquito nets -Provide insecticide sprays -Provide local and modern malaria medicine -Clean environment
Somali Bantu men (12)	-Hot weather -Poor food -Worries -Mosquito -Poor sanitation -Poor water system -Stress -worries -Over working -Don't know	-Hot/cold body -Heat in the stomach -Diarrhoea -Feeling hungry frequently -Headache -Dry mouth -Joint pain -Vomiting -Mouth sores	-Typhoid -Lost of blood -Body weakness -Jaundice -Mental disorder -Coma -Don't know	-Adequate water -Improve sanitation -Improve shelter and tents -Provide mosquito nets -Provide insecticide sprays -Provide traditional medicine/herbs -Don't know

Table 4.4: Ethiopians' perceptions of malaria and its complications

Group	Malaria causes	Malaria signs and symptoms	Malaria complications	Suggestions for malaria prevention
Ethiopian women (11)	-Hunger -Stress -Hot and dusty weather -Mosquito -Dirty environment -Eating left over food	-Hot/cold body -Body weakness -Headache -Diarrhoea -Vomiting -Cough -Pricking in the heart	-Typhoid -Abortion -Jaundice -Brucellosis -Death -Don't know	-Provide mosquito nets -Provide balanced diet -Improve health service -Move camp to a cool productive area -Drink local herbs /medicine frequently
Ethiopian men (9)	-Hot & cold weather -Poor diet -Poor sanitation -Mosquito -Stress -Over working	-Fever -Headache -Body weakness -Vomiting -Diarrhoea -Lost of weight -Frequent heart beat	-Madness -Typhoid -Jaundice -Don't know	-Provide good food -Avoid hot and dusty weather -Provide mosquito bed nets -Provide spraying insecticide -Clean environment

Table 4.5: Congolese' perceptions of malaria and its complications

Group	Malaria causes	Malaria signs and symptoms	Malaria complications	Suggestions for malaria prevention
Congolese women (11)	-Stress -Dusty hot weather -Poor food -Mosquito -Poor shelter -Unclean water	-General body pain -Headache -Weather change -Lost of appetite -Vomiting -Small rashes in the nose	-Mental disorder -Typhoid -Madness -Anaemia -Convulsion -Abortion -Death	-Provide mosquito-net -Provide smear lotion against mosquito -Provide mosquito sprays -Improve environment -Introduce malaria control programme in the camp
Congolese men (9)	-Weather -Poor diet -Frustrations -Mosquito -Sanitation -Typhoid	-Hot/cold body -General body weakness -Headache -Anaemia -Lost of appetite -Cough -Lost of voice	-Jaundice -Mental disorder -Stomach distension -Goitre -Don't know	-Improve treatment in the health facility -Improve water and sanitation -Provide effective drug and local medicine

Table 4.6: Ugandans' perceptions of malaria and its complications

Group	Malaria causes	Malaria signs and symptoms	Malaria complications	Suggestions for malaria prevention
Ugandan women (11)	-Poor diet -Weather change (hot/cold) -Stress -Drinking unboiled water -Eating uncooked food -Mosquito -House congestion -Standing water -Rubbish hips	-Fever -Headache -Joint pain -Vomiting -Shivering -Heat in the stomach -Sores round the mouth -Abortion in women	-Depression -Typhoid -Paralysis -Deafness -Back pain -Don't know	-Provide well balanced diet -Provide mosquito nets -Provide spraying insecticides -Improve management of malaria in the camp -Improve sanitation and water
Ugandan men (10)	-Weather, cold/hot -Stress and frustration -Poor diet -Mosquito -Poor sanitation -Poor housing	-Fever -Lost of appetite -Body weakness -Headache -Restlessness -Feeling thirsty	-Typhoid -Mental disturbances -Death -Don't know	-Provide mosquito nets -Provide enough medicine for treatment -Improve water and sanitation -Improve housing

Table 4.7: Burundians' perceptions of malaria and its complications

Group	Malaria causes	Malaria signs and symptoms	Malaria complications	Suggestions for malaria prevention
Burundian women (12)	-Hot/cold weather -Stress -Hunger -Mosquito -Don't know	-Fever -Vomiting -Lost of appetite -Body weakness -Joint pain -Shivering -Headache	-Typhoid -Diarrhoea -Madness -Abortion -Sudden loss of weight -Death -Don't know	-Provide mosquito nets -Provide medicine for prevention -Get rid of dirty water -Provide malaria vaccination -Provide effect drug for treatment
Burundian men (8)	-Hunger -Worries & frustration -Weather change (cold/hot) -Poor sanitation -Mosquito	-Hot/cold body -Lost of appetite -Vomiting -Joint pain -Stress -Lack of sleep -Body rash -Cough -Loss of weight	-Typhoid -Jaundice -Mental disturbances -Fever -Squinted eyes -Don't know	-Provide mosquito-net -Provide effective drugs and herbs -Improve sanitation and food (diet)

Table 4.8: Rwandans' perceptions of malaria and its complications

Group	Malaria causes	Malaria signs and symptoms	Malaria complications	Suggestions for malaria prevention
Rwandan women (11)	-Mosquito -Weather change (Cold/hot) -Poor sanitation -Dirty water -Poor food	-Hot Body -Vomiting -Lost of appetite -Stomach discomfort -Frustration -Cough -General body weakness	-Madness -Jaundice -Lost of weight -Stomach extension -Don't know	-Provide mosquito nets -Provide insecticide spray -Provide malaria vaccination -Provide effective malaria drug -Improve water and sanitation
Rwandan men (8)	-Mosquito -Stress -Weather change (Cold/ hot) -Poor food	-Lost of appetite - Fever -Vomiting -Continuous headache -Just not feeling well -General body pain	-Typhoid -Jaundice -Shaky body (fits) -Anaemia	-Provide mosquito bed-nets -Improve diet -Provide mosquito insecticides -Improve sanitation -Move the camp to a cool weather area -Improve malaria management in the camp

Table 4.9: Eritreans' perceptions of malaria and its complications

Group	Malaria causes	Malaria signs and symptoms	Malaria complications	Suggestions for malaria prevention
Eritrean women (12)	-Weather change (hot/cold) -Stress -Hunger -Mosquito - Poor environment	-General body weakness -Fever -Headache -Vomiting -Lost of appetite -Stomach discomfort -Heart pain -Stomach extension	-Typhoid -Madness -Jaundice -Convulsion -Don't know	-Provide good balance diet -Move the camp to a cool weather area -Provide mosquito nets -Improve treatment -Provide effective drug
Eritrean men (9)	-Poor diet -Weather (Hot/Cold) -Mosquito -Worries -Stress -Eating green vegetables	-Fever -Headache -Joint pain -Poor sanitation and water -Vomiting -Diarrhoea	-Typhoid -Jaundice -Mental problem -Yellow fever -Convulsion -Cough	-Provide effective malaria drug -Provide bed nets and spraying -Improve health service

In the above Tables (4.2-4.9), more similarities than difference can be noted concerning factors mentioned by the different nationalities with regards to knowledge about malaria. The most frequently reported causes of malaria by the majority of participants in each group included weather, worries, stress, and hunger/poor diet. While less frequently reported causes of malaria included mosquitoes, poor sanitation, poor water, doing heavy work, walking in dirty water, blood transfusion, eating left over food, evil spirit, house congestion and poor shelter. During the FGDs, a few participants from Somali and Burundi reported coming from areas in their country with less or no malaria and said they were not acquainted with malaria. Among these participants, there were a few who said they had no idea about the cause of malaria. In expressing their views, Burundi and Somali women had this to say:

"Malaria is not common in all parts of Burundi and I come from areas in Burundi with no malaria, so I really don't have knowledge about malaria and how people get it. (Burundi woman).

"I think we are lucky back home not to have much malaria. I never knew what causes malaria until I came to Kakuma *and was told that the hot sun is the one causing the malaria but I don't know really how true this is (Somali Bantu woman).*

Regarding knowledge about malaria signs and symptoms, many similarities can be seen in factors mentioned as the signs and symptoms of malaria by the different groups and nationalities. These tend to correspond well with biomedical recognised signs of malaria. Fever or hot body were the first and second most frequently mentioned signs of malaria by most participants from all nationalities, with the exception of Somali Mogadishu women who mentioned fever as the third most frequently sign and symptom of malaria and the Congolese women who never mentioned fever at all but mentioned body pain. General body weakness or joint pain was mentioned a sign and symptom of malaria by the majority of participants from Sudan, Uganda, Congo, Eritrea and Ethiopia.

The Somali differed from other nationalities in that typhoid and/or diarrhoea were among the top 3 signs and symptom of malaria mentioned by all the Somali groups. Less frequent factors mentioned by the different groups and nationalities as signs and symptoms of malaria included fits (convulsions), cough, deafness, back pain, death, sudden lost of weight, squinted eyes, anaemia, dizziness, lost of consciousness, stomach distension & goitre. In expressing their views on the signs and symptoms of malaria, the following had this to say:

"Malaria has many signs and symptoms but I always know I have malaria when my body is hot and my joints are paining". (Sudanese woman)

"Each time I have an attack of malaria, the signs and symptoms differ. Sometimes I have fever (Huma) and headache, other times I have joint pain and lost of appetite and there times when I have severe diarrhoea".(Eritrean woman).

Mental disorder also termed as madness or depression was widely recognised by participants as a complication of malaria. Other common complications reported frequently by all participants, regardless of their ethnicity were typhoid and jaundice. Less frequent complications of malaria mentioned included yellow fever, cough, spontaneous abortion, depression, coma, diarrhoea, lost of weight, sleepless nights, rolling eyes, brucellosis, stomach extension, dizziness, loss of blood and death. Suggestions for malaria prevention by the majority of participants was attributed to the need for mosquito nets, insecticide spraying, improvement of water and sanitation, provision of well balanced diet, provision of effective malaria drug and local medicines, and improvement of malaria management and health services in the camp. Other suggestions reported by a minority included, provision of smear lotion against mosquitoes, introduction of malaria control programmes in the camp, provision of malaria vaccination, and provision of good shelter. A few participants from the Somalis, Burundians and Ethiopians did not have any suggestions saying they believed malaria cannot be prevented in the camp.

4.3.5.1 Perceptions about malaria transmission

All of the participants were asked how malaria was transmitted. Most of the female participants from Somali, Ethiopia, and Eritrea mentioned that malaria can not be transmitted directly from one person to another. While the majority of participants, both males and females, from Uganda, Sudan, Rwanda and Congo said malaria can be transmitted from one person to another. However, the most frequently mentioned causes of transmission were weather, dust, stagnant water, poor diet, left over food, and blood transfusion. The mosquito was less frequently mentioned as a cause for malaria transmission.

4.3.5.2 Perceptions about dosage of malaria treatment

Study participants from all the nationalities were asked of their experiences with antimalarial and were asked how they administered the drugs in their treatment of the disease. All study participants, with a few exceptions from Eritrea and Rwanda, mentioned having taken CQ tablets before, and over half of the study participants from all groups indicated taking SP.

Knowledge of correct dosing with antimalarial drugs appeared to be quite low. More than half from all groups (the majority were women) who had taken CQ before reported administering a dosage that was incorrect compared to the WHO recommended guidelines. Reported usage of SP appeared to correspond more closely with recommended guidelines. Influencing factors reported by participants as contributing to incorrect drug administration were: feeling well after taking some few tablets and, thus, no need to waste the drug by completing it but rather keep it for the next malaria attack, no recovery seen while taking the drug, thus, no need to complete it because it has proved ineffective, the drug's taste is nasty and difficult to swallow, and the drug has several intolerable side effects e.g., itching, nausea, dizziness.

4.3.6 Malaria self-recognition

Study participants from all groups were asked if they felt they were able to recognise when they had malaria (mild and uncomplicated). A minority from Sudan and about half of the participants from the remaining groups said they were able to recognise when they had malaria in the camp. However, most of the participants from Sudan and almost half of the participants from the remaining groups, most of who were women, said that before, when they were in their areas of origin, they used to easily recognise malaria at the early stage of the disease, but in the camp, they were finding it difficult to recognise malaria at the early stage. When asked reasons for not being able to easily recognise

malaria at the early stage of the disease the majority of the Sudanese participants, and a few participants from the remaining groups, said since their displacement they had continuously been feeling unwell due to the violence, insecurity and instability that they had undergone. This, they said, had made it difficult for them to differentiate between the stress, worries and frustrations they were experiencing and the signs and symptoms of malaria.

A minority from Somali, both males and females, said that they were finding it difficult to recognise malaria because they had not encountered much malaria back home, so they were not used to the malaria signs and symptoms. In expressing their experience and feelings with regards to malaria recognition, quotes from a few participants from malaria endemic countries are indicated below. These quotes illustrate how some of the study participants feel unable to recognise mild malaria due to the violence, insecurity and instability they experienced.

"My daughter, how will I know if I have malaria? Since I have been displaced, I have never been myself. My 4 kids were killed while I was running. My husband's whereabouts is not known. I just ran with this one kid, this one you see and life in the camp here is very difficult. My mind is not at peace. I know this is what is causing me to be sick and it can't be cured unless I see my children again. Unless I go back to the type of family life I used to live, I will never become well again. So how do you expect me to know having malaria? I know malaria is a problem here in the camp but the situation I am in is more than the malaria you are asking me about". (Sudanese lady)

"It is when you are in a normal state of health and mind that you can recognise any abnormality in your body. But in my current state, I am telling you the truth. It is difficult for me to know I have malaria. Unless I am down completely is when I can suspect malaria and visit the health facility". (Rwandan lady)

"If I tell you that I know when I have malaria, I will be lying to you. Yes, I used to before when I led a happy life. But not now any more. Let me tell you, I have been staying in

hiding for more than 6 month in my village in Sudan. The security people were looking for me to kill me. Because I disappeared from the house, my family was badly tortured and I lost 2 of my children who were already big boys. I later managed to make my way out and came to the camp, losing everything. Since then, I am not myself. I am already a sick person. And as a result, it is difficult for me to easily know if I am sick from other diseases, unless at the very late stage." (A Sudanese men)

"When I was back home, anytime I am not feeling well, I will immediately realise and seek treatment. But now those feelings are no longer there after the crisis that happened to me and the family in Sudan. My daughters were raped in my eyes, my husband was taken and since then we never saw him again. I am sure he has been killed. I am suffering with the children in the camp here, having poor shelter and the food is not enough. I am not myself and I can't even recognise when I have malaria. One day I was carried from my house here to the hospital without knowing myself. They said it was the dangerous type of malaria. I was given medicine with drip and become well. (Sudanese lady)

"When I was with my parents in Sudan, I had no worries. Whenever I get headache or body pain or realise any other signs and symptoms, I rush and tell my mother who is most of the time in the house. She will immediately either take me to the hospital or clinic or give me some medicine. But now I have no one to turn to. I get headache continuously and it is difficult for me to know if it is headache because I think a lot of my parents whose whereabouts I don't know or if it is due to malaria. Unless I start vomiting and have continuous diarrhoea, I will never know I have malaria". (Sudanese youth)

4.3.7 Malaria treatment-seeking behaviours

Study participants were asked about their treatment-seeking patterns with regards to their actual and preferred first source of malaria treatment in the camp when they recognised malaria. Here, opinions on different sources of treatment were elicited.

4.3.7.1 Actual and preferred first source of malaria treatment among male participants from the different nationalities

The actual first source of malaria treatment used in the camp by the majority of the male participants from the different nationalities involved in the study was the outpatient public health facility. However, traditional treatment was the most common actual first source of malaria treatment used in the camp by the Somali Bantu male participants and home treatment by the Rwandan male participants. None of the male participants from the different nationalities mentioned private or illegal (illegal clinics refer to clinic functioning without the approval of the camp management) clinics as their actual first source of malaria treatment.

On the other hand, the most preferred first source of malaria treatment among the male participants from the different nationalities was traditional treatment. The majority of the male participants from Somali Bantu, Uganda, Rwanda, Burundi and Eritrea mentioned traditional treatment as their most preferred first source of malaria treatment. While among the majority of the Sudanese youth and the Ethiopian and Congolese male participants, the public health facility was their preferred first source of malaria treatment.

Minor differences were noted among the male participants from the different nationalities with regards to both their actual and preferred malaria treatment-seeking behaviours. Most of the Sudanese youth, and the Ethiopians and Congolese male participants mentioned the public health facility as both their actual and preferred first source of malaria treatment, while the majority of the Somali Bantu male participants were the only nationality who mentioned traditional treatment as both their actual and preferred first source of malaria treatment. Table 4.10 below summarises details of the male participants' actual and preferred first source of malaria treatment. The lists in each box are from the most frequently mentioned (top) to least frequently mentioned (bottom) first source of malaria treatment.

Table 4.10: Actual and preferred first source of malaria treatment among male participants from the different nationalities

PARTICIPANTS	SOURCE OF TREATMENT	
	Actual	**Preferred**
Sudanese Youth (15)	-Public health facility -Home treatment -Traditional treatment	-Public health facility -Home treatment -Traditional treatment
Sudanese (12)	-Public health facility -Home treatment -Traditional treatment	-Home treatment -Public health facility and traditional treatment -Private clinic
Somali Bantu (12)	-Traditional treatment -Public health facility and home treatment -Illegal clinic	-Traditional treatment -Home treatment -Public health facility and private clinic
Ethiopian (9)	-Public health facility -Home treatment -Traditional treatment and private clinic	-Public health facility, traditional treatment and private clinic -Home treatment
Congolese (9)	-Public health facility -Home treatment	-Public health facility and home treatment -Traditional treatment -Private clinic
Ugandan (10)	-Public health facility -Home treatment -Traditional treatment	-Traditional treatment -Home treatment -Public health facility -Private clinic
Rwandan (8)	-Home treatment -Public health facility -Traditional treatment	-Traditional treatment -Public health facility and home treatment -Private clinic
Burundian (8)	-Public health facility -Home treatment -Traditional treatment	-Traditional and home treatment -Public health facility
Eritrean (9)	-Public health facility -Home treatment	-Traditional treatment -Public health facility -Home treatment

4.3.7.2 Actual and preferred first source of malaria treatment among female participants

Among the women, the most frequently mentioned actual first source of treatment in five of the groups (Congolese, Ugandan, Rwandan, Burundian and Eritrean) was the public health facilities. The four remaining groups of women (Sudanese, Somali Bantu, Somali Mogadishu and Ethiopian) most frequently mentioned home treatment as their actual first source of treatment.

With regards to their preferred first source of malaria treatment, the majority of the female participants from all the nationalities, with the exception of the Ugandan participants mentioned traditional treatment as their preferred first source of malaria treatment. The Ugandan female participants mentioned the public health facility as their preferred first source of malaria treatment.

Table 4.11 below summarises details of the female participants' actual and preferred first source of malaria treatment. The lists in each box are from the most frequently mentioned (top) to least frequently mentioned (bottom) first source of malaria treatment.

Table 4.11: Actual and preferred first source of malaria treatment among female participants from the different nationalities

PARTICIPANTS	SOURCE OF TREATMENT	
	Actual	**Preferred**
Sudanese (13)	-Home treatment -Public health facility and traditional treatment	-Traditional and home treatment -Public health facility -Private clinic
Somali Mogadishu (14)	-Home treatment -Traditional treatment -Illegal clinic -Public health facility	-Traditional treatment -Home treatment -Public health facility
Somali Bantu (15)	-Home treatment -Traditional treatment -Public health facility -Illegal clinic	-Traditional treatment -Home treatment -Public health facility
Ethiopian (11)	-Home treatment -Public health facility -Traditional treatment -Illegal clinic	-Traditional treatment -Home treatment -Public health facility -Private clinic
Congolese (11)	-Public health facility -Home treatment -Traditional treatment	-Traditional treatment -Home treatment -Public health facility and private clinic
Ugandan (11)	-Public health facility -Home treatment -Traditional treatment	-Public health facility -Home and traditional treatment -Private clinic
Rwandan (11)	-Public health facility -Home treatment -Traditional treatment	-Traditional treatment -Public health facility and home treatment
Burundian (12)	-Public health facility -Home treatment -Traditional treatment	-Traditional and home treatment -Public health facility
Eritrean (12)	-Public health facility -Home treatment -Traditional treatment -Illegal clinics	-Traditional treatment -Home treatment -Public health facility

4.3.7.3 Comparison between the actual and preferred first source of malaria treatment among male and female participants

When comparing the actual and preferred first source of malaria treatment of the male and female participants, the data suggests that among most of the nationalities in the camp the most frequently mentioned first actual source of treatment for both males and females was public health facilities. However, the use of public health facilities as the first actual source of treatment was mentioned by more of the nationalities of men than women. The most frequently mentioned first actual source of treatment for all the male groups except the Somali Bantus and the Rwandans was the public health facilities. Only five of the nine women's groups had the public health facilities as the most frequently mentioned first source of treatment. More of the groups of women had home treatment as the most frequently mentioned actual first source of treatment. For both the male and female groups of Burundians, Ugandans, Eritreans and Congolese the public health service was the most frequently mentioned actual first source of treatment where as among the Rwandans, Ethiopians and Sudanese there were gender differences in the most frequently mentioned first actual source of treatment. The public health facilities were not the most frequently mentioned actual first source of treatment by either the male or female Somali Bantus, but while the most frequently mentioned actual source of first treatment among the Somali Bantu men was traditional treatment, among the women it was home treatment.

By contrast the public health facilities were the most frequently mentioned preferred first source of treatment by only three of the nationalities of men (Ethiopian, Congolese and Sudanese youth) and only one (Ugandan) of the women's groups. For all of the other groups (both male and female) except the Sudanese men, the most commonly mentioned preferred first source of treatment was traditional treatment. That is, in 13 of the 18 FGDs that were held, traditional treatment was the most frequently mentioned preferred first source of treatment.

Neither private clinics nor illegal drug shops were mentioned as either the first or second, preferred or actual source of treatment by any of the groups.

4.3.8 Delay in seeking malaria treatment

As mentioned above, the majority of participants from all groups sought some form of treatment of their preference within the first week of suspecting malaria. About half of them mentioned taking left over drugs or traditional herbs if available within the first two days of suspecting malaria. A minority took more than 2 days in seeking some of malaria treatment when ill. Therefore, most of the delays in seeking treatment among participants were based on seeking treatment from a health facility or delay in seeking the appropriate treatment. However, the delay among a minority of participants, especially participants from Sudan, Somali and Ethiopia who had undergone traumatic experience, was based on poor recognition of malaria signs and symptoms.

Although there was some variation among participants in the sources of treatment for malaria, the majority of participants from the different nationalities sought some form of treatment within 2 days of recognising malaria. However, many of the Sudanese and a few of the Somalis and Ethiopians said they took more than 2 days before they sought treatment. The remaining participants, mostly those who had experienced traumatic events, sought treatment in more than 2 days after suspecting malaria. A few of the Sudanese, Somalis and Ethiopians had to undergo imposed treatment by neighbours, friends or relatives as they had given up hope in life and did not want to seek treatment when ill.

The sources of treatment sought by participants from the different nationalities were made up of (in order of more to less frequent treatment source used): treatment in the heath facilities, self treatment with left over malaria drugs and analgesics in the house or bought from illegal drug shops, treatment using local/traditional medicines (roots, leaves and trunks of trees), and treatment at

the private clinics outside the camp. The traditional medicines were usually brought along by the refugees themselves and by newcomers/refugees to the camp or were occasionally provided by a few business people. A few traditional treatments such as roots or leafs of trees like the "nim" (muarbian leaves) tree were available in Kakuma but because the area is semi-arid, the trees were not well matured. About half of the participants from all groups indicated that using traditional medicine had been their priority in the treatment of malaria back home but said that it was difficult for them to get the medicine in the camp. Of the few traditional treatments available, participants from Sudan, Rwanda, Burundi, Congo and Uganda said these treatments were not as effective as the ones back home in treating malaria.

Concerning decision-making for malaria treatment, the majority of participants from all groups reported being decision-makers themselves. Most of them, being single parents or young boys (the lost boys), were heads of households. However, a few women from Sudan, Somali, Ethiopia, Congo and Rwanda who were married said they had to consult with their husbands and come to an agreement before seeking treatment. In their original area of settlement, the majority of the female participants reported that they had to consult with elderly close relatives before they would seek treatment. These relatives who controlled the decisions were mostly mothers, aunts, and grandmothers. By contrast, the majority of men from Eritrea and Burundi said they had to consult with their wives before seeking treatment.

4.3.9 Perceptions about quality of malaria management in the health facilities in the camp

To explore the refugees' perceptions on the use of health facilities and quality of malaria management in these facilities, the refugees were asked what problems they had in using the health facilities. Their views are summarised in table 4.11.

Table 4.12: Problems encountered by participants regarding use of the health facilities in the camp for management of malaria

Problems
• *Waiting times and queue are too long for patients to be seen by a doctor.*
• *Health staffs are not friendly and never reassure patients.*
• *No priority is given to seriously ill patients in terms of queuing.*
• *Laboratory tests for malaria are rarely done in the clinics. Diagnosis is mostly done through signs and symptoms.*
• *The clinics sometimes run short of malaria drugs forcing patients to come back another day, which means queueing again and delaying appropriate treatment.*
• *Drugs used for malaria treatment are not effective and do not cure the malaria. It is either expired or not strong enough for specific symptoms.*
• *Some health staff discriminates between ethnic groups. They give their own ethnicity or friends preferential treatment compared to others.*
• *Referral and follow-up of patients is very poor.*
• *In case of resistance to treatment, the same drug is repeated in most cases and injections are rarely given. There is a dependence on tablets.*
• *Patients are not well examined and most diagnosis is made through history taking and in a rush because of too many patients.*
• *Those giving out drugs are as well not friendly and never take time to explain the instructions to patients in an understandable manner.*
• *There is shortage of staff as compared to the big number of refugee population in the camp. Furthermore, the distance to the health facility for the some residents is far.*
• *Some staff seems not to be qualified from the way they manage patients, as evidenced by many inaccurate malaria diagnoses.*
• *Very limited health education about malaria prevention in the camp. Some refugees have never come across health education on malaria.*

4.3.10 Suggestions for improvement of quality of malaria management

Participants were asked of their suggestions on improvement of quality of malaria management in the camp. They recorded the following suggestions (Table 4.13) for improvement and provision of quality services at the health facilities in the camp, including those who used the health facility as their first choice in seeking malaria treatment.

Table 4.13: Suggestions for improvement of health services at the health facilities in the camp

Suggestions
• *More health workers should be recruited to reduce the long queue in the health facility and the rash in management of patients.*
• *The responsible agency should look into it that staff do not discriminate between patients.*
• *Priorities should be given to very ill patients to see the doctor immediately then allow the rest of the patients to queue.*
• *Health staff should be friendly and kind to patients and give them reassurance.*
• *Management of malaria in the health facility should be accurate and complete.*
• *Referral system to the hospital and follow-up of patients should be improved.*
• *Effective drugs that treat malaria should be provided in the health facility.*
• *In case a given drug does not cure malaria, the next time the patient goes back, the drug should be changed.*
• *While giving drugs out, clear explanation on how to take the drugs should be given.*
• *Health education about malaria and its prevention should be frequent.*
• *Diagnosis of malaria through laboratory test should also be encouraged.*
• *Enough malaria drugs should be provided to avoid shortage.*

4.4 SUMMARY

The majority of study participants were quite aware of the common diseases in the camp. They perceived malaria as a disease of major burden in the camp, even more than HIV/AIDS and they ranked it as the major common health problem, followed by diarrhoea and RTI. Although they linked malaria to external cultural factors eating row food, evil spirit, squinted eyes, their perceptions were very much linked to biomedicine. They adopted the biomedical word "malaria" as the local term used in the camp to describe febrile illnesses/malaria.

Participants' had some knowledge about malaria and its complications but their knowledge about the disease cause and transmission was limited. Descriptions of the symptoms of malaria and its complications were principally in agreement with biomedical definitions. Stress and weather changes were frequently mentioned by most participants from all groups as the most common cause of malaria in the camp. With regards to malaria transmission, most of the participants from all groups were either not aware that malaria can be transmitted or did not understand the disease itself. They mentioned factors such as weather, dust, stagnant water, poor diet, and leftover food as the cause of malaria transmission. This again relates to the understanding that the majority of participants from all groups did not associate mosquitoes with malaria.

Discussions also revealed that the majority of participants from all groups had good knowledge about signs and symptoms of malaria. They frequently attributed malaria with fever, headache, general body weakness, lost of appetite and vomiting. Mental disorder termed also as 'madness' or 'depression' in this study was recognised by the majority of participants from all groups as one of the complications of malaria. Nevertheless, typhoid and jaundice were also reported frequently as complications.

About half of the participants from all groups had problems in distinguishing malaria from stress and a few of the Sudanese, Somalis and Ethiopians, were too stressed or traumatised and never bothered to seek treatment when sick with

malaria. They also reported being disassociated from their coping mechanism and did not know what to do when ill.

Treatment seeking opportunities in the camp comprised of both biomedical and non-biomedical health care and can be summarised as official, self, private and traditional treatment. Official treatment included public heamth facilities in the camp. Self-treatment included taking leftover drugs in the house from previous treatment at the health facilities or obtaining it from illegal drug shops. Private treatment was referred to as private clinics outside the camp and traditional treatment was referred to as taking herbal remedies/local medicines. Despite the dislike of the service, official treatment (public health facility) was reportedly widely used by the majority of participants from all groups, with the exception of a few Somalis, as the actual first source of malaria treatment. This was due to the realisation that it was easily accessible and free of charge but the quality of management at these facilities was perceived as poor.

The majority of study participants, both males and females mentioned traditional treatment and home management of malaria as their preferred first source of malaria treatment. Females expressed their preference for traditional treatment as a first source of malaria treatment more than men. Men conversely expressed their preference for home management of malaria as their first source of treatment for malaria relatively more than women. Participants from Somalia were the majority who reported traditional treatment as their actual first source of treatment in the camp compared to participants from other nationalities. The traditional treatment was brought to the camp by new refugee arrivals to the camp and by a few traders. The Somalis were also the only group that washed their stomach traditionally by drinking fluid from a local leaf that causes diarrhoea before they decided to seek other sources of malaria treatment.

Although preference for traditional treatment (herbs, roots, leaves, or trunks of trees) was very high among most of the study participants from the different nationalities, it was difficult to obtain the treatment from the camp.

Therefore, these participants had no option but to resort to treatment at the public health facilities. Very few participants from Ethiopia, Congolese, Somali, Sudan and Burundi reported the private clinics as their actual first source of malaria treatment and a few Somalis and one Ethiopian reported the illegal clinics in the camp as their actual first source of malaria treatment.

The majority of the Sudanese and about half of the participants from the remaining groups were among those who reported to have faced difficulty in recognising suspected malaria at the early stage. Most of the Sudanese youth used the public health facilities in the camp as their first preferences. This is because most of these youths were unaccompanied boys who lost their parents and family members and had no one to assist them take decisions. Differences were also noted between women and men in seeking treatment. Most women preferred traditional medicine than men.

In short, the results from the FGDs in the preliminary study suggest that despite the fact that most of the study participants come from malaria endemic countries, they still found it difficult to cope with malaria in Kakuma. The discrepancy between malaria in their area of settlement and that in Kakuma camp is attributed by the refugees by the difficulty to recognise malaria at the early stages and response to treatment.

The preliminary study has generally raised the following questions

- Why is malaria in the camp perceived as different? Is it true that the malaria in the camp is more 'severe' than that in the refugees' place of origin?
- How does the psycho-social status of participants affect their treatment seeking behaviours for malaria? Is it the difficulties, trauma and violence experienced by the refugees that affects how malaria is perceived in terms of its severity and complications?
- What is the standard of malaria management in the camp? Is it really malaria or an over-diagnosis of malaria at the public health facilities in the camp?

CHAPTER 5: PERCEPTION OF MALARIA, EXPERIENCES OF TRAUMA AND SUPPORT GROUPS: IMPACT ON TREATMENT-SEEKING

5.1 INTRODUCTION

The results of the preliminary study, derived from focus group discussions, highlighted a number of factors influencing malaria treatment-seeking behaviours among refugees in the camp. One of the major findings was the relationship between the effect of past experience and peoples' perceptions of their health status. This relationship was particularly noticeable among study participants who had experienced violence and persecution and, as a result, were traumatised. These participants frequently associated stress and frustration with malaria and had difficulty in recognizing when they were sick. Anecdotal data suggested that peoples' experiences of violence and trauma and their reasons for coming to the camp varied considerably, but the extent to which this relationship influenced treatment-seeking behaviour for malaria was not clear. As part of the broader investigation into the effective case management of malaria in Kakuma refugee camp, a study was, therefore, designed to investigate the effect of psycho-social stress on peoples' perception of health and ill health and to examine the extent to which these psycho-social problems affected treatment-seeking behaviours for malaria among refugees in Kakuma camp. The aim of the study was to identify those 'most' and those 'least' affected by trauma and compare their perceptions and behaviours in relation to treatment-seeking behaviours for malaria.

The specific interests of this study were to investigate:

1. The perception of the burden of malaria in the camp among refugees who

had been diagnosed with psycho-social problems compared to those who were not affected by psycho-social problems.

2. The effect of trauma on the refugees' perceptions of their health status and their recognition of malaria.

3. Variations in treatment-seeking patterns for malaria among the psycho-socially affected and non-affected refugees.

In addition to reporting violence and persecution, the majority of participants in the preliminary studies also mentioned having lost some or all of their relations or family members who had previously taken the lead in decision-making with regards to their treatment-seeking behaviours for malaria and other diseases. To triangulate the data from the preliminary focus group discussions and to further clarify the impact of breakdown in therapy management groups on treatment-seeking behaviours for malaria, a study was designed to investigate the effect of displacement on the refugees' therapy management groups, and the extent to which the loss of this groups had affected the refugees' treatment-seeking behaviours for malaria. The objectives of this study were to:

Investigate the types of support groups found among the refugees in the camp and examine how they differ from the support groups they had in their place of origin.

Investigate the effect that the presence or absence of therapy management groups had on treatment-seeking behaviour for malaria among the psycho-socially affected and non-affected refugees in the camp.

5.2 METHODS OF THE STUDY

A cross-sectional descriptive study was undertaken over a period of 6 month between May 2002 and May 2003 in Kakuma refugee camp in North Western Kenya. The study sample was drawn from all adult refugees in the camp,

regardless of their sex. Only adults were involved in the study because while the burden of malaria in endemic settings is greatest among children under 5 years of age and pregnant women, most of the refugees diagnosed as having psycho-social problems were adults and very few were pregnant. To investigate the effect of trauma and breakdown of support groups on treatment-seeking behaviour, two groups of study participants were defined and selected. The first group included refugees who were psycho-socially affected and who were labelled 'cases', while the second group was made up of refugees who were not markedly psycho-socially affected and these were labelled the 'controls'. The psycho-socially affected or 'cases' refers to patients assessed and diagnosed by the mental health clinic staff in the camp as having mental and social problems affecting their health status. The mental health clinics in the camp are under the responsibility of the International Rescue Committee (IRC). The psycho-socially affected participants were purposely identified at IRC mental health clinics by going through the clinics' registration books that contained over 3000 listed names of patients assessed and diagnosed by IRC psychiatrist nurses as psycho-socially affected. The inclusion criteria for the study included all patients who were attending the mental health clinic for follow-up visits during the three weeks selection period (n=179), and assessed and diagnosed for post traumatic stress disorder (PTSD) with no history of aggressive behaviour (n=143). Participants identified in this way were approached during their follow-up visits to the clinics and counselling centers, and asked if they would agree to be involved in the study. Those who accepted to be involved in the study (n=62) were visited in their homes at a time convenient to them and were interviewed by the research team using an in-depth semi-structured topic guide (see appendix 1).

The second group of study participants, who can be referred to as the 'controls', were selected by approaching the nearest neighbour of a 'case' who could be matched in terms of socio-demographic characteristics and agreed to participate in the study. The 'controls' were also interviewed in their own homes by the research team using the same topic guide as was used for the 'cases'.

Before each in-depth interview, the aim of the study was explained to the participant, privacy assured and consent sought (see appendix 8 for consent form). It was clearly explained to each participant that they could withdraw at any time if they wished without any adverse consequences. Based on the information from the focus group discussions in the preliminary study the topic guide with closed and open ended questions as noted above was developed for use in the semi-structured interviews. The guide was piloted among a group of 16 refugees (8 each for the psycho-socially affected and non-affected group) from different nationalities in the camp. Where necessary, modifications were then incorporated into the final version of the guide. The interviews included the collection of socio-demographic data and stories on personal refugee experiences as well as discussions on perceptions of health and ill health, knowledge about malaria, stress, and treatment-seeking behaviours for malaria. In addition, participants discussed the effect of support groups on decision-making with regards to malaria treatment-seeking behaviours, their experience of traumatic events and the impact of these experiences on their treatment-seeking for malaria.

The research team was made up of 14 members. These were the principal investigator, 6 trained local persons (interviewers and assistants) who were all refugees living in Kakuma with a community health background and 7 local interpreters who were also refugees living in Kakuma. Nine of the team members were male and six were female. The team members were selected purposely with the help of community leaders and staff working in the various agencies in the camp. The interviewers and assistants were identified based on their health background and their experience in assessments and surveys. Translators were selected based on fluency in spoken and written English and the required languages/dialect that needed translation. Priority was given to translators with a good knowledge of more than one dialect. The principal investigator had knowledge of the two languages spoken by two different Sudanese communities in the camp and so a translator was not needed when interviewing participants from these communities. The team underwent a one

week of training on research techniques and the methods to be used during the data collection. This was followed by a practical training where the principal investigator carried out three interviews in the community as an example, while being watched by the team members under training. In turn the interviewers were then asked to each carry out interviews under the principal investigator's supervision during the pilot study of 16 interviews. One of the interviewers who performed the best during the training and had good experience in surveys and assessments was selected as the research assistant to share responsibility for the team with the principal investigator. Following the training, the team was divided into three groups. Each group was made up of one interviewer and one assistant and for each interview they were joined by the appropriate translator. Each interview was, therefore, carried out by three people; one interviewer accompanied by a translator to ask the questions and one assistant acting as an observer and recorder. The principal investigator led 52 of the interviews (26 psycho-socially affected and 26 non-affected). The research assistant led 40 of the interviews (20 psycho-socially affected and 20 non-affected), and the remaining 32 interviews (16 psycho-socially affected and 16 non-affected) were led by an experienced interviewer on the team. During the interviews, participants were first asked a general question about their experience as refugees in the camp and they were encouraged to tell their stories. In addition to providing useful data, this was a motivating process to help the interviewee to relax and to build a rapport between the participant and the interviewer. It proved very effective as participants developed an interest in the interviews and were keen to tell their stories. Following the general background stories, the interviews in general lasted not more than 30 minutes each. At the end of each working day, the team members came together to review the days work and cross check the information received.

To triangulate the data and clarify issues that arose from the individual interviews, six focus group discussions were held with groups of psycho-socially affected and non-affected female refugees from the three major nationalities represented in the camp. These were the Sudanese, Somalis and the

Ethiopians. Only female participants were involved in the discussions because it proved too difficult to get the men to agree to come together for a group discussion. The same criteria that had been used to select participants for the semi-structured interviews were applied to identify participants for the discussions. Separate discussions were held with each nationality and each psycho-socially affected and non-affected group.

Each FGD was composed of 8-12 participants and did not last more than 2 hours. The research was undertaken by two teams. Each team was made up of a facilitator, an observer/translator, and a note-taker and each team conducted three FGDs. The research team members were identified from among the individuals who had undertaken the in-depth interviews in the preliminary study. One team was headed by the principal investigator and the other by the research assistant. The discussions were held in the three different community centers belonging to each nationality involved in the study. Before each discussion, the aim of the study was explained, privacy assured and consent sought. It was emphasized to participants that participation was voluntary and they could withdraw at any stage of the data collection process. The discussions were not taped as three quarters of the study participants were not comfortable with the discussions being recorded. At the end of each discussed topic, a summary of opinions was made by the facilitator and was agreed upon by the study participants.

5.3 DATA ANALYSIS

The socio-demographic and quantitative data (e.g., duration of time to treatment at health facilities and other quantifiable variables) from the interviews were double entered into EPI Info (version 2000) for data management and for comparison of characteristics between the groups. The qualitative data from the in-depth individual interviews and focus group discussions were analysed manually by developing categories for collected information using the topic and interview guides as a guideline. Transcripts from the interviews and discussions

were typed into the computer in Word and then analysed. A constant comparative method of data analysis was used. Key words and common themes and concepts were identified and elaborated upon through an iterative process. Quotations were selected for the purpose of illustrating expressed opinion when reporting results. The results are presented in the following sections.

5.4 RESULTS OF THE STUDY

5.4.1 Study participants involved in the study

Participants from eight different nationalities were included in the study. Table 5.1 below illustrates the numbers of participants of each nationality involved in the interview component of the study.

Table 5.1: Nationality and number of study participants interviewed

Nationality	Psycho-socially affected	Not affected	Total in number
Sudanese	19	19	38
Somalia	12	12	24
Ethiopian	8	8	16
Congolese	4	4	8
Ugandan	5	5	10
Rwandan	6	6	12
Burundian	4	4	8
Eritrean	4	4	8
Total	62	62	124

5.4.2 Characteristics of in-depth interview participants

Sixty two 'affected' participants agreed to take part in the in-depth interviews and as far as possible, these 'cases' were matched with 'controls' of the same sex, age, ethnic group, religion, education level and duration of stay in the camp. Semi-structured interviews were therefore conducted among 62 'matched' pairs. The characteristics of the interviewees are shown in Table 5.2.

Table 5.2: Characteristics of the participants interviewed

Characteristics	Psycho-socially affected n=62 No.(%)	Psycho-socially non-affected n=62 No.(%)	Total n=124 No.(%)
Age in years			
18-25	8 (13)	5 (8)	13 (11)
26-35	14 (22)	12 (19)	26 (21)
36-45	23 (37)	20 (32)	43 (35)
46-55	12 (19)	18 (29)	30 (24)
>55	5 (8)	7 (11)	12 (9)
Gender			
Male	34 (55)	34 (55)	68 (55)
Female	28 (45)	28 (45)	56 (45)
Educational level			
▪ No education	22 (35)	25 (40)	47 (38)
▪ Primary	26 (42)	21 (34)	47 (38)
▪ Intermediate/Junior	9 (15)	11 (18)	20 (16)
▪ Secondary/Mid profession	3 (5)	4 (6)	7 (6)
▪ College/University	2 (3)	1 (2)	3 (2)
Religion			
Christian	30 (48)	38 (61)	68 (55)
Muslims	24 (39)	18 (29)	42 (34)
Others	8 (13)	6 (10)	14 (11)
Duration in the camp			
2-3 years	6 (10)	8 (13)	14 (11)
4-6 years	14 (22)	16 (26)	30 (24)
7-9 years	21 (34)	19 (31)	40 (32)
10 years	12 (19)	14 (22)	26 (21)
>10 years	9 (15)	5 (8)	14 (11)

While it was generally possible to match for age, gender, educational level, religion and duration of stay in the camp, there were differences between the 'cases' and 'controls' in terms of occupation and marital status. The data in Table 5.3 show that about three quarters of the affected participants were unemployed compared to one third of the non-affected participants. The study participants diagnosed with PTSD were less likely to be married and more likely to have lost a spouse than the non-affected participants.

Table 5.3: Differences in characteristics between 'case' and 'control' interviewees

Characteristics	Psycho-socially affected n=62 No. (%)	Psycho-socially non-affected n=62 No. (%)	Total n=124 No. (%)
Occupation			
Housewife	5 (8)	13 (21)	18 (14)
Employee	7 (11)	16 (26)	23 (18)
Self employed	4 (6)	12 (19)	16 (13)
Unemployed	46 (74)	21 (34)	67 (54)
Marital status			
Married	11 (18)	19 (31)	30 (24)
Not married	5 (8)	4 (6)	9 (7)
Separated	7 (11)	12 (19)	19 (15)
Divorced	3 (5)	2 (3)	5 (4)
Widow/widower	36 (58)	25 (40)	61 (49)

5.4.3 Traumatic events experienced by Interviewees

Regardless of their nationality, most of the participants from all groups had experienced one or more traumatic events. Traumatic events are defined as torture, sexual abuse, loss of family members, witnessing killing and living under threat. Table 5.4 suggests that the experience of trauma was common across all nationalities but that there were differences in the frequency of reported traumatic events between the affected and non-affected participants.

While there were little differences between the affected and non-affected groups in the number who had lost family members, almost twice as many of the psycho-socially affected participants had suffered torture and these 'cases' were also more likely to have witnessed killing than the controls. The rate of sexual abuse was low among study participants from both groups but more of the psycho-socially affected participants reported having suffered this type of trauma. This thesis was not specifically about an investigation of PTSD and it was not possible to explore the traumatic problems and their possible consequences in any greater depth. Such a study would need a specialist in post traumatic stress disorder, and fell outside the bounds of this thesis. The aim of involving refugees who were psycho-socially affected in this study was limited to determining their treatment-seeking behaviours for malaria in relation to their psycho-social problems.

Table 5.4: Frequency of traumatic events reported by the psycho-socially affected and non-affected interviewees

Study groups	Psycho-social status	Torture	Sexual abuse	Loss of family members	Witness killing	Living under threat
Sudanese	Affected (19)	15	4	19	12	6
	Non-affected(19)	9	2	18	7	3
Somali	Affected (12)	8	3	11	9	4
	Non-affected(12)	7	1	10	5	3
Ethiopia	Affected (8)	5	1	7	4	2
	Non-affected (8)	3	0	6	2	3
Congolese	Affected (4)	3	0	3	1	1
	Non-affected (4)	1	0	3	1	2
Ugandan	Affected (5)	3	0	4	1	2
	Non-affected (5)	2	1	3	1	2
Rwandan	Affected (6)	3	1	6	5	2
	Non-affected (6)	2	0	6	3	2
Burundian	Affected (4)	3	0	4	1	1
	Non-affected (4)	2	0	4	2	2
Eritrean	Affected (4)	2	0	4	2	2
	Non-affected(4)	1	0	4	1	1
Total	Affected	**42**	**9**	**58**	**35**	**20**
	Non-affected	**27**	**4**	**54**	**22**	**18**

5.4.4 Characteristics of the study participants involved in the focus group discussions

The six focus group discussions were comprised of two groups of each of the three nationalities of study participants (Sudanese, Somali and Ethiopian). That is, there were an equal number of groups of Psycho-socially affected and non-affected participants from each nationality. The psycho-socially affected ('cases') were matched as closely as possible with the non-affected ('controls')

of the same sex, age, ethnic group, religion, education level and duration of stay in the camp. As with the interviewees, the majority of the women involved in the FGDs had been in the camp for between 5 and 10 years and it appeared that overall the 'cases' or affected FGD participants had suffered more traumatic events than the 'controls' or non-affected participants. There were exceptions to this for specific types of trauma. Among the Ethiopians there was one more report of witnessing killings among the controls than among the cases and in both the Somali and Sudanese controls there were two more reported cases of 'living under threat' than among the cases. Details of participants' characteristics are presented in Table 5.5 below.

Table 5.5: Characteristics of participants for the focus group discussion

Characteristic	Sudanese (24)		Somalis (16)		Ethiopian (16)	
	FGD1(12) 'case'	FGD2(12) 'control'	FGD3(8) 'case'	FGD4 (8) 'control'	FGD5 (8) 'case'	FGD6 (8) 'control'
Age in years	No. %	No.%	No. %	No. %	No. %	No. %
18-25	2 (17)	3 (25)	0	2 (25)	1 (12)	1 (12)
26-35	2 (17)	3 (25)	2 (25)	2 (25)	2 (25)	2 (25)
36-45	5 (42)	4 (33)	3 (38)	2 (25)	4 (50)	4 (50)
46-58	3 (25)	2 (17)	3 (38)	2 (25)	1 (12)	1 (12)
Education						
No education	8 (67)	8 (67)	5 (62)	5 (62)	6 (75)	4 (50)
Primary	3 (25)	3 (25)	3 (38)	2 (25)	2 (25)	3 (38)
Intermediate	1 (8)	1 (8)	0	1 (12)	0	1 (12)
Occupation						
Housewife	2 (17)	1 (8)	1 (12)	1 (12)	1 (12)	1 (12)
Employee	1 (8)	1 (8)	0	0	1 (12)	0
Self-employed	1 (8)	2 (17)	1 (12)	3 (38)	0	2 (25)
Unemployed	8 (67)	8 (67)	6 (75)	4 (50)	6 (75)	5 (62)
Marital status						
Married	2 (17)	2 (17)	1 (12)	2 (25)	2 (25)	3 (38)
Single	1 (8)	2 (17)	1 (12)	1 (12)	1 (12)	1 (12)
Separated	5 (42)	3 (25)	3 (38)	3 (38)	2 (25)	2 (25)
Divorced	1 (8)	2 (17)	0	1 (12)	1 (12)	1 (12)
Widow	3 (25)	3 (25)	3 (38)	1 (12)	2 (25)	1 (12)
Religion						
Christian	11 (92)	12 (100)	1 (12)	0	3 (38)	2 (25)
Muslims	1 (8)	0	7 (87)	8 (100)	0	0
Others	0	0	0	0	5 (62)	6 (75)
Duration in camp						
2-3 years	1 (8)	2 (17)	1 (12)	2 (25)	0	1 (12)
4-6 years	6 (50)	7 (58)	4 (50)	4 (50)	4 (50)	6 (75)
7-9 years	3 (25)	2 (17)	3 (38)	1 (12)	3 (38)	1 (12)
10 years & over	2 (17)	1 (8)	0	1 (12)	1 (12)	0
Traumatic events						
Torture	7 (58)	5 (42)	7 (87)	6 (75)	5 (62)	3 (38)
Sexual abuse	3 (25)	1 (8)	2 (25)	1 (12.)	2 (25)	0
Death in family	11 (92)	10 (83)	8 (100)	7 (88)	6 (75)	6 (75)
Witness killing	5 (42)	3 (25)	6 (75)	4 (50)	2 (25)	3 (38)
Living under threat	6 (50)	8 (67)	5 (62)	7 (88)	5 (62)	4 (50)

N.B Participants were allowed to have more than one experience with regards to traumatic event encountered

5.4.5 General perceptions of the malaria burden in the camp

To explore the participants' perceptions of the malaria burden in the camp, participants from all nationalities included in the study were asked their views on common diseases in the camp. From the individual interviews, almost all of the non-affected participants (59;95%) perceived malaria as one of the commonest diseases of great burden in the camp. They related the burden of the disease to its severity and mentioned how difficult it was to cure malaria in the camp.

"Malaria of the desert is always said to be severe and indeed I have proved it from the malaria we have in the camp here." (Non-affected Somali man from the interviews)

Similar findings were elicited during the focus group discussions where the majority of participants in non-affected groups said that malaria in the camp was the commonest disease of great burden and they related the burden of malaria to the severity of the disease, the frequent attacks from the disease and the difficulty in recovering from the disease after treatment. Some of the non-affected Sudanese women in the FGDs mentioned that they thought the malaria in the camp was either a new type of malaria or another disease with similar signs and symptoms to malaria.

"I am not sure if this is malaria. We have had malaria several times back home but it is not as severe as this. It should be typhoid or another disease. Since our blood are not tested for other diseases in the public health facilities, how true will we know if this is really malaria?" (Non-affected Sudanese woman in the FGD)

On the other hand, most of the non-affected Somali women in the FGDs mentioned that malaria in the camp was severe because of lack of effective medicine to treat it. They said that the longer it stayed in the body, the more poisonous it became.

"This malaria in the camp is so severe that only traditional medicine can kill it. There is a particular traditional medicine that is so strong but can't be found in the camp here (Non-affected Somali woman in the FGD)

By contrast, to the non-affected participants, over half of the affected interviewees of all nationalities, (especially the Sudanese and Somali), perceived malaria as one of the common diseases in the camp, but while common it was not considered to be a great burden. Instead, more than three quarters of the affected interviewees (51;82%) perceived their psycho-social problems to be a greater burden than malaria. They reported how difficult it was for them to cope with the depression they were experiencing and how their lives had changed following their displacement. They preferred talking about their traumatic experiences, which they associated with their poor health, rather than talking about malaria. In illustrating their views on the severity and burden of the psycho-social problems they were experiencing, two of the women had this to say:

"It is only those who have experienced traumatic events like me that will understand what I am saying. Yes, malaria is common in the camp but it can't be compared to the long sleepless nights, continuous fever, headache, and worries I am experiencing as a result of what I have undergone". (Affected Sudanese woman from the interviews)

"I wished you could be talking to us of how we should cope with our traumatic experience rather than malaria. My problem is the stress I am undergoing and not malaria". (Affected Congolese woman from the interviews)

Similar views were expressed in the FGDs where the psycho-socially affected participants perceived malaria in the camp as a common disease and mentioned that although malaria was a burden to them, the burden was not as great as the stressful experiences they were encountering in the camp. They perceived the stress they were experiencing as more severe than malaria in the camp but also mentioned the frustrations they had to undergo in caring for themselves and their children with malaria, looking for food, queuing for a long time in the health facilities and suffering under the great heat and difficult living

conditions in the camp. One of the participants went further to give a suggestion which according to her could end the frustration caused by malaria in the camp.

She said:

"If you really want to help us from the burden of malaria in this camp, the only way is to take us out of this place for resettlement in America." (Affected Somali woman in the FGD).

5.4.6 Participants' perceptions of the signs and symptoms of malaria

The principal signs and symptoms of malaria recognised by the majority of the interviewees, regardless of their psycho-social status, were fever (n=101;81%), headache (n=78;63%%), and body weakness/fatigue (68;55%), and those recognised by a third to a half of participants were loss of appetite (60;48%), and vomiting (43;35%). Table 5.6 below illustrates and summarises the opinions of interviewees on the signs and symptoms of malaria.

Table 5.6: Interviewees' perceptions of the signs and symptoms of malaria

Study groups	Psycho-social status	Fever	Headache	Body Weakness	Loss of appetite	Vomiting
Sudanese	Affected (19)	11	9	8	13	4
	Non-affected(19)	18	12	6	7	6
Somali	Affected (12)	12	5	7	7	5
	Non-affected(12)	12	6	8	5	8
Ethiopia	Affected (8)	8	4	4	5	3
	Non-affected (8)	8	6	5	4	4
Congolese	Affected (4)	3	3	4	2	2
	Non-affected (4)	4	4	3	3	2
Ugandan	Affected (5)	5	3	4	3	1
	Non-affected (5)	5	4	3	2	2
Rwandan	Affected (6)	4	4	4	0	0
	Non-affected (6)	5	5	3	2	0
Burundian	Affected (4)	2	3	3	0	2
	Non-affected (4)	3	3	2	2	2
Eritrean	Affected (4)	2	4	2	2	0
	Non-affected(4)	4	3	2	3	2
Total	Affected (62)	**47**	**35**	**36**	**32**	**17**
	Non-affected(62)	**59**	**43**	**32**	**28**	**26**

As was found in the preliminary study, the signs and symptoms of malaria mentioned by the interviewees corresponded well with the biomedical recognised signs and symptoms of malaria. All of the Somali, Ethiopian and Ugandan interviewees, whether affected or non-affected, mentioned fever as a sign of malaria. All the non-affected Congolese mentioned fever as a symptom of malaria and all except one non-affected interviewee from each of the other nationalities mentioned fever as a symptom of malaria. However, among these nationalities (Sudanese, Congolese, Rwandan, Burundian and Eritrean) at least one and sometimes several of the affected participants didn't mention fever as a

sign of malaria. For the second most commonly mentioned symptom of malaria, headache, only half of the Somalis (whether affected or non-affected) and two thirds of the non-affected Sudanese perceived headache to be a sign of malaria but among all the other nationalities at least three quarters of the non-affected participants perceived headache as a sign of malaria. Among all the nationalities, except the Burundians and the Eritreans, more of the non-affected than affected interviewees perceived headache as a sign of malaria. Looking at an overall comparison between the affected and non-affected interviewees the data show that more of the non-affected participants than affected participants mentioned fever (59;47), headache (43;35) and vomiting (26;17) as symptoms of malaria where as more of the affected than non-affected interviewees mentioned body weakness (36;32) and loss of appetite (32;28) as symptoms of malaria.

These data are comparable with findings from the preliminary study and with the data from the main study FGDs. The results from these discussions suggested that fever and headache were cited by the majority of the non-affected participants as a signs of malaria while the symptoms body weakness and loss of appetite were more frequently mentioned as a sign of malaria by the affected than the non-affected participants. However, in contrast to the interview data, more of the affected than non-affected participants in the FGDs mentioned vomiting as a sign of malaria.

5.4.7 Participants' perceptions of the signs and symptoms of stress

Table (5.7) below illustrates the perceptions of the psycho-socially affected and non-affected interviewees on the signs and symptoms of stress.

Table 5.7: Interviewees' perceptions of the signs and symptoms of stress

Study groups	Psycho-social status	Fever	Headache	Fatigue	Anxiety/ Worries	Poor appetite	Sweat
Sudanese	Affected (19)	7	14	0	9	9	0
	Non-affected(19)	0	11	7	0	0	0
Somali	Affected (12)	7	10	0	11	0	7
	Non-affected(12)	0	5	0	0	4	3
Ethiopia	Affected (8)	0	6	0	0	0	0
	Non-affected (8)	0	0	0	0	2	0
Congolese	Affected (4)	0	3	0	2	2	0
	Non-affected (4)	0	2	2	0	0	0
Ugandan	Affected (5)	3	4	0	0	0	2
	Non-affected (5)	2	3	0	1	0	0
Rwandan	Affected (6)	3	0	1	0	3	2
	Non-affected (6)	0	3	0	0	0	0
Burundian	Affected (4)	2	3	0	0	0	0
	Non-affected (4)	3	0	0	0	2	0
Eritrean	Affected (4)	0	0	0	3	2	0
	Non-affected(4)	0	2	0	0	0	0
Total	**Affected/ non-affected**	**22 5**	**40 26**	**1 9**	**25 1**	**16 8**	**11 3**

Approximately half the affected Sudanese, Somali, Ugandan, Rwandan and Burundian interviewees' perceived fever to be a symptom of stress. By contrast, only five of the non-affected interviewees, two Ugandans and three Burundians, perceived fever as a sign of stress. These data suggest that while 'fever' is not commonly recognised as a language of distress among the non-affected participants of most nationalities interviewed, fever may be a culturally recognised symptom of stress among the Ugandans and Burundians. By contrast, it seems that several of the Sudanese, Somali and Rwandan who were diagnosed with PTSD felt that fever was a symptom of stress.

The data on headache among the non-affected interviewees suggests that headache may be a more widely recognised symptom of stress among all the nationalities (except among the Burundians and Ethiopians). However, it is also generally more frequently mentioned as a symptom of stress by the affected than the non-affected interviewees with three quarters of the affected interviewees' from all nationalities, except the Eritreans and Rwandans, perceiving headache as a symptom of stress.

Similar findings were elicited during the focus group discussions. The majority of the non-affected participants from all the nationalities in the FGDs (Sudanese, Somali and Ethiopian) did not associate fever and headache with stress while the majority of the psycho-socially affected participants did associate fever and headache with stress. In expressing their views, affected participants had this to say:

"I believe fever and headache has a connection with stress. Ever since I have been displaced and have lost all my business, I have been having fever and headache on most occasions, despite taking malaria drugs many times. I have come to realize that when I stop worrying a lot, the fever and headache disappears but always comes back when I think a lot". (Affected Sudanese woman in FGD).

"When I cry a lot, I have severe headache and I believe it has an association with my stress". (Affected Ethiopian woman in FGD).

The two other commonly mentioned symptoms of stress reported by the affected Sudanese, Congolese and Eritrean interviewees were anxiety/worries and poor appetite. Anxiety/stress was also mentioned by most of the affected Somali interviewees but among this nationality it was the non-affected who mentioned poor appetite as another sign of stress while both groups mentioned sweating as well. Sweating was also reported as a symptom of stress by the affected Ugandans and Rwandan interviewees.

5.4.8 Differences in perceptions of the signs and symptoms of malaria and stress among the psycho-socially affected and non-affected interviewees

The findings in Table 5.8 below illustrate that almost all (57;92%) of the non-affected interviewees associated fever with malaria alone compared to only two thirds (40;65%) of the affected interviewees. Over a third (22;35%) of the affected interviewees said fever was either a symptom of both malaria and stress or stress alone. In addition over half of the non-affected interviewees (36;58%) perceived that headache was only a symptom of malaria where as two thirds of the affected interviewees (40;65%) perceived headache as a symptom of stress and malaria or stress alone, and of those almost a half (27;45%) said headache was a symptom of stress alone.

Table 5.8: Similarities of the reported signs and symptoms of malaria and stress among the interviewees

Symptom	Fever		Headache	
	Affected (62)	Non-affected (62)	Affected (62)	Non-affected (62)
Malaria only	40	57	22	36
Malaria and stress	7	2	13	7
Stress only	15	3	27	19
Total	**62**	**62**	**62**	**62**

These data suggest that considerably more of the affected interviewees had difficulty in distinguishing between the signs and symptoms of malaria and stress than did the non-affected participants.

5.4.9 Treatment-seeking patterns among psycho-socially affected and non-affected study participants

To investigate the impact of PTSD on treatment-seeking, both in the interviews and in the focus group discussions, participants were asked where they first sought treatment when they suspected they had malaria. The results confirmed the findings of the preliminary study in suggesting that there were four main sources of malaria treatment in the camp. These were: the public health facilities, self treatment in the house with left over drugs, traditional treatment and private treatment. The Table (5.9) below summarises patterns of first choices of malaria treatment among the psycho-socially affected and the non-affected interviewees in the camp.

Table 5.9: First choice of malaria treatment among interviewees

Study groups	Psycho-social status	Public health facilities	Self treatment	Traditional treatment	Private facilities	Illegal shops
Sudanese	Affected (19)	7	9	3	0	0
	Non-affected(19)	6	8	3	1	1
Somali	Affected (12)	4	5	1	0	2
	Non-affected(12)	5	3	1	1	2
Ethiopia	Affected (8)	3	3	1	1	0
	Non-affected (8)	4	2	1	0	1
Congolese	Affected (4)	2	2	0	0	0
	Non-affected (4)	2	2	0	0	0
Ugandan	Affected (5)	2	2	1	0	0
	Non-affected (5)	3	1	1	0	0
Rwandan	Affected (6)	3	3	0	0	0
	Non-affected (6)	4	1	0	0	1
Burundian	Affected (4)	2	2	0	0	0
	Non-affected (4)	2	1	0	1	0
Eritrean	Affected (4)	2	1	0	0	1
	Non-affected(4)	2	1	1	0	0
Total	Affected Non-affected	**25** **28**	**27** **19**	**6** **7**	**1** **3**	**3** **5**

The results show that among all the nationalities just under a half (53;43%), ranging from between a third (Sudanese 13;34%) to just over a half (Rwandan 7;58%), of the interviewees report using the health facilities as their first source of treatment for malaria. The second most frequently mentioned first source of treatment was self treatment at home using left over drugs. This pattern of treatment-seeking was reported by just over a third (46;37%) of the interviewees, ranging from a quarter (Eritrean) to a half (Congolese) in any

given nationality. If each nationality's cases are compared to their respective controls then there appears to be little difference in the frequency of reported first use of the public health facility between the affected and non-affected groups. However, the affected from each nationality (except the Eritreans and Congolese) were slightly more likely to self treat with left over drugs in the home as their first option compared to their non-affected counterparts. Among the Eritreans and Congolese, the affected and non-affected were equally likely to report self treatment at home as their first source of treatment. When these data are added together, almost half of the affected participants (27;43%) report using self treatment at home as their first treatment compared to just under a third (19;30%) of the non-affected.

Traditional treatment was mentioned as the first source of treatment by equal numbers of affected and non-affected Sudanese (3;3), Somali (1;1), Ethiopian (1;1), and Ugandan (1;1) interviewees. One non-affected Eritrean also reported using traditional treatment as their first treatment for malaria. Traditional treatment was not mentioned by any of the Congolese, Rwandan or Burundian interviewees. The Somalis, whether affected (2) or non-affected (2), were the most likely to report using illegal shops as their first source of treatment (4;17%) and use of these sources was also reported by one Sudanese, one Ethiopian and one Rwandan (all non-affected) and by one affected Eritrean. The use of private facilities was only mentioned by four participants, one Sudanese, one Somali and one Burundian (all non-affected) and one affected Ethiopian. Overall reported use of private clinics, illegal shops and traditional treatment was slightly higher among non-affected (15/62) than affected (10/62). These data suggest that while the differences in treatment-seeking between the study participants appears to be small, it may be that as a first option, the non-affected (43;69%) were more likely to be proactive in seeking treatment outside of their home environment than the affected (35;56%).

The data from the focus group discussions, as with the data from the preliminary study, suggests that while many of the participants do use the public

health facilities as their first source of treatment for malaria in the camp, they would prefer to use traditional medicine. This was particularly true among the Somali and Sudanese groups and they complained that the traditional medicines they liked to use were very scarce in the camp. About one third of the participants in the FGDs from Somali, most of whom were non-affected, mentioned using illegal drug shops in treatment of malaria. Most of these participants mentioned that they preferred the illegal shops because they were given injectable drugs for malaria. They believed that injectable drugs were more effective than taking the tablets provided at the public health facilities. In expressing their views in relation to their choices of treatment for malaria, some of the study participants had this to say:

"The type of malaria in the camp here can easily be treated by injectable drugs that go straight to the blood and not those tablets given to us in the health facilities. When I have malaria, I now only go to our small Somali clinics (illegal) and they give me malaria injection. It is so effective and worth paying". (Non-affected Somali woman in the FGD)

"My first choice of malaria treatment has always been traditional medicine. Back home, I rarely visit the health facility. I take a cup of traditional medicine once every week and I rare fall sick of malaria. Now I am forced to visit the health facility when I have malaria because I can't get the traditional medicine here in the camp". (Non-affected Sudanese man from the interviews).

These data suggest that there is some variation between the affected and non-affected participants in terms of sources of care but they do not provide any information on time to treatment-seeking. To investigate the impact of psycho-social status on prompt access to treatment, the reported time of the two groups to seeking treatment at the public health facilities was compared. The findings are shown in table 5.10 in the next section.

5.4.10 Time to treatment at the health facilities by the study participants

The data from the preliminary study suggested that for many of the refugees the first appearance of fever was not necessarily a sign that they had malaria. If the fever was mild they would frequently wait for a day or two before they suspected they had malaria and started to seek treatment for the disease. In this part of the study the interviewees were asked how long it took them to seek treatment at the health facilities from when they first recognised or suspected malaria (which could be a day or two after the onset of a mild fever). The data from their responses suggests that the psycho-socially affected interviewees are less likely to seek treatment within two days of suspecting malaria than are the non-affected interviewees (see Table 5.10 below).

Table 5.10: Time to treatment at the health facilities when malaria suspected: psycho-socially affected and non-affected interviewees

Psycho-social status of participants	Reported time to treatment at health facility	
	< 1-2 days	> 2 days
Affected (62)	22 (35%)	40 (65%)
Non-affected (62)	44 (71%)	18 (29%)

The data reveal that two thirds of the non-affected participants who were interviewed reported that they were likely to seek treatment from the public health facilities within 1-2 days of suspecting that their symptoms were malaria. By contrast, only one third of the affected participants reported that they were likely to seek treatment from the public health facilities within 1-2 days of suspecting that they might have malaria.

Similarly, the focus group discussions revealed that the majority of the non-affected Somali, Sudanese and Ethiopian women mentioned visiting the health facility within 1-2 days of recognising malaria signs and symptoms, while only about half of the affected participants were likely to seek treatment within the same period. In expressing their views on time to treatment and their ability to recognise malaria, the participants had this to say:

"My problem is not seeking treatment but recognising malaria. How can I recognise malaria if headache and fever has become part of my daily life in the camp here, as I have to go through a lot of stressful experiences." (Affected Burundi man from the interview).

"The health facility is just next to my house. So the moment I feel unwell and suspect malaria, I immediately just rush to the clinic". (Non-affected Sudanese woman from the interviews).

"When I suspect malaria, I first wait and monitor my situation. If I become weak is when I decide to go to the health facility". (Non-affected Ethiopian woman in the FGDs)

5.4.11 Therapy management group and its impact on treatment-seeking behaviours for malaria among study participants

In order to understand the effect of therapy management groups on treatment-seeking behaviour, it is important to compare the type and function of familial groups involved in giving support to individuals (support groups) in the area of origin with the type and function of groups established within the camp. To explore the composition and characteristics of the support groups of all nationalities, both in their areas of origin and in the camp, the interviewees were asked to describe the types of support groups that they were familiar with and to provide an explanation of what they were used for. Details are presented in Table 5.11 below.

Table 5.11: Support group composition of affected and non-affected interviewees of all nationalities in the areas of origin and in the camp

Study groups	Psycho-social status	Types of support group in areas of origin		Types of support group in the camp	
		Nuclear	Extended	Community	Extended
Sudanese	Affected (19)	19	5	3	1
	Non-affected(19)	18	7	16	3
Somali	Affected (12)	10	6	3	1
	Non-affected(12)	11	8	10	2
Ethiopia	Affected (8)	7	2	2	-
	Non-affected (8)	8	3	7	1
Congolese	Affected (4)	4	1	1	-
	Non-affected (4)	4	-	3	2
Ugandan	Affected (5)	4	1	1	-
	Non-affected (5)	5	-	3	-
Rwandan	Affected (6)	5	2	1	-
	Non-affected (6)	4	3	3	2
Burundian	Affected (4)	4	1	1	-
	Non-affected (4)	3	2	3	-
Eritrean	Affected (4)	4	1	1	-
	Non-affected(4)	3	2	3	-
Total	Affected (62) non-affected (62)	**58** **56**	**19** **25**	**13** **48**	**2** **10**

Note: Interviewees were allowed to mention more than one type of support group

The data from Table 5.11 reveals the types of support groups study participants had in their areas of origin and in the camp. In the areas of origin two types of support groups were identified by all the nationalities, a nuclear and an extended family type. The nuclear type of support group can be described as being made up of kinship relations, which in the African context and from participants' description, included: mothers, fathers, brothers, sisters, grand-

parents husbands, wives, first cousins, first aunts and uncles. The extended type of support group was described as additionally including other relatives such as: more distant cousins and relatives. While all except a very few of the interviewees of all nationalities reported that they had had a nuclear support group in their area of origin, fewer reported the existence of an extended support group and the Congolese and the Ugandans only had the nuclear type of support group. In their place of origin both types of support groups were used by all the nationalities to provide financial and emotional support. The nuclear support group was reported to be the principal source of support for treatment-seeking decisions by all nationalities, except the Burundians and Ethiopians. For the Burundians and Ethiopians support for treatment-seeking decisions was provided by the extended support group. The Burundians were the only group that mentioned receiving domestic services as support from their nuclear support group. For all the other nationalities this type of support was provided by their extended support group (where one existed). Overall, little variation was found among participants of all nationalities in terms of types of support group and actual support provided by these groups in their areas of origin.

By contrast, in the camp the two types of support groups mentioned could be categorised as community support groups and extended family support groups. In the camp, the nuclear type of support group was said not to exist and the majority of participants who reported having a support group, said that they had become part of a community type of support group. This type of group was made up of friends, neighbours, tribesmen, colleagues and church members. A very few participants said that they did have extended support group, made up of family and distant relatives in the camp and the non-affected (10/62) were more likely to report having this type of group in the camp than the affected (2/62). When asked the type of support provided by the community support group, the interviewees from all the nationalities in the camp mentioned emotional and domestic services as the main support provided by their support group members. It was only the Somalis who in addition, mentioned that

support in decisions to seek treatment was provided by their community support group members.

In comparing the existence and composition of participants' support groups in the camp with those in their areas of origin, a difference was noted. All participants had support groups in their areas of origin but in the camp, the majority of participants with support groups were the non-affected participants. Only about a quarter (15/62) of the affected interviewees reported having support groups in the camp compared to almost all of the non-affected. However, the type of support group the interviewees reported having in the camp differed from that in their areas of origin. The majority of interviewees from all groups with support groups in the camp had the community type of support group that was based on friendship, while in their areas of origin, most interviewees from all groups had the nuclear type of support group that was based on kinship relations. In the camp, the majority of interviewees reported depending on their support group mostly for emotional support or domestic services but in the area of origin, they had depended on their support groups for decision-making in seeking treatment as well as for financial support, emotional support and domestic services. These findings show that the newly established support groups in the camp differed in terms of type and support provided compared to their support groups back in their areas of origin. In addition, they suggest that the majority of the psycho-socially non-affected interviewees had managed to become part of new community support group in the camp while the majority of affected interviewees had failed to establish new support groups. The data are summarised in Table 5.12 below.

Table 5.12: Number of participants with and without support groups in the camp

Study participants	Status of interviewees' support group	
	Support group	No support group
Affected	15(24%)	47(76%)
Non-affected	51(82%)	11(18%)

Data from the focus group discussions elicited similar findings. Participants were asked about the characteristics of their support groups in their areas of origin and in the camp and how helpful these groups were influencing decision to seek treatment for malaria in the camp. The majority of the participants from all of the non-affected groups, mentioned having community support groups in the camp that comprised of not more than 1-3 members. According to their descriptions, the ties and links between these group members were weak. In comparison, the majority of participants from all three nationalities mentioned that in their areas of origin, they formerly had the nuclear type of support group that comprised of not less than five members with strong ties and good relations among themselves. They revealed how helpful these members had been in providing them with support that included decision-making to seek treatment, emotional support, financial support and domestic services. They referred to the type of support group they had in their area of origin as groups based on trust, intimacy and blood relation. In contrast, most of them considered the new support groups created in the camp as groups of convenience. In expressing their views on the type of support groups they created in the camp, one of the women had this to say:

"It is not easy to trust someone who is not related to you. Most of the support group *members we have are people we met in the camp whom we just want to keep*

company with but not to involve them in our personal affairs". (Affected Ethiopian woman in the FGD).

In expressing the importance of emotional support and domestic service when sick, one of the women said:

"I need a person to talk to when I am lonely, a person to help me when I am sick (e.g. collect water, buy me something from the market) and a person I can keep company with in times of need". (Non-affected Sudanese woman in the FGD).

5.4.12 : The use of support groups in decision-making to seek treatment

The results in the previous section suggest that when the refugees were asked directly what help they received from the support groups they formed in the camp, they rarely mentioned that they used the members of these groups to help in decisions to seek treatment. However, when they were probed about what happened when they last became ill, their responses suggested that the community support groups in the camp were being used to a certain extent to seek treatment for malaria. When the participants were asked specifically about who they turned to for advice in times of need and for help with decisions about treatment-seeking when they were sick with malaria, the majority of interviewees who said they had a support group reported using that group in decision-making for treatment-seeking (see Table 5.13). Out of the 51 non-affected interviewees with a support group, three quarters of them (39;76%) reported that they had used that group to assist them in treatment decisions, for these individuals at least, these groups could, therefore, be described as acting as their 'therapy management group'. Only a quarter of the affected interviewees reported having a support group (15;24%), and of these, less than half (6;40%) reported actually using that support group to help in decisions about treatment. Furthermore, several of the affected interviewees, both with and without support groups, reported that they had had treatment imposed upon them by friends, neighbours or community health workers.

Table 5.13: The impact of support groups on decision-making in seeking treatment

Study groups	Decision-making for treatment-seeking		
	Self	Support group	Imposed
Affected with support group (n=15)	7 (47%)	6 (40%)	2 (13%)
Affected without support group (n=47)	41 (87%)	-	6 (13%)
Non-affected with support group (n=51)	12 (24%)	39 (76%)	-
Non-affected without support group (n=11)	11 (100%)	-	-

These data suggest that for the majority of non-affected participant with a support group, those groups are sometimes a source of decision-making in treatment for malaria. Among the few affected participants who reported being part of a support group, those groups appear to be less important in decision-making for treatment of malaria. These data suggest that the experiences suffered in becoming a refugee impact both on the composition of the support groups used by individuals and the ways in which the support itself is sort and used. That is, while all the refugees interviewed said that they had a group of people who were involved in decisions about treatment in their place of origin (a therapy management group), in the camp situation this was not the case, and the impact appears to have been greatest among those diagnosed with PTSD. While these data suggest that being part of a support group affects the locus of decision-making, they don't provide information on the impact of this on time to treatment at the public health facilities. To look at this effect, reported time (after the recognition of malaria) to treatment at public health facilities in the camp between interviewees with and without a support group was compared. The findings are illustrated in Tables 5.14 below.

Table 5.14: Time to treatment at the public health facilities among interviewees with and without support groups

Time to treatment	Affected		Not affected	
	Support No.%	No support No.%	Support No.%	No support No.%
< 1-2 days	5 (33)	17 (36)	36 (71)	8 (73)
> 2 days	10 (67)	30 (64)	15 (29)	3 (27)
Total	15 (100)	47 (100)	51 (100)	11 (100)

Earlier results on the affect of PTSD on time to treatment at the public health facilities suggested that those with PTSD may have been more likely to take longer to seek treatment than those without PTSD. The data shown in table 5.14 above suggests that the presence or absence of a support group does little to alter this picture. Almost three quarters of the psycho-socially non-affected interviewees, whether they had a support group or not, sought treatment from the health facility less than 2 days after they first suspected malaria, while two thirds of those affected, whether they had a support group or not, took more than 2 days to seek treatment for malaria from a health facility. These data suggest, therefore, that for these interviewees the effect of psycho-social status has a greater influence on time to treatment at the public health facilities than the presence or absence of community support groups.

5.5 SUMMARY

Malaria was perceived to be a common disease in the camp by all the study participants. However, there were differences among the psycho-socially affected and non-affected participants with regards to their perceptions about the relative burden of malaria. The psycho-socially non-affected participants

perceived malaria as the disease with the greatest burden in the camp while the non-affected participants perceived their psycho-social status to be a greater burden than the burden of malaria.

To a large extent, the symptoms recognised as being signs of malaria by the study participants, regardless of their nationalities or psycho-social state, showed considerable convergence with the bio-medically recognised signs and symptoms of malaria. There were a few differences related to the physiological and psychological aspect of perceived signs and symptoms of malaria among the nationalities but these were less frequently mentioned. Perceptions of the signs and symptoms of stress varied slightly among nationalities and the findings suggested that there maybe the possibility that 'fever' is a culturally recognised symptom of stress among the Burundians and Ugandans. Among the other nationalities, fever doesn't appear to be a common culturally recognised sign of stress. However, a few differences in perceptions of the symptoms of stress were found between the psycho-socially affected and non-affected participants. The data suggested that some of the psychologically affected participants had difficulty in distinguishing between the symptoms of malaria and those of stress. This implies that some of the refugees who are diagnosed with PTSD may be less able to distinguish when they have malaria than those who do not exhibit the psycho-social signs of stress.

In terms of seeking treatment, the data suggested that the two most commonly mentioned first sources of treatment for all participants were either use of the public health facilities or self treatment with drugs left over at home. About 80% of participants mentioned one of these two options (43% public health facilities and 37% home treatment) but the affected interviewees were slightly more likely to mention their first treatment as being at home with left over drugs than were the non-affected participants.

A considerably higher proportion of non-affected participants than affected participants had support groups in the camp. Most of the support groups in the

camp were community type of support groups, whereas in their areas of origin, almost all of the participants had belonged to a nuclear type of support group. While the community support groups may have been used to provide support for decisions to seek treatment, the presence of these groups did not appear to have an affect on the time taken to seek treatment at the public health facility. However, psycho-social status did seem to have major influence on time to seek treatment at the public health facilities (after recognition of malaria). Almost two thirds of the affected interviewees, whether they had a support group or not, reported that they took more than two days to seek treatment at the public health facilities. By contrast, almost three quarters of the non-affected interviewees, whether they reported having a support group or not, said that they took less than two days to seek help for malaria at a public health facility.

CHAPTER 6: QUALITY OF MALARIA MANAGEMENT

6.1 INTRODUCTION

Several of the studies reviewed in chapter two found that patients' perceptions of the quality of management of illness affected treatment seeking behaviours. One of the primary concerns about malaria, mentioned frequently by the participants in the preliminary study, was their perception of the poor management of malaria by the clinicians and their unease about the way they were treated at the formal health facilities in the camp. Good management of malaria relies on accurate diagnosis as well as on appropriate treatment, but, the review also demonstrated that malaria is almost impossible to diagnose clinically, even for highly qualified health personnel. To investigate the extent to which the refugees' perceptions of the standard of malaria management were an accurate reflection of practices at the health facilities, a study was undertaken to determine factors influencing the quality of malaria management in the formal health facilities in the camp. The study included an investigation of the health care providers' perceptions of the burden of malaria in the camp, as well as an assessment of their knowledge, attitude and practices in the management of patients and of malaria.

The framework most frequently employed for measuring quality of health care provision in both developed and developing countries is based on three measures of quality: structure, process and outcome (Brook *et al.*, 1996; De Geynt, 1995; Donabedian, 1980; Munoz, 2002). Structural measures include the organisational set up of the health system, as well as measures of the available capacity in health personnel and health facilities that form the structural basis of health care. Process measures include an evaluation of the

encounter between the health care provider and the patients, including the process of diagnosis.

Outcome measures involve measuring the subsequent health status of patients following the clinical encounter. Measurement of this factor requires in-depth follow up of a patient following the clinical encounter and this was beyond the scope of this project. In this study, the other two measures, 'structure' and 'process', were employed and used to evaluate the quality of malaria management in the camp.

To assess the quality of the process of malaria management, Donabedian's (1994) definition of quality was adopted. That is, the observed process was compared to 'good performance' as laid down by the IRC set standard guidelines (protocol) for the management of malaria in the camp.

6.2 GUIDELINES FOR MALARIA MANAGEMENT AND CONTROL IN THE CAMP

According to the head of the IRC curative services, the IRC guidelines for the case management of malaria in the camp were developed as a simplified version of the Kenyan national guidelines' requirements for the management and control of malaria. The guidelines were developed alongside the WHO recommended approaches for case management of malaria (MOH-Kenya, 1998). For children under-five years of age, the guidelines were developed alongside the Integrated Management of Childhood Illnesses (IMCI) strategy. The IMCI strategy aims to improve health workers' performance by helping them to recognise, treat and prevent malaria appropriately through training them to use a clinical algorithm to detect the commonest causes of childhood illnesses (that include malaria) and by providing desktop guidelines for history taking and examination. General medical procedures in the management of diseases have also been included as part of the process in taking history and conducting physical examinations. An outline of the contents of IRC guidelines

for the management of malaria in the camp, as explained by the head of the curative health services, has been summarised in the following section.

6.2.1 Guidelines for the case management of malaria

The IRC guidelines used for the case management of malaria in Kakuma refugee camp include: greeting patients as they enter the consultation room; recording the patient's name, age, sex and address; and taking the patient's history and performing a diagnosis using the recommended diagnostic guidelines. In cases of fever, the guidelines recommend making inquiries on the duration of the fever, the nature of the fever (continuous or intermittent), as well as on the presence of cough, difficulty or fast breathing, stiff or painful neck, runny nose, or sore red eyes. A general medical examination should be performed along with the provision of an explanation to the patient for the reason for the examination. Following a diagnosis, appropriate treatment should be prescribed together with an explanation to the patient on how to administer the prescribed drugs. Patients should also be informed about the expected results of treatment, possible side effects, and when to return to the health facility if necessary. The clinician is also meant to provide a brief health education session about the diagnosed diseases and to refer patients to a higher level of care (hospital) where complications are observed.

6.2.2 Guidelines for the treatment of malaria

The IRC guidelines for the treatment of malaria in the camp follow the Kenyan national guidelines for the treatment of malaria in Kenya. These include the use of SP as the first line treatment for suspected uncomplicated malaria and quinine or amodiaquine as the second line treatment for complicated malaria cases. However, CQ was still being used for the treatment of some cases of malaria in the formal health facilities in the camp during the data collection period (2001-2002) as earlier mentioned in Chapter Three.

6.2.3 Guidelines for slide taking and reading

The IRC guidelines for microscopic laboratory diagnosis for malaria includes wiping a patient's left third finger tip with a swap dipped in spirit or savlon, pricking the finger with disposable needle or lancet and allowing blood to ooze out. The blood should be dropped onto a clean glass slide and the slide identified with a number. A thick and thin smear should be made and the slide allowed to air dry and stained with giemsa stain. The blood slides should be examined under a microscope by dropping immersion oil on the smears and lowering the 100x oil immersion objectives over the selected portion of the blood film so that it touches the immersion oil. The guidelines recommend that the examination of thick smears includes at least 100 good fields before a slide can be pronounced negative for malaria parasites and species.

6.2.4 Guidelines for drug dispensing

The IRC guidelines for drug dispensing in the health facilities include: receiving a prescription from patients, confirming that they are the correct prescriptions, interpreting the prescriptions to make sure that they are understandable and where there are any unclear or dubious instructions, clarifying the prescription with the prescriber. In addition, dispensers are charged with ensuring drugs are available and expiry dates valid. They should also label drugs clearly, indicating directions for use and communicating to patients the correct way to administer the drugs, even if patients were given instructions during consultation. This latter guideline is aimed to reinforce and enhance compliance.

6.2.5 Guidelines for the prevention of malaria

The guidelines for the preventive aspect of malaria control in the camp include: raising awareness on common health problems, especially within communities and in the health facilities, referring patients in need of health services to the

formal health facilities, reporting on health issues emerging within communities and households and following up patients that need attention.

6.3 METHODS OF THE STUDY

Both quantitative and qualitative research methods were used to obtain a comprehensive view of malaria management at the outpatient health facilities. The methods included: reviewing records and noting the physical structure and equipment in the health facilities; semi-structured interviews using topic guides to determine health care providers' knowledge, attitude and reported practice in management and control of malaria, as well as observations using a checklist to describe the actual attitude and practice.

6.3.1 Research team

The research team was made up of the researcher, the research assistant and two of the assistants who had been involved in the preliminary study and in the study on treatment seeking. All of the health care providers spoke English, so no translators were required. The research assistant was a Sudanese local, with good background in health and with experience in surveys and assessments. The two other team members were identified from among the interviewers initially trained for refugee interview study. They received additional instruction on what was required from them in this part of the project, specifically in terms of the interviews and methods for the observations. The research team of 4 was divided into two groups with 2 members in each. One group was led by the researcher and this group interviewed 29 health care providers and observed 15 of these providers during their clinic sessions. The other group was led by the research assistant and they interviewed 21 health care providers and observed 9 of them during their clinic sessions.

6.3.2 Data collection tools and pre-testing

Interview guides and checklists were drafted in English while at the London School of Hygiene and Tropical Medicine. Development of these tools was in consultation with the principal investigator's supervisor, and on the basis of available literature. Separate topic guides were developed for the interviews with the different health cadres responsible for malaria management in the camp and the tools were pre-tested through a pilot study. The study was clinic based (for both the interviews and observations). To ensure quality control, the principle investigator frequently monitored the data collection activities in the field and checked the interview guides and checklists at the end of each working day for inconsistencies and completeness. Inconsistent or missing data items were marked and reviewed with the interviewers concerned (see appendix 2-4 for the topic guide and checklists).

6.3.3 Interviews

Before each interview or set of observations, voluntary informed consent was obtained from each participant (see appendix 9 for consent form). The interviewers explained the research project, its objective and methods, the importance of their involvement, and the plan for use of the research outcomes. Confidentiality and privacy was assured. All of the outpatient health facilities were involved in the study and the participants were interviewed in the health facilities over a period of six weeks during the months of September and October 2002. Each interview lasted approximately 30 minutes.

6.3.4 Observations

Two types of observation were conducted. These were, firstly, the observations of the quality of structure of the outpatient health care facilities and, secondly, observations of clinical practice in the management of malaria by the health providers. The observations were conducted by the same research team that

conducted the in-depth interviews with the providers. Two groups of health care providers were directly observed undertaking their routine work in the practical aspect of malaria management in the camp. These groups were the clinical health workers (clinical officers and medical assistants) and the drug dispensers. These two groups of health cadres were selected for observation because they are directly involved in the clinical management of malaria at the outpatient health facilities. The observations were conducted in a total of 32 days over a period of 7 weeks during October and November 2002. Clinics 1, 2 and 4 each had three clinical health workers and six days was spent at each of these three clinics collecting observation data. Four days were spent collecting data in clinic 3 which had two clinical health workers, and ten days was spent collecting data from clinic 5 which had five clinical health workers. The IRC guidelines for the management and control of malaria were used to construct a structural observation guide which was used to collect the data. Each observation period lasted for 45 minutes to 1 hour. During this period the researchers sat in the consulting room and observed and recorded the clinical management by the provider of all patients presenting for consultation (with the exception of patients presenting with complicated signs and symptoms of malaria who were usually referred to the hospital). Each health worker was observed during two 1 hour observation periods. All observations took place in the health facilities during the morning hours between 8:00 a.m. and 11.00 a.m. During each observed consultation, the duration of interaction between the clinical health workers and patients was recorded. The observations of drug dispensers started when the patient presented the prescription to the dispenser.

The waiting (dispensing) time was defined as the time that elapsed between the presentation of a prescription sheet by the patient and the receipt of the prescribed drug by the patient.

At the end of each day of observations an hour was reserved to review the consultation-register book at the health facilities to confirm the recorded details of patients' complaints, diseases diagnosed and medication prescribed. The

dispensary register book was also reviewed for confirmation of details of prescription sheets and type and amount of drugs dispensed.

A Hawthorne Effect (Mayo, 1933; Roethlisberger and Dickson, 1939) might be expected during the observations in that the health care providers may well be expected to alter their behaviour in the presence of an observer. However, it is likely that any alteration would be towards perceived best practice and, therefore, it was assumed that the observed provider behaviour was likely to reflect the providers' best practice.

6.4 DATA ANALYSIS

The quantitative data from the structured observations were categorized, coded double entered onto a computer, checked for inconsistency and analysed using EPI INFO version 6 (Dean *et al.*, 1991). The socio-demographic and quantitative data from the semi-structure interviews were also analysed in EPI INFO version 6 while the qualitative data from the interviews were analysed manually by developing categories for collected information, as described in the previous result chapter. Transcripts from each interview were typed into the computer in Word and then analysed. The topic guide was used to help develop an initial coding sheet and a constant comparative method of data analysis was used to identify key words and concepts. The most compelling quotations were selected for the purpose of illustrating specific opinions and ideas.

6.5 STUDY RESULTS

6.5.1 Organisational structure of the outpatient health facilities

6.5.1.1 Physical structures of the outpatient public health facilities

There are five outpatient community based health facilities that are strategically located in areas to facilitate access for the whole refugee population. However, the health care providers have reported that they are not sufficient to meet all

the health needs of the large population of refugees (est. 87,360). The five outpatient health care facilities in the camp all have similar physical structures and each is divided into 8 main rooms. These include a registration room, under-five consultation room, above five years old consultation room, dressing room, injection room, mother and child health room, pharmacy, (including a store) and a mental health room. A small two-roomed building is annexed to each of the health clinics and is used for the nutrition programme. During the survey, clinic 5 was being extended and more rooms were being constructed because of the increase in number of new refugees attending the clinic.

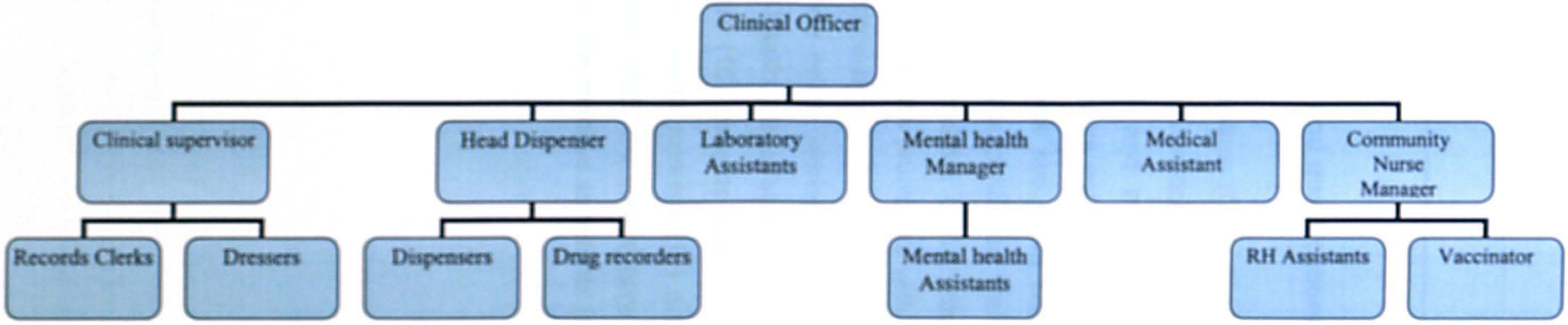
6.5.1.2 Furniture and equipment in the health facilities

In each outpatient health facility the basic furniture should include chairs, tables, benches and cupboards and the basic health equipment should include sphygmomanometers, stethoscopes, microscopes, thermometers and dressing trays. It proved difficult and sensitive to get an accurate record of the exact amount of basic furniture and equipment that was available in each facility because the health care providers in charge of each facility were not very enthusiastic about letting the research team check and record the amount of furniture and equipment available. The observations of the clinical practice suggested that, even if available, some of the equipment such as the sphygmomanometers, and stethoscopes were not frequently used in any of the five outpatient health facilities.

6.5.1.3 Management of the outpatient health facilities

The outpatient health facilities are under the management of a senior clinical officer who reports to the head of curative services based at the main camp hospital. Each senior clinical officer has an assistant and both rotate within the five clinics to supervise the work on daily or weekly basis depending on the need for assistance and more supervision. Figure 6.1 below indicates the organisational chart of the outpatient health facility staff.

Figure 6.1: Health staff organogram at the outpatient health facilities



6.5.1.4 Outpatient health staff and qualifications

In the five outpatient health facilities (OPD departments), the total health staff consists of 2 clinical officers, both national staff, who have undergone a 3 year diploma training in preventive and curative medicine; 21 refugee medical assistants with 18 months certificate training in preventive and curative medicine; 20 nutritional health workers with two years certificate training in nutrition; 12 drug dispensers with 3 months certificate training on drug dispensing; 15 laboratory assistants with 9 months basic laboratory certificate training; 30 community health workers/ health promoters with 9 months certificate training in preventive health; 5 community enrolled nurses with 9 months certificate training in nursing and 15 mental health workers with 9 months certificate training on community and mental health. Other staff associated with the outpatient health facilities include dressers (10), records clerks (12), vaccinators (18), registrars (10), maternal and child health workers (10) and water and sanitation health workers (5). Among these staff, the clinical care for malaria is provided by the clinical officers (n=2) and the medical assistants (n=21). See Table 6.1 below for details.

Table 6.1: Permanent staff at time of study in the public health facilities

Health care providers	Clinic 1	Clinic 2	Clinic 3	Clinic 4	Clinic 5
Medical Assistants (21)	4	4	4	4	5
Laboratory assistants (15)	3	3	2	3	4
Drug dispensers (12)	2	2	2	2	4
CHW (30)	6	6	6	6	6
Mental health assistants (15)	3	3	3	3	3
MCH workers (10)	2	2	2	2	2
Nutritionists (20)	4	3	3	5	5
Community nurses (5)	1	1	1	1	1
Dressers (10)	2	2	2	2	2
Vaccinators (18)	4	3	2	4	5
Record clerks (12)	2	2	2	2	4
Registrars (10)	2	2	2	2	2
WATSAN workers (5)	1	1	1	1	1
Total	36	34	32	37	44

Note: The table indicates only permanent staff based in the health facilities during the time of the study

6.5.1.5 Refresher courses

The majority of the staff in the health clinics said they were rarely given refresher courses or sent for further training. The community health workers and medical assistants reported that they had once received annual refresher courses but this was now unreliable and the provision of refresher courses was not consistent. The Head of the curative service said that each health cadre was supposed to receive refresher training twice a year but because of financial constraints and the work-load in the health facilities, the refresher courses were not taking place as proposed.

6.5.1.6 Health facility opening hours and attendants

Each outpatient health facility functions 6 days a week from Monday to Saturday. From Monday to Friday, the staff work 7 hours per day from 8:00 am to 5:00 p.m. with a break of 2 hours each day from 1:00 p.m. to 3:00 p.m. On Saturdays the clinic is open for 4 hours from 8:00 a.m. to 12:00 noon after which the clinic closes and the staff start their weekend. These are the official opening hours, however, during 18 months of ethnographic fieldwork it became clear that on many occasions the clinics often closed at 3.30 or 4pm on week days, or the staff were late returning from lunch so that in the afternoons the clinics were frequently open only for an hour or so.

On average, the number of OPD visits per month in each of the five facilities ranged from 1,900-3,400. This gives a combines total of 9,500-17,000 consultations per month at the five OPD facilities. Details of consultations by clinic are shown in Table 6.2. The data from this table suggest that there is a peak in attendance during May and September in all clinics. December has the lowest number of consultations. This is likely to be a consequence of Christmas holidays when the number of staff available at each clinic is lower. These data also suggest that patient load per clinical health worker in each clinic is fairly high. For example if clinic 1 is on average open for consultations 34 hours per week (6 hours per day Monday - Friday and 4 hours on Saturday) and at any one time it has three clinical staff then each of these staff should be seeing between 6 (in October) and 8 (in June) patients per hour. These data are likely to be an under representation of the number of patients seen in the morning sessions since informal observations over 18 months would suggest that many patients turn up early and by 3.30pm there are frequently no patients left waiting to be seen.

Table 6.2: Seasonal variation in the number of all cause consultations at each clinic

Month/Year	Clinic 1	Clinic 2	Clinic 3	Clinic 4	Clinic 5	Total
April 02	2570	2502	1605	3026	2683	12,386
May 02	3052	3433	2738	3500	4110	16,833
June 02	3344	2843	2087	2770	3313	14,357
July 02	2419	3631	1879	2550	2653	13,132
August 02	2539	3781	1620	2878	3522	14,340
September 02	2892	3716	1905	2810	5302	16,625
October 02	2214	2616	2072	2708	4184	13,794
November 02	2798	2700	1902	2714	4777	14,891
December 02	1985	1798	1298	2016	2860	9,957
January 03	2612	2877	1835	2822	4626	14,772
February 03	2670	2729	1941	2566	4551	14,457

To look at seasonal variations in the percentage of those consultations that are diagnosed as being malaria, the total monthly consultations were compared to the monthly data on malaria cases diagnosed at the health clinics. The results in Table 6.3 show that between April 2002 and April 2003, of the monthly total consultations in the five health clinics, the percentage of patients diagnosed and treated for malaria at these clinics ranged from a low consultation of 31% in March 2003 to a high consultation of 47% in June and February 2002.

Table 6.3: Seasonal variations in number of diagnosed malaria cases per month in the outpatient health facilities, April 2002 to April 2003

Month	Total consultations (all causes)	Total diagnosed malaria cases	% of total consultations that were diagnosed for malaria
April 02	12,386	4,741	38%
May 02	16,833	7,802	46%
June 02	14,357	6,713	47%
July 02	13,132	5,062	38%
August 02	14,340	5,218	36%
September 02	16,625	5,955	36%
October 02	13,794	4,665	34%
November 02	14,891	5,717	38%
December 02	9,957	3,980	40%
January 03	14,772	5,615	38%
February 03	14,457	6,840	47%
March 03	14,309	4,487	31%
April 03	15,447	5,083	33%

The break down by age of all cause consultations was not available from the record books. That is, it was not possible to determine how many of the consultations per month were with children under-five years of age and how many of the consultations per month were with patients over five years of age. However, the malaria specific data were broken down by age and it was, therefore, possible to determine what percentage of the total malaria cases were in children under-five years of age and what percentage were in patients over five years of age. These data are shown in table 6.4.

Table 6.4: Proportion of malaria cases diagnosed in patients under-five and over five years of age out of the total malaria cases diagnosed at the health clinics

Month	Total number of malaria cases	Malaria cases in <5 (% of total malaria case)		Malaria cases in >5 (% of total malaria cases)	
		No.	(%)	No.	(%)
April 02	4,741	1,867	(39)	2,874	(61)
May 02	7,802	3,471	(44)	4,331	(56)
June 02	6,713	2,776	(41)	3,937	(59)
July 02	5,062	1,615	(32)	3,447	(68)
August 02	5,218	1,859	(36)	3,359	(64)
September 02	5,955	2,045	(34)	3,910	(66)
October 02	4,665	1,784	(38)	2,881	(62)
November 02	5,717	2,214	(39)	3,503	(61)
December 02	3,980	1,568	(39)	2,412	(61)
January 03	5,615	2,347	(42)	3,268	(58)
February 03	6,840	2,399	(35)	4,441	(65)
March 03	4,487	1,976	(44)	2,511	(56)
April 03	5,083	2,222	(44)	2,861	(56)

The data in table 6.4 above show that of the total proportion of malaria diagnosed at the health clinics, the majority were over five years of age than under-five years of age. However, without the data on total clinic attendance by these age groups, it is not possible to make any comments about the relative burden of malaria in those under-five years of age compared to those over five years of age.

The data in this and previous sections provide a picture of the structure of the health system in the camp and an outline of the work load and relative proportion

of that work load that the providers ascribe to malaria. However, it does not reflect health care providers' characteristics and perceptions about malaria and its management in the camp, which are also important.

6.5.2 Characteristics of the providers studied

6.5.2.1 Study participants

The population of participants involved in the study of the case management of malaria consisted of all the health care providers directly involved in the management and control of malaria at the outpatient health facilities (referred to also as clinics) and their associated catchments areas in the camp. This included all clinical health workers, laboratory assistants, drug dispensers and community health workers who had worked in one of the five facilities for not less than one year and who were available (not on leave) during the study period. Community health workers working in the catchments areas associated with each of the five outpatient health facilities were specifically selected. A total of 50 health care providers were included in the study and details of the numbers of each type of provider and which part of the study they were involved in are provided in Table 6.5 below.

Table 6.5: Cadres of health care providers interviewed and observed

Health cadres (n=50)	Interviewed n=50	Observed n=24
Clinical Officers (2)	Yes	Yes
Medical assistants (14)	Yes	Yes
Laboratory assistants(9)	Yes	No
Drug dispensers (8)	Yes	Yes
Community Health workers (17)	Yes	No

The majority of these health care providers (47;94%) were locals recruited by the IRC from among the refugees in the camp. The few remaining providers (3;6%) were national staff recruited from Nairobi, the capital of the study country. Details of the health care providers' characteristics are illustrated in Table 6.6 below.

Table 6.6: Characteristics of the study participants

Characteristics	Clinical Officers (n=2)	Medical Assistants (n=14)	Laboratory Assistants (n=9)	CHW (n=17)	Dispenser (n=8)
Age in years					
19-44	1	7	9	12	8
45-55	1	6	0	4	0
>55	0	1	0	1	0
Gender					
Male	1	14	7	9	7
Female	1	0	2	8	1
Educational level					
• Primary	0	0	2	3	2
• Intermediate/Junior	0	1	3	5	4
• Secondary	0	11	4	9	2
• College/University	2	2	0	0	0
Religion					
Christian	2	7	5	8	4
Muslims	0	5	3	6	3
Others	0	2	1	3	1
Nationality					
Sudanese	0	8	5	10	4
Ethiopian	0	2	1	2	2
Eritrean	0	0	1	1	0
Somalis	0	3	2	2	1
Burundian	0	0	0	1	0
Congolese	0	0	0	1	1
Kenya	2	1	0	0	0
Duration of service					
1-3 years	2	8	3	10	5
4-5 years	0	4	4	3	2
>5 years	0	2	2	4	1

The two clinical officers working in the outpatient public health facilities in the camp had no permanent base, they rotated between the five facilities to supervise the clinical aspects of the work on a weekly basis or according to need. The medical assistants were based in one of the five health clinics (OPD) and rotated annually.

6.5.3 Perceptions of the malaria burden and refugee treatment-seeking behaviours in the camp

6.5.3.1 Perceptions of health care providers

The perceived high burden of malaria among the refugees in the camp was one of the factors highlighted by the preliminary study as influencing malaria treatment-seeking behaviours of the displaced population in the camp. In a similar manner, the providers' perceptions of the malaria burden in the camp may also influence their diagnostic and prescribing behaviour and their views on patient behaviours are likely to affect their patient management. To ascertain their views, the providers were asked (in the semi-structured interviews) their opinions regarding the burden of malaria in the camp and the factors they thought contributed to delays in patients seeking treatment. All of the health care providers said that the burden of malaria in the camp was high and mentioned drug compliance, delays in seeking treatment, and parasite resistance to drugs as possible factors affecting the high malaria burden in the camp. However, there was considerable variation between the cadres in their views as to other factors which might influence the high burden and these are summarised in Table 6.7.

Table 6.7: Perceived reasons for high burden of malaria in the camp

Reason	Clinical Health Workers (16)	Laboratory assistants (9)	Drug dispensers (8)	CHWs (17)
Drug compliance	11	5	5	8
Delay in seeking treatment	11	5	5	6
Imported malaria	16	5	-	2
Parasite resistance to drug	5	5	5	8
Misdiagnosing of malaria	-	4	8	13
Insufficient knowledge about malaria	5	-	3	6
Limited choices of malaria treatment	-	-	-	7

Note: More than one reason was indicated by health care providers as factors contributing to malaria burden in the camp

The data in table 6.7 suggest that the views of the clinicians and laboratory assistants tend to differ from the views of most of the community health workers and drug dispensers with regards to the reasons for the malaria burden in the camp. All of the clinicians and more than half of the laboratory assistants (5;55%) mentioned imported malaria as one of the possible factors responsible for the high malaria morbidity in the camp where as only 12% (2) of the CHWs and none of the dispensers mentioned this as a possible reason for the high burden of malaria. By contrast, all the drug dispensers, and three quarters of the CHWs (13;76%) mentioned misdiagnosis of malaria as a possible factor which contributed to the malaria burden in the camp. This compares to less than half of the laboratory assistants (4;44%) and none of the clinicians who held this view.

The drug dispensers (5;62%) were more in agreement with two thirds of the clinicians (11;69%), and over half of the laboratory assistants (5;55%) in their views that inappropriate treatment-seeking behaviour for malaria was a possible factor contributing to malaria burden, but only about one third (6;35%) of the CHWs agreed with this assessment. Over half of the laboratory assistants (5:55%) and drug dispensers (5;62%) reported the possibility of parasite resistance to the drugs (CQ & SP) used in treatment of malaria in the camp as a factor contributing to malaria burden in the camp and almost half of the CHWs agreed with this assessment (8;47%). However, fewer of the clinicians (5;31%) appeared to think that this was a problem. About a third of all the clinicians (5;31%), drug dispensers (3;37%) and CHWs (6;35%) mentioned insufficient knowledge about malaria as a possible factor contributing to malaria burden in the camp but none of the laboratory assistants mentioned this only. Just under half of the CHWs (7;41%) mentioned limited choices of malaria treatment as a possible factor contributing to the malaria burden in the camp. In summary, these results suggest that the clinicians are more likely to blame the patients for malaria burden in the camp while the CHWs are more likely to blame the clinicians for this burden. Table 6.7 below summarises health care providers' perceived reasons for high burden of malaria in the camp.

6.5.3.2 Delay in seeking treatment

The health care providers were asked why they thought the refugees might delay in coming to the health facilities to seek treatment for malaria. The factors mentioned most frequently by the health care providers as being possible reasons for delays in treatment-seeking included: drug compliance, cultural beliefs, traditional treatment, difficulty in recognizing malaria at the early stage of illness, difficulty in differentiating malaria signs and symptoms from other diseases, traumatic experiences, poor management of malaria at the health facilities, insufficient malaria knowledge, limited choices of malaria treatment,

lack of social support, drug ineffectiveness, high illiteracy rate, and difficult living conditions in the camp. The variations in views among the health cadres in the factors that influence delays in seeking treatment for malaria are shown in Table 6.8 below.

Table 6.8: Perceived reasons for delays in treatment-seeking for malaria

Perceived reasons for delay in seeking malaria treatment	Health care providers			
	Clinical Health Workers(16)	Laboratory assistants (9)	Drug dispenser (8)	Community health workers (17)
Drug compliance	15	6	6	10
Culture & traditional beliefs	15	-	-	-
Traditional treatment	-	2	2	3
Difficulty in malaria recognition	4	3	-	-
Difficulty in differentiating malaria from other diseases	5	-	-	-
Traumatic experiences	5	-	-	5
Poor management of malaria cases	-	-	-	10
Insufficient malaria knowledge	2	2	6	2
Limited choices of treatment	-	-	-	2
Lack of social support	2	-	-	3
Drug ineffectiveness	-	6	-	3
High illiteracy rate	8	-	-	-
Difficult living condition	1	-	2	-

Note: Participants mentioned more than one factor as reason for delay in seeking malaria treatment

The data from table 6.8 suggest that the majority of all providers felt that drug compliance (using left over drugs from a previous illness episode before visiting a health facility) was a factor influencing delays in seeking treatment from the public health facility. The majority of clinical health workers (15;94%) also said that culture and traditional beliefs affected timing of treatment at the health facilities but this was not mentioned by any of the other cadres. In addition, the majority of the other reasons given by the clinical health workers for treatment delays (difficulty in malaria recognition, difficulty in differentiating malaria from other disease, insufficient malaria knowledge and high illiteracy rate) related to poor knowledge among the patients. In contrast, over half of the CHWs (10;59%) said that poor management of malaria cases at the clinic was a factor contributing to delays in seeking treatment from the clinic. However, almost a third of clinical health workers (5;31%) and CHWs (5%29%) agreed that traumatic experiences were likely to be a factor contributing to delays in seeking treatment at the health facilities.

6.5.4 Malaria management at the outpatient public health facilities

6.5.4.1 Reported management

In addition to investigating perceptions of disease burden and reasons for delays in treatment, the providers of clinical care at the health facilities were asked about their malaria management practices. The two clinical officers and the 14 medical assistants (16 clinical workers) were asked how they managed malaria cases at the outpatient health facilities in the camp. Overall little variation was found among the clinical health workers from the different outpatient health facilities with regards to their clinical practice in management of malaria. That is, there appeared to be no systematic variation in practice by clinic, with as much variation in reported practice occurring among health workers within one clinic as among clinics. The majority of the data are, therefore, presented collectively.

Most of the of the clinical health workers (12;75%) mentioned following the IRC guidelines' for the case management of malaria in the camp, but a quarter (4;25%) of the clinical health workers (one each from clinics 1,3,4 and 5) said that they were unable to strictly follow all the procedures as outlined in the guidelines due to the large number of patients presenting to the health facilities and the limited time they had to effectively carry out their work. These four clinical health workers said that they took a brief history of patients, and only examined when necessary, before reaching a diagnosis and prescribing the appropriate drugs.

The clinical health workers were asked what they did when they first came into contact with patients during consultations at the health facilities. All of the clinical health workers (16;100%) interviewed mentioned that they usually greeted patients, offered them a seat and asked them the purpose of their visit to the health facility. The clinical health workers were also asked if they took a history from the patients during the consultations at the health facilities. All of the clinical health workers (16;100%) said that they usually took a history from the patients during the consultations. However, only two clinical health workers (one clinical officer and one medical assistant) reported asking patients presenting with fever the duration and nature of fever as well as other questions related to febrile illnesses. A quarter (including the other clinical officer) (4;25%) reported asking about the duration (but not the nature) of the fever as well as questions related to other febrile illnesses, while three clinical health workers (19%) indicated asking about the duration and nature of fever but no other questions. Almost a half (7;44%) said that they only asked about the duration of the fever. The results are summarised in Table 6.9.

Table 6.9: Reported history taking for patients presenting with fever

Enquiry about fever	Clinical Officers (2)	Medical Assistants (14)	Total
Duration of fever only	-	7	7
Duration and nature of fever	-	3	3
Duration of fever and questions related to other febrile diseases	1	3	4
Duration and nature of fever and other questions related to febrile diseases	1	1	2

The clinical health workers were asked how frequently they physically examined patients presenting at the formal outpatient health facilities with uncomplicated febrile illnesses. Around two thirds (10;63%) of the clinical health workers from all five facilities said that they frequently conducted a general examination which included: examination of the eyes, mouth and hands for pallor and dehydration, throat and ears for infection, and the abdomen for enlarged spleen and liver. These ten clinical health workers also reported that they measured auxiliary temperature using a thermometer. Where a temperature of more than 37.5C was recorded this was considered a sign indicative of fever. Of the 10 clinical health workers who reported carrying out a physical examination of patients, 4 of them were among the 7 clinical health workers who mentioned asking patients presenting with fever the duration of the fever only, 2 of them were among the 3 who mentioned asking patients presenting with fever the duration and nature of the fever and 1 of them was from among the 4 who mentioned asking patients with fever the duration of the fever and history of other febrile illnesses. Neither

of the two clinical health workers who reported asking a full set of questions, also reported making a general physical examination.
The remaining one third (6;37%) of the clinical health workers said that, due to limited time and the large number of patients presenting to the health facilities, they only conducted a partial physical examination. For any given patient, the extent of the examination and which particular examinations were used depended on patient's complaints and their condition during presentation at the health facility.

The clinical health workers were then asked if, when they decided to carry out a physical examination, they actually explained to patients the reasons and procedures for examination. Only three clinical health workers (3;19%), (two of whom had mentioned carrying out general examinations of patients and one of those who reported carrying out partial examination of patients), said that they usually explained to the patient the reason for being examined and the procedures of the examination. The majority (13;81%), however, mentioned that it was not necessary to explain to patients reasons for the examination because patients would not understand. Three of these thirteen said that even if they wanted to explain to patients the examination procedures, given the workload in the health facilities and the number of patients they had to see in a day, time would not allow them to do so. In addition, two of these three indicated that explaining to patients examination procedures was a western style of handling patients which is not applicable in Africa. In expressing their views on the issue, one of the medical assistants had this to say:

"In Africa we don't explain to patients procedures of physical examination. These are western cultures and are not meant for us."

Following the general questions on their history taking and examination of patients, the clinical health workers were asked how they reached a diagnosis of malaria among patients presenting with suspected uncomplicated malaria or

febrile illnesses. All of the clinical health workers said that they used both presumptive and laboratory diagnosis for suspected uncomplicated malaria. Presumptive diagnosis based on clinical features was reported to be the most common way of diagnosing suspected malaria because of too many patients presenting at the formal outpatient health facilities to allow for laboratory diagnosis of all of them. When asked about the type of patients they referred to the laboratory for a malaria parasite test, all of the clinical health workers (16;100%) indicated that there were several criteria that they used for selection of patients to be referred to the laboratory for a malaria parasite test. These criteria included: patients who presented at a late stage of the disease, patients with complicated histories that were difficult to diagnose presumptively and patients who failed to recover from malaria after completing a full dose of antimalarial treatment. With regards to the type of laboratory tests ordered for malaria, all the clinical health workers (16;100%) said that the microscopic blood test for malaria parasites was the only test available in the outpatient health facilities to confirm their clinical diagnosis. The clinical health workers were each then asked their opinions on the reliability of the laboratory tests. Over two thirds of the clinical health workers (11;69%) said that they trusted the malaria results they received from the laboratories, but the remaining one third (5;31%) said that to some extent they doubted the results and thought most of the laboratory results were not reliable. The reasons that these five clinical health workers gave for not trusting the results were: poor skills among the laboratory technicians, the possibility that drug compliance would affect the presence of parasites causing the negative results and, finally, that quality of the microscope in the health facilities, which rely on the presence of sunlight, was poor.

The clinical health workers were also asked whether, having made a diagnosis, they informed patient of the diagnosis they had reached. Three quarters (12;75%) of the clinical health workers said that they did inform patients of their

diagnosis, but a quarter of them (4;25%) said they did not because they did not consider it to be necessary.

Following a diagnosis of malaria, the clinical health workers were asked about the type of antimalarial treatment they would prescribe. All of the clinical health workers reported following the IRC's recommendation for malaria treatment in the camp, which (at the time of the interviews) included CQ as the first line drug and SP as the second line treatment for suspected uncomplicated malaria. Quinine or AQ tablets were recommended for the third line treatment for complicated malaria cases. However, all of the clinical health workers indicated that patients were frequently reluctant to accept a prescription for CQ, complaining either that it produced side effects or that it didn't work. Under these circumstances the clinical health workers said that they were forced to prescribe SP as a first line treatment. In addition, while some of the clinical health workers were happy with the continued use of CQ as the first line drug, others would have preferred to switch fully to the use of SP.

Despite the fact that CQ as the first line treatment for malaria in Kenya had been banned by the Kenyan Ministry of Health, these data show that in the autumn of 2002 the IRC was still supplying the outpatient health facilities with CQ and recommending them to use it. It was not until January 2003 that the IRC recommended the switch to the use of SP only as the first line treatment of malaria in the camp. This was after the use of the last stock of CQ.

After the diagnosis of malaria and the prescription of an antimalarial drug, the clinical health workers were asked whether they explained to patients how to administer the anti malaria drugs they prescribed. In addition, they were asked if they thought the patients adhered to the treatment instructions that they had been given. A quarter (4;25%) said that they explained to patients how to administer the drugs and thought that patients did adhere to the instructions. Just less than half (7;44%) of the clinical health workers said that they explained to

patients how to administer the malaria drugs prescribed but they had doubts about whether patients adhered to the instructions or not. The remaining clinical health workers (5;31%) said that they had no time to explain to patients how to administer the prescribed drugs and indicated that it was the work of the drug dispensers to explain to patients how to administer the drugs they dispensed. In a further question the clinical health workers were asked if they informed patients about the side effects of the drugs that they prescribed. Half of the clinical health workers (8;50%), all of whom had mentioned instructing patients on how to administer the drugs prescribed, said that they did usually inform patients about possible side effects of the drugs. The remaining half (8;50%) said that they didn't inform patients about the possible side effects of drugs, and almost all of them attributed this to their lack of time.

Regarding individual health education during consultations, most (10;62.5%) of the clinical health workers said that they usually gave the patients brief health education concerning the diagnosed disease while the remaining third (n=6;37.5%) said they didn't give any health education due to limited consultation time. The use of prophylaxis as a preventive measure for malaria in the camp was stated by all clinical health workers as non existent and not recommended by IRC.

6.5.4.2 Observed case management

To determine the correspondence between what the clinical health workers reported they did and what they actually practiced, they were observed in their clinics over a series of consultation sessions to see their actual (or best) practice in the management of malaria cases. A total of 320 consultations were observed. These involved the management of 194 patients over five years of age and 126 children less than five years of age. The clinical health workers (16;100%) were observed through a total of 32 sessions with each clinical health

worker being observed over 2 sessions. For each clinical health worker one observed session took place in the clinic for children under-five years of age and the other observed session took place in the clinic for patients over five years of age. Each session lasted for between 45 minutes and one hour during which 10 consultations were observed. This gave a total observation of 320 consultations. Table 6.10 illustrates the results from the observations.

Table 6.10: General characteristics and description of consultations in the outpatient health clinics

General characteristics	Consultations <5 years (n=126)	Consultations >5 years (n=194)
First encounter with pt	**No. %**	**No. %**
Patient/Co patient greeted	107 (85)	139 (72)
Name, address, sex & age recorded	125 (99)	192 (99)
Duration of consultation		
<3 mins	70 (56)	109 (56)
3-5 mins	48 (38)	73 (38)
6-10 mins	8 (6)	12 (6)
Symptoms reported		
Fever only	42 (33)	36 (19)
Fever and headache	2 (2)	44 (23)
Fever and cough	31 (25)	18 (9)
Fever & body weakness	3 (2)	22 (11)
Fever with other symptoms	12 (10)	13 (7)
Cough	20 (16)	30 (15)
Other symptoms (no fever)	16 (13)	31 (16)
History taking: Inquiry		
Duration of fever only	36 (28)	53 (27)
Duration & nature of fever	29 (23)	46 (24)
Duration of fever & questions related to other febrile illness	16 (13)	20 (10)
Duration & nature of fever & questions related to febrile illness	9 (7)	14 (7)
Inquiry on symptoms of other illness	28(22)	42 (22)
No enquiry or probing	8 (6)	19 (10)
Clinical examination		
Temperature checked/taken	17 (13)	22 (11)
Body checked for pallor	10 (8)	14 (7)
Respiratory tract checked	26 (21)	17 (7)
Abdomen checked	2 (7)	8 (4)
Other parts of body checked	7 (6)	12 (6)
Laboratory diagnosis		
Lab examination for malaria ordered	16 (13)	46 (24)
Diagnosis reached		
Lab diagnosed malaria cases	5 (4)	9 (5)
Clinically diagnosed malaria cases	63 (63)	118 (61)
Malaria with RTIs	14 (11)	12 (6)
Others	44 (35)	55 (28)
Treatment prescribed*		
Fansidar	37 (29)	79 (41)
Chloroquine Tablets	42 (33)	29 (15)
Quinine/Amodiaquine Tablets	3 (2)	31 (16)
Antimalarial plus antibiotics	14 (11)	12 (6)
Antibiotics	18 (14)	32 (16)
Others	26 (21)	23 (12)

The data in table 6.10 suggest that overall the management of patients under-five years differed very little from the management of patients over five years. While the majority of the patients (or their care-givers) were greeted when they entered the consultation room, more than half of the consultations in both age groups lasted less than three minutes (<5 yrs, 56%; >5yrs, 56%), just over a third lasted between three and five minutes (<5yrs, 38%; >5yrs 38%), and less than 10% lasted more than five minutes (<5yrs, 6%; >5yrs, 6%).

History taking appears to have been limited, with about a quarter of patients in each age group (<5yrs, 28%; >5yrs, 27%) only being asked the duration of the fever and no other questions, and a few patients being asked no questions at all. Physical examinations appear to be rare although more under-five year old patients were observed being examined than patients over five years of age. Some patients had more than one type of physical examination but the majority of patients in both age groups were not examined at all. Of the total patients diagnosed for malaria, less than a quarter were physically examined. In addition, during the observed sessions while the majority of the patients reported having a fever, only 13% of those under-five years of age and 11% of those over 5 years of age had their temperatures taken with a thermometer. Checking the respiratory tract was more common among children under-five than in patients over five (<5yrs,25%; >5yrs,7%), even though the reported prevalence of cough was similar between the age groups (<5yrs, 16%; >5yrs,15%).

In terms of symptoms that were most commonly present among patients during the observation sessions, around 70% of the total patients (71% of those under 5 years and 69% of those over five years) presented with fever. Fever with headache was more commonly reported in patients over 5 years of age (23%) while fever with cough was more commonly seen among patients under-five years of age (25%). After fever and headache, cough was the third most frequently mentioned symptom, and a half of the total patients (both under 5

years of age and over five years of age) who did not have fever presented with cough to the health facilities.

With regards to the 223 patients presenting with fever to the health facility, 221 or 99% of them were diagnosed with malaria. Of the 90 children under-five with fever, 82 (91%) were diagnosed with malaria or malaria with RTIs. On the other hand, among the participants over five years of age, all (100%) of them with fever (n=133) were diagnosed with malaria and in addition, 6 without fever were diagnosed with malaria (the total number of patients over five years of age diagnosed with malaria was 139). Overall 65% of the 126 children under-five years of age presenting to the clinical health workers during the observation sessions were diagnosed to have malaria and 72% of the 194 patients over five years of age presenting to the clinical health workers during the observation sessions were diagnosed with malaria.

Despite the IRC guidelines, among the over five year old patients, the most frequently prescribed antimalarial drug was Fansidar. Fifty seven percent (79/139) of all the patients over five years of age who had been diagnosed with malaria were given this drug. During the observed consultations, fewer than a quarter (20%) (29/139) of patients over five years of age with malaria were actually prescribed with chloroquine. Among the patients under-five years of age, the prescribing of Fansidar was slightly less, with 45% (37/82) of those diagnosed with malaria being prescribed the drug. The prescription of chloroquine in this age group was more frequent with 51% of children under-five years of age diagnosed with malaria being prescribed the drug. The clinical health workers had mentioned in their interviews that they sometimes came under pressure from patients to prescribe a particular drug and it is possible that the female care takers of children under-five were less likely to demand a particular drug from the clinical health workers than were adult male patients

During the observed consultations, treatment instructions given to patients and children's parents or care takers were very limited. Only about one third of patients above five years and a quarter of children's parents or care takers were given instructions on how to administer the prescribed drugs. Less then a quarter were informed about side effects of drugs prescribed and only a very few were given brief health education on the diagnosed disease.

6.5.4.3: Reported practice by clinical health workers verses actual practice in case management of malaria

The data on observed practice in the management of malaria in the previous section would suggest that the reported behaviour of the clinical health workers varies considerably from their usual practice. To investigate this difference in greater detail the findings from the interviews were compared to the data collected during the observations. These data (Table 6.11), illustrating the differences that existed between what the clinical health workers said that they did and what was actually observed in the management of malaria at the health clinics, suggest that not all clinical health workers practiced what they reported they practiced while managing malaria cases at the outpatient health facilities in the camp. These findings show that during the observed sessions none of the clinical health workers fully followed the IRC guidelines for the case management of malaria although 12 of the clinical health workers had said in the interviews that they always or usually followed the guidelines. By contrast, the four clinical health workers who said that they only partially followed the guidelines were observed undertaking this practice. All of the clinical health workers had said that they always greeted a patient and gave them a seat where as in fact fewer than half of the clinical health workers (7:44%) were observed always greeting their patients and only three quarters (12;75%) were seen to always give their patients a seat. On the other hand, all of the clinical health workers said that they took the name and address of every patient and in all of the observed

sessions they were all observed recording the name, address, and age of each patient. In terms of history taking, only 4 out of 7 clinical health workers who said they usually enquired about the duration of fever were observed actually undertaking this practice. Furthermore, of the remaining 9 clinical health workers who said that they probed more deeply into the duration and nature of the fever, only 5 were observed doing so during the observed sessions. The reported frequency of physical examinations also appears to have been exaggerated since while 10 of the clinical health workers said that they usually carried out a general exam, only 2 were regularly seen to undertake this practice during the observed sessions. In addition, only 3 out of the 6 of those who said that they usually carried out a partial examination were actually observed carrying this out and only 1 of the 3 who said they explained the examination process were seen doing so. Only 4 out of 12 clinical health workers who mentioned informing the patient of the diagnosis reached were observed actually undertaking this practice. Treatment instructions given to patients were very limited. Only 3 out of 13 clinical health workers who indicated giving patients treatment instructions were observed actually undertaking this practice and 2 out of the 8 clinical health workers who informed patients about the side effects of the drugs prescribed were observed actually undertaking this practice.

Table 6.11: Reported practice by clinical health workers verses observed practice in the management of malaria cases

Indicators	Usual practice by clinical health workers (16) in case management of malaria	Reported usual practice No.%	Actual practice No.%
Adherence to guidelines in case management of malaria	-Guidelines fully followed -Guidelines partially followed	12(75) 4(25)	0 4(25)
First contact with patient	-Patient greeted -Patient given a sit -Name, address and age recorded	16(100) 16(100) 16(100)	7(44) 12(75) 16(100)
History taking	**Inquiry made on:** -Duration of fever only -Duration and nature of fever -Duration of fever and questions related to other febrile illness -Duration and nature of fever questions related to other febrile illness	 7(44) 3(19) 4(25) 2(12)	 4(25) 2(12.5) 2(12.5) 1(6.25)
Medical Examination	-General examination carried out -Partial examination carried out -Pts explained examination process	10(63) 6(37) 3(19)	2(12.5) 3(19) 1(6)
Diagnosis	-Laboratory examination ordered for particular patients as reported -Presumptive diagnosis based on clinical features mostly used -Patient informed of diagnosis	16(100) 16(100) 12(75)	16(100) 16(100) 4(25)
Treatment	-Patients given treatment according to reported guidelines -Patients given instructions of how to administer drugs -Patients informed of drug side effects	16(100) 11(69) 8(50)	16(100) 3(19) 2(12.5)
Health education	-Individual brief health education given during consultation	10(62.5)	2(12.5)

6.5.4.4 Laboratory diagnosis: Reported behaviour

Accurate diagnosis of malaria is essential to ensure appropriate treatment and management. The process of laboratory diagnosis for malaria in the camp was investigated through interviews with the laboratory assistants (n=9). Their views were elicited on the laboratory diagnosis of malaria at the formal health facilities in the camp. The interviews included information on: the type of laboratory test for malaria they carried out; their perceptions of the accuracy and reliability of the results usually produced; the difference, if any, noted in results with regards to seasonality, and the difficulties they faced in carrying out their work. All of the laboratory assistants working in the outpatient health facilities said that they carried out peripheral smear tests for malaria parasites. They reported that they stained the smears with giemsa stain but, as was found during the parasite prevalence survey (results in the following chapter), in actual practice, they often used Field's stain. In each of their clinics they reported receiving between 8-20 patients referred for blood test for malaria parasite per working day. Out of the 8-20 blood slides obtained, they said that they usually confirmed between 1 and 5 (12.5%-25%) blood slides as being positive for malaria parasites. The majority of these were *P. falciparum.* The percentage of positive results showed little variation by season. When they were asked their perceptions of the accuracy and reliability of the results for malaria parasites that they produced, just under half of the laboratory assistants (4;44%) said that they trusted their results. More than half of the laboratory assistants (5;56%) said that they doubted the results. The reasons they gave for their concerns were: firstly that the type of microscope (leica with sunlight mirror) they used in the outpatient health facilities was not good enough to detect the parasites when there was not enough sunlight, and secondly they felt that the training they received was insufficient to enable them produce quality work. When they were asked for their views on why the malaria results they produced were in most cases negative, despite their perception of high malaria morbidity in the camp, the majority of the laboratory assistants

(6;67%) reported several factors which they thought contributed to the frequent negative results. These factors included: weather pattern (3;33%), self treatment with anti malaria drugs (5;56%), the poor quality of microscopes used in the outpatient facilities (4;44%), and insufficient training (5;56%). The five participants who were concerned about their lack of training were all younger (in their twenties or early thirties) than their colleagues who were more sure of their own performance (in their late forties and fifties). Two of the older laboratory assistants who had more experience than the others said that they believed most of the patients sent for laboratory test had actually been misdiagnosed for malaria and they actually they had other illnesses. These two laboratory assistants differed from their colleagues with regards to experience in the job and their formal education background. One had worked in the outpatient laboratory facility for about 8 years and the other for 6 years. Both had their formal education to the secondary level before being trained as a laboratory assistant, unlike their colleagues who had less than 5 years in the job and were educated to the intermediate (Junior) level. In expressing their views, one of the experienced laboratory assistants had this to say:

"Not all fevers people have are malaria. Look at the poor hygiene behaviour in the camp. I also suspect typhoid should be a problem. Many other diseases present with fever as well. But in these clinics, the moment you mention fever, you are diagnosed for malaria".

Further information on the quality of laboratory diagnosis is presented in the following chapter on the parasite survey.

6.5.4.5 Drug dispensing

The opinion of drug dispensers (8;100%) was elicited to determine their dispensing practice and the types of antimalarial drugs being dispensed, as well as their relationships with prescribers (clinical health workers). They were also

asked about their perceptions of whether patients understood and adhered to treatment instructions, their general opinion on drug compliance in the camp, and any difficulties they had that hindered their work.

6.5.4.6 Reported drug dispensing

When they were asked about their dispensing practice, all of the dispensers (8;100%) said that they had to prepare the drugs to be dispensed by checking availability and expiry dates of the drugs in the health facility store and by making sure that new tins of drugs to be dispensed were opened according to their expiry dates. Drugs with short expiry dates were dispensed first. Before dispensing the drugs, all dispensers (8;100%) said that they first interpreted the patient's prescriptions and then confirmed it. The majority said they had no problems in interpreting and understanding the prescriptions they were given. Despite complaining of limited time they said that in addition to preparing the prescribed drugs and giving them to the patient, they also gave instructions on how to administer the drugs appropriately according to the prescription. Three quarters (6;75%) of the dispensers said they made sure patients understood the instructions communicated to them. They reported that they warned patients to strictly follow the instructions given, and told them of the consequences of not complying with the instructions. Almost all of these dispensers (5) mentioned using symbolic instructions as a communication method to pass on information to patients who had difficulty in understanding the verbal instructions. With regards to the antimalarial drugs dispensed, all dispensers (8;100%) mentioned SP, CQ, quinine or amodiaquine as the antimalarial drugs that they often dispensed. The majority (6;75%) mentioned both SP and CQ as the most frequent anti-malaria drugs dispensed.

The drug dispensers were asked about their relationships with the clinical health workers. All of the dispensers (8;100%) said that they had a good relationship

with the clinical health workers who wrote the prescriptions. With regards to factors hindering their work, all of the dispensers mentioned more than one factor affecting the efficiency of their work. These included: the language barrier (6;75%), limited time (7;87.5%), unreadable prescriptions (2;25%), and work overload in the health facilities (5;62.5%). The dispensers said that there were nine different nationalities in the camp, which were further sub-divided into several ethnic groups, and each group speaks a different language. The majority of the dispensers (6;75%) doubted if patients always clearly understood the explanations they gave on how to correctly administer the medication or drugs, particularly when instructions were given through translators. The time factor was a major problem for most of the dispensers and they indicated how difficult it was to clearly explain to patients how to administer the drugs dispensed and to make sure patients understood the instructions in the limited time available. However, 2 of the dispensers thought patients did adhere to treatment instructions that were given with the help of translators. These two differed from the rest with regards to their formal educational background. They were the only two who were educated to the primary level, compared to the others who were mostly educated to the intermediate and secondary level.

6.5.4.7 Observed drug dispensing

As with the clinical health workers, drug dispensers were observed to determine their practice in dispensing drugs, to investigate the correspondence between what they reported and what they actually practiced. All the dispensers (8;100%) interviewed were observed while dispensing drugs to 320 patients. These were the same patients the clinical health workers were attending too when they were being observed. Table 6.12 describes the characteristics of dispensers during their practice at the health facilities.

Table 6.12: General characteristics and description of dispensing practices in all the five outpatient health clinics

General characteristics (All 8 dispensers observed)	Total consultation observed from all five clinics (n=320)	
	NO	%
Dispensers understood & could translate prescription		
Prescription clear and readable	301	94.1
▪ Prescription not clear and needed to be cross-checked with patient or prescriber	19	5.9
Dispensers correctly identified prescribed drugs		
▪ Availability of drugs checked	320	100
▪ Expiry date checked	320	100
▪ Old drug stock used first	320	100
Dispensers correctly interpreted prescription		
▪ Name of drugs clearly labelled	316	98.8
▪ Dosage indicated as prescribed	311	97.2
▪ Duration indicated as prescribed	295	92.2
Dispensers communicated the correct way		
▪ Communicated exactly as prescribed	289	90.3
▪ Symbolic instruction used for of illiteracy	24	7.5
▪ Warning and cautions provided to enhance compliance	33	10.3
Dispensing (interaction) time		
< 2 min	178	55.6
2-3 min	91	28.4
4-5 min	36	11.3
6-10 min	12	3.8
>10 min	3	0.9
Total antimalarial drugs dispensed		
▪ Fansidar tabs	116	36.3
▪ Chloroquine tabs	71	22.2
▪ Quinine/Amodiaquine tabs	34	10.6

The data in table 6.12 suggest that almost all of the prescriptions received by the dispensers were clear and easily interpreted. Dispensers correctly identified prescribed drugs and checked the availability and expiry dates of the drugs before they were dispensed. Over 90% of the drugs dispensed were clearly labelled, duration and dosage of the drugs indicated and instructions

communicated to patients correctly as prescribed. Only about 10% of the patients were warned on the importance of adhering to treatment and even fewer (7.5%) were given symbolic instructions. Waiting time, as defined as time from the moment prescriptions were given to the time drugs were received, was short. The time varied from 1 to 10 minutes, with over half of the patients receiving drugs in 1-2 minutes, and only 3 patients having to wait for 10 minutes.

To determine the correspondence between drug dispensers' reported practice and what they actually practiced, the data on reported practice was compared to observed practice. The results are shown in table 6.13.

Table 6.13: Reported practice by drug dispensers' verses observed practice in dispensing antimalarial drugs

Indicators	Practice in case management of malaria at health facilities	Reported practice No. %	Actual practice No. %
Receiving prescriptions	Dispenser received prescription and crosschecked name with patient	8(100)	8(100)
Preparing anti malaria drugs to be dispensed	Availability of drug checked	8(100)	8(100)
	Expiry date checked	8(100)	8(100)
	Old stock used first	8(100)	8(100)
Interpreting prescription Correctly	Name of drugs clearly labelled	8(100)	7(87.5)
	Dosage indicated as prescribed	8(100)	8(100)
	Duration indicated as prescribed	8(100)	6(75)
Communicating drug instructions to patients during dispensing process	Communicated instructions correctly	8(100)	7(87.5)
	Made sure patient understood instructions	6(75)	2(25)
	Used symbolic instructions as well	5(63)	2(25)
	Provided warning and caution to enhance compliance	6(75)	1(12.5)
Type of anti malaria drug dispensed	Fansidar, Chloroquine, Quinine/amodiaquine	8(100)	8(100)

The data in Table 6.13 show that, in general, there was little difference between the reported and actual practice of drug dispensers in dispensing drugs to patients in the outpatient health facilities. All dispensers mentioned interpreting prescriptions correctly without difficulties but observations showed that one of the dispensers had a problem in labelling drugs accurately as prescribed. He had a very bad handwriting which was unreadable. With regards to duration of drugs, two dispensers, sometimes didn't label drugs with the correct duration as prescribed.

However, while in the preparation of the drugs the reported behaviour corresponded closely with the observed behaviour, for the actual delivery of the drug to the patient there were considerable differences between reported and observed behaviour. The treatment instructions given to patients by drug dispensers were frequently insufficient. Only 2 out of 6 dispensers who said they gave instructions were observed actually giving patients instruction on how to administer the antimalarial drug appropriately. Furthermore, only 2 out of 5 dispensers who reported using symbolic instructions for patients who had difficulty in understanding verbal instruction were observed actually giving symbolic instructions. With regards to warning patients and cautioning them on the importance of complying with drug administration, only 1 out of 6 dispensers who reported giving warnings actually did provide patients with such warnings.

6.5.5 Health Education

Community health workers were asked about the nature of their job with regards to malaria control in the camp. All of the community health workers (n=17;100%) said that health education awareness was their major health activity in the control of malaria in the camp. They reported that it was their responsibility to raise awareness about the causes of malaria, its mode of transmission, the clinical features of the disease, the importance of early treatment and compliance with

antimalarial drugs. It was also their responsibility to raise awareness about malaria preventive methods. They also reported that during home visits they would refer ill patients suspected of malaria to the health facilities. When asked about their perceptions of the community's knowledge about malaria, most (12;71%) of the community health workers said that, in their opinion, knowledge about malaria in the majority of the community was poor. A few (5;29%), however, thought that the refugees had a relatively good knowledge of malaria from the cultural point of view, and that these ideas coincided, to some extent, with the biomedical views. When asked how they thought their work contributed to the prevention and control of malaria in the camp, the majority (14;82%) of the community health workers said that it was difficult to tell, but at least they believed most of the refugees were becoming more aware of malaria and methods for its prevention. They also thought that many of the refugees were beginning to realize the importance of seeking treatment at an early stage of the disease and complying with treatment instructions. The remaining three community health workers, however, said that they were not seeing much impact in their efforts to raise awareness about malaria in the camp. They felt that there was little response from the community and that many of the refugees were reluctant to accept changes in behaviour in an effort to control malaria in the camp. They attributed this reluctance and these difficulties to the violence and trauma most refugees had undergone and the difficult living conditions in the camp that were forcing people to turn more of their attention to a search for survival.

6.6 SUMMARY

The aim of this chapter was to investigate the quality of malaria management in the formal health facilities in the camp. It assessed the perceptions of health care providers on burden of malaria in the camp and determined their knowledge, attitude and practice in management and control of malaria.

The study revealed that many of the health care providers were concerned about a high malaria burden in the camp. The health care providers associated the burden with both clinical and non clinical problems in the camp. Differences were noted among the health cadres with regards to their perceptions of the factors contributing to burden of malaria in the camp. Apart from drug compliance and resistance, the clinical health workers (clinical officers, medical assistants) mentioned imported malaria, and delay in seeking treatment as factors contributing to malaria burden in the camp, while the non-clinical health workers (dispensers, community health workers) mentioned inaccuracy in malaria diagnosis and poor quality of malaria management at the health facilities as factors contributing to malaria burden in the camp. Clinicians tended to blame the refugees for the high burden of malaria and delays in seeking treatment while the CHWs tended to blame the burden and treatment-seeking delays on the poor management and diagnosis of malaria by the clinical health workers at the public health facilities. The perception of the non-clinical health workers was similar with the opinions of refugees who took part in the FGDs in the preliminary study. That is, both groups felt that misdiagnosis of malaria and poor management of patients at the formal health facilities was one of the major factors affecting treatment-seeking behaviour for malaria in the camp. However, data from the interviews with all of the health cadres and the results from the preliminary studies and the interviews with the refugees suggest that not completing a course of drugs and saving some at home to use in the next illness episode (before visiting the health facility) was a fairly common practice.

Looking at the structural component of quality of malaria management, the data suggest that the organisation functions relatively efficiently, the physical structures of the health facilities were well constructed and although some appeared too small to occupy the daily attendance, none of the health care providers or patients complained about the physical structures of the health

facilities. However, they did indicate that they thought there were not enough facilities to meet the health demands of the total refugee population. A few of the health care providers, e.g. the laboratory assistants, were not satisfied with the quality of equipment provided in the facilities. However, it was also observed that not all the medical equipments provided in the health facilities were used by the clinical health workers in case management of malaria.

While the physical structure appeared adequate, there were problems with under-staffing and insufficient training. All cadres of health staff complained of too many patients and too little time, and the data from the consultation records together with the data collected during the observation sessions and general ethnographic fieldwork would tend to support these claims. The training of the health care providers was insufficient, there was a chronic lack of refresher training, supervision or quality control measures and most of the providers (particularly among the laboratory technicians) had no confidence in carrying out their work appropriately.

Looking at the process of the quality of the management of malaria in the health facilities, the results have shown that although the health care providers knew about the content of the IRC guidelines, and their reported behaviour was in accordance with the National and IRC guidelines, the actual observed practice rarely followed the guidelines. Interestingly, despite the fact that most of the health care providers (33;66%) appeared to have good knowledge about their respective guidelines in management of malaria in the camp, no hard copies of the guidelines for malaria management were available in any of the five outpatient health facilities and none were available in the IRC head office in the camp or in the sub office in Kakuma camp.

Malaria diagnosis in the camp was mostly presumptive, based on clinical features. The majority of the consultations lasted not more than 5 minutes, with most of the consultation happening in 2-3 minutes. History taking and clinical

examination among patients under-five years of age and over five years of age were totally insufficient. Data from the observations showed that the onset and nature of fever most patients presented with to the health facilities were not investigated and history taking was either partial or non-existent. As the signs and symptoms of malaria overlap with several other acute febrile illnesses, adequate history taking and clinical examinations are essential in the presumptive diagnosis of a disease, otherwise the risk of over-diagnosis or under-diagnosis remains high. During the observed sessions 82% of the children under-five with a fever were diagnosed with malaria but, more importantly perhaps, all the over fives with fever were diagnosed with malaria, and in addition, six patients over five years of age who didn't present with fever were also diagnosed with malaria. During the observed sessions approximately 69% of the patients seen (221 out of 320 total consultations) were diagnosed with malaria. By contrast, the monthly records from the health clinics suggest that on average between 31% and 47% of total consultations are diagnosed with malaria. The higher percentage diagnosed during the observed sessions may be just a consequence of the small number, but it may reflect the clinical health workers' response to being observed by researchers who were known to be interested in malaria.

The clinical health workers said that they adhered to the IRC's guidelines in treatment decisions but from the observations it appeared that the majority of patients diagnosed with malaria were prescribed with SP. While these prescribing practices may have been in line with the Kenyan National Guidelines, they were not in accordance with the IRC guidelines that were in operation at the time of the study. Treatment instructions given to patients were insufficient as well. More than two thirds of patients were not given instructions on how to administer the drug and for the few who were instructed how to administer the drugs dispensed, no effort was made to help them understand the instructions being given. In addition, only two of the clinical health workers and one of the

drug dispensers gave any advice on possible adverse side effects or cautions about completing a full dose of the drug. However, the majority of the drug dispensers demonstrated appropriate practice in dispensing antimalarial drugs to patients, but a few did not follow the guidelines strictly in dispensing drugs. Even if almost all the drug dispensers correctly communicated instructions to patients, no efforts were made to ensure patients understood what they had been told. Language was a barrier to effective communication as not all dispensers knew the different languages spoken in the camp and had to work through translators who were not very knowledgeable about communication in dispensing of drugs.

The laboratory investigations for malaria parasite in the camp were limited. Only a few patients were sent for laboratory diagnosis of malaria and these were mainly: patients who presented at the late stage of the disease, patients with a complicated history that was difficult to diagnose presumptively and patients who failed to recover from fever after taking anti malaria treatment. Laboratory results for malaria parasite tests were mostly negative. There are three possible reasons for this. Firstly, the malaria burden in the camp is not as high as perceived by health care providers; secondly, decisions made to send patients to the laboratory for further investigation were not appropriate or thirdly that the standard of slide taking and/or reading was too poor to identify parasitaemia. It should be noted that just over half of the laboratory assistants had little confidence in themselves, saying the training they received was inadequate for them to perform quality work and they were uncomfortable with the type of equipment used for laboratory diagnosis of malaria at the outpatient health facilities.

CHAPTER 7: MALARIA PREVALENCE SURVEY

7.1 INTRODUCTION

Refugee perception of a significant malaria burden in the camp is one of the factors highlighted by the preliminary study as affecting treatment seeking behaviours for malaria. Participants perceived malaria in the camp to be a great burden and more severe than malaria in their places of origin. Most of the participants mentioned that the drugs provided at the health facilities were not effective enough to cure the severe type of malaria occurring in the camp. Therefore, the justification of this study was the question raised by the preliminary study "*Is this really malaria or is there an over-diagnosis of malaria that is really other kinds of febrile illnesses?*" The aim of the survey was to determine the true prevalence of malaria in the camp.

7.2 STUDY METHOD

Two household surveys were carried out in the camp. The first one was conducted during the early dry season in September 2002 and the second survey was conducted during the late dry season in April 2003. The initial plan was to carry out the first survey during the dry season and the second survey during the rainy season to determine the seasonal variation of malaria prevalence in the camp. Unfortunately this was not possible due to unusual variation in the season and the limited time available for field work. The principal investigator later learnt that the rains started in June instead of April 2003. The study population comprised of all refugees in the camp. The camp is divided into three phases namely Kakuma I, II, and III, all of which were surveyed. The sample size was calculated using EPI Info 6, a statistical computer programme.

A total of 260 households were surveyed. 138 households were surveyed during the early dry season (a total sample of 927 participants) and 122 households were surveyed during the late dry season (711 participants). Everyone in a selected household was included in the survey and each household had an equal chance of being selected. The survey was conducted from a high vantage point using the global positioning system (GPS) method. This involved identifying the central point of each of the three phases in Kakuma camp with the help of the agency (GTZ) responsible for shelters and construction in the camp. The process started with spinning a pen on a flat ground from a central point in each phase. The direction the pen pointed was followed for selection of households. Every fifth house was selected, recorded and given a registration code. If the identified house was found empty, or in case of any rejection, the next nearest house was selected. The process continued with every next fifth house in the same direction until the edge of the camp was reached. Then the process was restarted from the central point until the required sample size was obtained from each of the three phases. New arrivals during the survey period were not included in the study.

The survey team was made up of 22 members identified with the help of the key figures and staffs working with various organisations in the camp. The team was comprised of the principle investigator, 6 trained local persons and 15 translators. Team members were divided into three groups of 3 people each. Each group was composed of an interviewer, a laboratory assistant and the most appropriate translator. The three laboratory assistants that participated in the study were laboratory staffs from the public health facilities in the camp. Structured interviews and observations on the cleanliness and sanitary conditions of household surroundings were carried out before smears were taken. A structured questionnaire and checklist was piloted to a group of 7 people of different nationalities and a few necessary amendments were made.

The first group led by the principle investigator surveyed 54 households that

included one third of the identified households in Kakuma I and all the houses in Kakuma III. The second group surveyed 32 households in Kakuma II and the third group surveyed 52 households in Kakuma I.

In each selected household, verbal or written consent was obtained from heads of households. For household members above 18 years of age, individual consent was obtained. For all participants the purpose of the survey was explained and it was made clear that participation was voluntary and consent could be withdrawn at any time. Confidentiality and privacy was ensured. Permission was asked if it was possible to return for those who were absent. If so, the name, age and sex of the absentees were recorded. Each participant was interviewed using the structured questionnaire. Information was gathered on each person's socio-demographics, movement in and out of the camp, history of fever in the last three days, and their current use of anti malarial drug. This was followed by collection of a thick film blood smear obtained by finger prick, air dried and stained with giemsa and field stain and examined by microscopy in the main camp hospital. Results were given to participants and those diagnosed positive for malaria parasite were referred to the nearest outpatient health facility for antimalarial treatment, which was free of charge. People found in selected households who were not members of those households but wanted to be tested for malaria parasite were referred to the health facilities. If they insisted, they were tested for malaria but were not included in the survey. Household members found sick and in need of assistance were either referred to the nearest outpatient health facility or community health workers were notified.

The slides containing peripheral blood smears were first examined for malaria parasite using a microscope (Leica, Olympus) at Kakuma laboratory in the camp hospital. The slides were examined by two IRC technicians over a period of 8-10 weeks after each survey. Some of the slides were stained with Giemsa, while others with Field's stain and were examined under oil immersion at a magnification of 1000x.

The quality control of the stained blood slides were carried out at the African Medical Research Foundation (AMREF) Laboratory and at the London School of Hygiene and Tropical Medicine (LSHTM) Laboratory.

7.3 DATA ANALYSIS

Data from the structured interviews were categorised, coded and entered onto a computer, EPI Info statistical programme, and than transferred to Stata, a statistical computer programme, for analysis. Before analysis, the data were checked for consistency, values out of range and duplicates. The double entry files were validated to ensure no inconsistencies were detected. Simple descriptive and cross-tabulation tables were used in the presentation of results. The findings are presented below:

7.4 RESULTS

7.4.1 Characteristics of study participants

The study involved eight of the nine nationalities in the camp and covered the whole camp. The survey included all age groups and the majority of study participants were adults. Children under-five accounted for less than one third of the total participants. Males were the majority and accounted for more than half of the total participants. Most of the participants were either educated to the primary level or had no formal education. A few were educated to the intermediate, secondary or university level. Most of the participants included in the survey were jobless. About one third of them were students and very few were either employed by international organisations in the camp or were self employed. Less than a quarter of the participants were married. The remaining participants were single, separated, or widowed. Christians were the majority, followed by Moslems. The majority of participants included in the study, with the exception of children, had been in the camp for more than six years. Details of the socio-demographic data of participants involved in both the early dry and late dry surveys are presented in Table 7.1 below:

Table 7.1: Socio-demographic characteristics of study participants

Characteristics	Early dry season (n=927) No. (%)	Late dry season n=(711) No. (%)	Total n=1,638 No. %
Age group (Yr.)			
0-4	171 (18)	106 (15)	277 (17)
5-9	89 (10)	117 (17)	206 (13)
10-14	126 (14)	94 (13)	220 (13)
>14	541 (58)	394 (55)	935 (57)
Sex			
Female	394 (43)	307 (43)	701 (43)
Male	533 (57)	404 (57)	937 (57)
Education level			
No formal education	352 (38)	264 (37)	616 (38)
Primary	396 (43)	291 (41)	687 (42)
Intermediate/Junior	102 (11)	100 (14)	202 (12)
Secondary/mid profession	68 (7)	50 (7)	118 (7)
College/University	9 (1)	6 (1)	15 (1)
Occupation			
Employee	31 (3)	34 (5)	65 (4)
Self employed	57 (6)	57 (8)	114 (7)
Unemployed	275 (30)	200 (28)	475 (29)
Housewife	86 (9)	52 (7)	138 (8.4)
Student	264 (29)	198 (28)	462 (28.2)
Others	214 (23)	170 (24)	384 (23.4)
Marital status			
Married	148 (16)	121 (17)	269 (16.4)
Separated	110 (12)	59 (8)	169 (10.3)
Divorced	4 (0.4)	8 (1)	12 (0.7)
Widow	55 (6)	27 (4)	82 (5.1)
Widower	62 (7)	27 (4)	89 (5.4)
Single(children inclusive)	548 (59)	469 (66)	1,017 (62.1)
Religion			
Christians	548 (59)	408 (57)	956 (58.4)
Muslims	235 (25)	214 (30)	449 (27.4)
Others	144 (16)	89 (13)	233 (14.2)
Duration of stay (camp)			
<1-6 yrs)	380 (41)	192 (27)	572 (35)
>6-10 yrs	440 (47)	428 (60)	868 (53)
>10 yrs	107 (12)	91 (13)	198 (12)

7.4.2 Diagnosis of the blood slides

Results of the first examination of the slides at Kakuma laboratory are presented in Table 7.2 below.

Table 7.2: Findings from first reading of smears at Kakuma laboratory

Smears	No. of slides (% positive & negative)	
	Early dry survey No. %	Late dry Survey No.%
Positive	67 (7.2)	2 (0.3)
Negative	860 (92.8)	709 (99.7)
Total	927 (100)	711 (100)

Out of a total of 927 blood slides from the early dry survey examined for malaria parasite, 67 slides tested positive for malaria, giving 7.2% positivity, while of the 711 blood slides from the late dry season survey examined for malaria parasite, only 2 tested positive for malaria giving a positivity of 0.3%. The decline in prevalence is consistent with a reduction or absence of transmission as the dry season progressed. The findings from the late dry season contradict findings from a survey conducted around the same month of April 1999 by the agency (IRC) responsible for health service in the camp as noted earlier in chapter one (section 1.8). IRC conducted a study to confirm the true proportion of malaria cases recorded through laboratory diagnosis, as they doubted the reported incidence rates of malaria based on presumptive clinical diagnosis at the public health facilities. IRC randomly selected 540 samples of blood films from the public health facilities and examined for malaria parasites by microscopy at the main camp hospital. Out of the 540 samples, 373 tested positive for malaria, giving 69% positivity. One important difference between the two surveys is that the one conducted

by IRC in April 1999 took place during the rainy season while the one conducted in April 2003 took place during the late dry season due to late arrival of the rainy season.

7.5 QUALITY CONTROL

In order to ensure accuracy in diagnosis of the blood smears, a follow up laboratory examination was carried out independently in AMREF and LSHTM laboratories on the same slides. Slides selected for the quality control included all the 67 positive slides and 100 of the negative slides from the early dry survey and the 2 positive slides and 100 negative slides from the late dry survey. All the positive slides were selected purposively to confirm that they were truly positive. But for the negative slides, one slide box of 100 slides each was selected at random from both surveys. The slides within each box were not arranged numerically and it was assumed that each of the boxes with the negative slides was a representative of the total negative slides from the first examination.

The majority of the blood smears, especially those from the late dry survey, were reported by both AMREF and LSHTM laboratories to be badly prepared and not adequately stained. As a result, when the blood smears were re-examined using a microscope, the parasites were difficult to detect. Therefore, only slides from the early dry survey could undergo quality control.

7.5.1 Re-examination of slides from the early dry season at AMREF laboratory

The first quality control of the blood smears first examined at Kakuma laboratory was carried out in AMREF laboratory. During transportation of the slides from Kakuma to Nairobi, 3 of the slides examined at Kakuma broke. These comprised of 2 positive slides and I negative slide. Therefore a total of 164 (65 positive slides and 99 negative slides) and not 167 slides was re-examined by AMREF and the results were compared to findings from first examination at Kakuma Laboratory and presented in table 7.3 below.

Table 7.3: Summary of comparison results between AMREF and Kakuma laboratory

		AMREF laboratory results		
		Positive No. (%)	**Negative No. (%)**	**Total No. (%)**
Kakuma Laboratory results	Positive	7 (11)	58 (89)	65 (100)
	Negative	2 (2)	97 (98)	99 (100)
	Total	9 (5)	155 (95)	164 (100)

Examination of the blood slides in Kakuma laboratory reported a total of 65 smears as positive for malaria parasite and 99 smears negative for malaria parasite. At AMREF, only 9 smears were reported positive for malaria parasite and 155 smears negative for malaria parasites. 58 smears reported at Kakuma laboratory as positive for malaria parasites tested negative for malaria parasites when re examined at AMREF Laboratory, giving a false positivity rate of 89% (58/65). 2 smears reported negative for malaria parasite at Kakuma laboratory tested positive for malaria parasites at AMREF laboratory when re-examined, giving a false negativity rate of 2% (2/99).

These corrected percentages for false positivity and negativity was applied to the overall prevalence rate, as diagnosed by the Kakuma laboratory, using the process indicated in Table 7.4 below.

Table 7.4: Corrected results of the overall prevalence rate after applying the false positivity and negativity results from AMREF to the original data from the early dry survey

	Original data from Kakuma	AMREF results:	Estimated false positives	Estimated true positives	Corrected total positives	Estimated prevalence using AMREF correction
Positive	67	89.2% false positivity rate	89.2 x 67 = 60	67-60 = 7	7+17 = 24	
			Estimated false negatives	**Estimated true negatives**	**Corrected total negatives**	24/927 = 2.6%
Negative	860	2.0% false negativity rate	2.0% x 860 = 17	860-17 = 843	843+60 = 903	

Table 7.4 above reveals that the corrected estimate of positive blood smears among the Kakuma recorded positives was 7 and not 67 and the estimated number of positives among the negatives was 17. This gives a revised positivity rate of 2.6% (24/927) and indicates that malaria was being under-diagnosed at the Kakuma laboratory. Table 7.5 below summarises the corrected positive and negative results of the blood smears in a simple way as follows:

Table 7.5: Summary of the corrected positives and negatives by AMREF

Smears formerly diagnosed as:	Corrected positives No. (%)	Corrected negatives No. (%)	Total No. (%)
Positive	7 (10)	60 (90)	67 (100)
Negative	17 (2)	843 (98)	860 (100)
Total	24 (2.6)	903 (97.4)	927 (100)

7.5.2 Re- examination of blood slides from the early dry survey at LSHTM

The blood smears were re-examined again at the LSHTM after undergoing the first quality control at AMREF where most of the smears were reported to have been read with difficulty due to inappropriate preparation and staining. Out of a total of 164 blood smears selected for quality control from the early dry survey, 32 smears broke when being transported from Kenya to UK and 11 smears were reported unreadable. Therefore, only 121 smears were successfully re-examined. The findings from the LSHTM readings of the smears differed quite markedly from those of AMREF and it was decided the LSHTM findings be used to assess the accuracy of the first reading in Kakuma laboratory because the microscopist at LSHTM was known to be well trained and her diagnoses were cross-checked by the LSHTM chief technologist, whereas we have no knowledge of the training and real skills of the AMREF microscopist. Results from the quality control of the smears at the LSHTM have been presented in Table 7.6 below in comparison with results from the first reading of the smears at Kakuma laboratory.

Table 7.6: Summary of comparison results between LSHTM and Kakuma laboratory

		LSHTM LABORATORY FINDINGS		
Kakuma laboratory findings		**Positive smears No. %**	**Negative smears No.%**	**Total No. %**
	Positive	8 (17)	40 (83)	48 (100)
	Negative	20 (27)	53 (73)	73 (100)
	Total	28 (23)	93 (77)	121 (100)

Out of the 121 blood slides re examined at LSHTM laboratory, only 28 smears were reported as positive for malaria parasites and 93 smears negative for malaria parasites. At Kakuma laboratory, 48 of these smears were reported positive for malaria parasite and 73 smears negative for malaria parasite. 40 smears reported at Kakuma laboratory as positive for malaria parasites tested negative for malaria parasites when re-examined at the LSHTM laboratory, giving a false positivity rate of 83.3% (40/48). 20 smears reported negative for malaria parasite at Kakuma laboratory tested positive for malaria parasites at the LSHTM laboratory when re-examined, giving a false negativity rate of 27.4% (20/73).

These corrected percentages for false positivity and negativity was applied to the overall prevalence rates, as diagnosed by the Kakuma laboratory, using the process indicated in table 7.7 below.

Table 7.7: Corrected result of the overall prevalence rate after applying the false positivity and negativity results from LSHTM to the original data

	Original data	LSHTM results:	Estimated false positives	Estimated true positives	Corrected total positives	Estimated prevalence using LSHTM correction
Positive	67	83.3% false positivity rate	83.3% x 67 = 56	67-56 = 11	11+236 = 247	247/927 = 26.6%
			Estimated false negatives	**Estimated true negatives**	**Corrected total negatives**	
Negative	860	27.4% false negativity rate	27.4% x 860 = 236	860-236 = 624	624+56 = 680	

Findings indicate that the corrected estimate of positive smears among the Kakuma recorded positives was 11 and not 67. The estimated number of positives among the negatives was 236. This gives a revised positivity rate of 26.6% (247/927), and indicates that Kakuma laboratory was underestimating true positivity (See Table 7.5 below). This contrasts with the AMREF cross checking results which indicated that the Kakuma laboratory was overestimating true positivity. Table 7.8 below summarises the corrected positive and negative blood smears from the prevalence survey as follows:

Table 7.8: Summary of corrected positive and negative blood smears from the prevalence survey

Smears formerly diagnosed as:	Corrected positives No. (%)	Corrected negatives No. (%)	Total No. (%)
Positive	11 (16)	56 (84)	67 (100)
Negative	236 (27)	624 (73)	860 (100)
Total	247 (26.6%)	680 (73)	927 (100)

In trying to complement findings from the surveys through laboratory investigation with prevalence of malaria obtained through clinical features, records at the five public health facilities were checked. The figures recorded for malaria were extracted for the month in which the survey took place (September 2002), the month before and after the survey and the months (October-November 2002) in which observations of health care providers were conducted as noted in the previous chapter. It was not possible to get figures recorded for malaria in days or weeks at the public health facilities, otherwise it would have been preferable and more reliable in comparing the findings from the survey with the findings for positive cases of malaria recorded at the public health facilities through clinical diagnosis during the survey period. The findings of recorded cases of malaria based on presumptive clinical diagnosis for the month of August-November 2002 are presented in Table 7.9 below.

Table 7.9: Recorded prevalence/incidence of malaria diagnosed through clinical features at the five clinics in the camp, August - November 2003

	Total clinic attendance	Patients diagnosed as having malaria	Malaria incidence rate (Total camp pop: 87,360)
August 02	14,340	5218 (36%)	5.9%
September 02	16,625	5955 (36%)	6.8%
October 02	13,794	4665 (34%)	5.3%
November 02	14,891	5717 (38%)	6.5%

The data reveals a difference between the prevalence rate of malaria obtained through the survey and the incidence of malaria in the general population recorded at the public health facilities, mostly presumptively, through signs and symptoms. The prevalence rate (2.6%) of malaria obtained by AMREF was lower than the incidence of malaria in the general population as recorded at the public health facilities (Table 7.9), while the prevalence rate (26.6%) of malaria obtained by LSHTM was higher than the incidence of malaria in the general population as recorded at the public health facilities in the camp. There is a relationship between incidence and prevalence: incidence per month = prevalence/duration of the disease as proportion of one month. We do not know duration of a case/parasitaemia but if we assume it to be 2 weeks or 0.5month, there is a relation between recorded incidence and prevalence i.e. the incidence of 6% per month equals approximately an AMREF prevalence of 2.6%.

Several factors are known to influence laboratory results for malaria parasites. A sub-analysis was carried out in an effort to determine likely factors that might have influenced the findings of laboratory investigations for malaria parasite in this study, and to investigate if a correlation existed between positive smears from LSHTM and these factors.

7.6 SUB-ANALYSIS OF FINDINGS FROM THE LSHTM LABORATORY

7.6.1 Characteristics of the study population

The sub-analysis comprised of findings from the quality control of the smears re-examined at the LSHTM laboratory that involved blood smears obtained from 121 participants. Over half of these participants were adults and less than quarters were children under-five years. Most of the participants were male and less than half of the participants were females. The majority of participants were either educated to the primary level or had no formal education. The majority of the participants were single and not employed. Christians were the majority, accounting for about two thirds of the total participants while Muslims accounted for about one third of the total participants. Over half of the participants had lived in the camp for less than 6 years and just about half of them had lived in the camp for more than 6 years. Details of participants' characteristics are presented in Table 7.10 below:

Table 7.10: Sub-analysis of quality control findings at the LSHTM laboratory

Characteristics	Positive smears (n=28) No. (%)	Negative smears n=(93) No. (%)	Total n=121 No. (%)
Age group (Yr.)			
0-4	7 (25)	17 (18)	24 (20)
5-9	0	13 (14)	13 (11)
10-14	5 (18)	15 (16)	20 (16)
>14	16 (57)	48 (52)	64 (53)
Sex			
Female	15 (54)	36 (39)	51 (42)
Male	13 (46)	57 (61)	70 (58)
Education level			
No formal education	13 (46)	35 (38)	48 (40)
Primary	10 (36)	43 (46)	53 (44)
Intermediate/Junior	2 (7)	8 (9)	10 (8)
Secondary/mid profession	3 (11)	7 (8)	10 (8)
Occupation			
Employee	0	3 (3)	3 (2)
Self employed	4 (14)	2 (2)	6 (5)
Unemployed	12 (43)	24 (26)	36 (30)
Housewife	1 (4)	9 (10)	10 (8)
Student	4 (14)	33 (35)	37 (31)
Others	7 (25)	22 (24)	29 (24)
Marital status			
Married	3 (10.7)	12 (13)	15 (12.4)
Separated	5 (17.9)	10 (11)	15 (12.4)
Divorced	1 (3.5)	0	1 (0.8)
Widow	3 (10.7)	6 (6)	9 (7.4)
Widower	1 (3.5)	4 (4)	5 (4)
Single(children inclusive)	15 (53.6)	61 (66)	76 (63)
Religion			
Christians	17 (61)	62 (66.7)	79 (65.3)
Muslims	6 (21)	21 (22.5)	27 (22.3)
Others	5 (18)	10 (10.8)	15 (12.4)
Duration of stay (camp)			
<6 yrs	12 (43)	50 (53.8)	62 (51)
>6-10 yrs	14 (50)	35 (37.6)	49 (40)
> 10 yrs	2 (7)	8 (8.6)	10 (8)

7.6.2 History of fever among study participants

Participants were asked about history of fever during the survey period and in the last three days of the survey. Out of a total of 121 (100%) study participants, 56% mentioned having fever. This gives a total of 68(100%) participants with fever. Table 7.11 below illustrates the comparison between fever and the laboratory findings for malaria parasite.

Table 7.11: Comparison of findings from LSHTM with history of fever

Fever	Blood smears for malaria parasite		
	Positive No. (%)	Negative No. (%)	Total No. (%)
Yes	15 (22)	53 (78)	68(100)
No	13 (25)	40 (75)	53(100)
Total	28 (23)	93 (77)	121(100)

The data reveal that of the total participants (68;100%) who mentioned having fever during the survey period or in the last three days of the survey, less than one third (15;22%) were diagnosed positive for malaria. This indicates that not all fevers were due to malaria.

7.6.3 Antimalarial drug

Participants were asked if they were on antimalarial during the survey period or within the last one week of the survey. A total of 7(6%) out of 121(100%) study participants mentioned being on antimalarial during the survey. Of these 7(100%), only one participant was diagnosed positive for malaria. These findings have been illustrated in Table 7.12 below.

Table 7.12: Comparison of findings with history of antimalarial drugs

Anti malarial drug	Blood smears for malaria parasite		
	Positive No. (%)	Negative No. (%)	Total No. (%)
Yes	1 (14)	6 (86)	7 (100)
No	27 (24)	87 (76)	114 (100)
Total	28(23)	93 (77)	121 (100)

7.6.4 History of travel

Earlier findings indicated that some of the refugees in the camp travelled out of the camp occasionally. In trying to determine the possibility of imported malaria during the occasional travels, history of travel was taken from participants during the survey. Results indicated that 6 (5%) out of a total 121(100%) study participants had travelled out of the camp since their arrival. Of these 6(100%), only one (1;17%) participant had been diagnosed positive for malaria by Kakuma laboratory and this was confirmed by LSHTM Laboratory. This participant, aged 27 years, reported he had travelled out of the camp to Sudan for three weeks and had returned 12 month before the survey was conducted, thus indicating transmission of malaria parasites within the camp. The findings are illustrated in table 7.13 below:

Table 7.13: Comparison of findings with history of travel

Travel	Blood smears for malaria parasite		
	Positive No. (%)	Negative No. (%)	Total No. (%)
Yes	1(17)	5 (83)	6 (100)
No	27 (23)	88 (77)	115 (100)
Total	28 (23)	93 (77)	121(100)

7.6.5 Sanitation/Drainage

During the survey, each household included in the study was observed for cleanliness within the compound and at the surroundings for identification of mosquito breeding sites. A house was rated very clean if there was no grass, rubbish heaps, or standing water around or within the house compound. Fairly clean was the rating given to if there was a bit of grass, rubbish heaps or standing water seen around or within the house compound, but easily unnoticed. A house was given a 'poor' rating if there grass, rubbish tips and standing water around and within the house compound. Table 7.14 below presents the findings from observation of household surroundings during the survey.

Table 7.14: Comparison of findings with sanitation at participants' residence

Sanitation	Blood smears for malaria parasite		
	Positive No. (%)	Negative No. (%)	Total No. (%)
Clean	14 (31)	31 (69)	45 (100)
Fairly clean	11 (16)	57 (84)	68 (100)
Poor	3 (37.5)	5 (62.5)	8 (100)
Total	28(23)	93 (77)	121 (100)

Data from Table 7.14 above reveals that of the total participants (45;100%) staying in households with clean surroundings that were free from grass, rubbish heaps and standing water, about one third (14;31%) were diagnosed positive for malaria. Of the total participants (68;100%) who lived within fairly clean surroundings that contained little rubbish around and standing water that was easily unnoticed, 11(16%) were diagnosed positive for malaria. Only a total of 8(100%) participants lived in areas within the camp with poor sanitation that contained rubbish heaps and dirt that were easily noticed within the compounds and its surrounding but standing waters was not easily noticed. Of these total (8;100%), more than one third (3;37.5%) were diagnosed positive for malaria. These finding gives no evidence that malaria risk is associated with poor sanitary conditions in the camp.

7.7 SUMMARY OF FINDINGS

The aim of this study was to determine the existence and prevalence rate of malaria in the camp. The findings are based on the survey conducted during the early dry season. The first reading of the smears for malaria parasite at

Kakuma laboratory indicated a prevalence rate of 7.2% but the comparison with the quality results at AMREF and LSHTM gave contradicting results. Examinations of the slides for malaria parasites at AMREF laboratory reported a revised positivity rate of 2.6% indicating malaria was being over diagnosed at the Kakuma Laboratory, while examination of malaria parasite at LSHTM laboratory reported a revised positivity rate of 26.6% indicating malaria was being under estimated at Kakuma laboratory.

Findings from the quality control at AMREF and LSHTM revealed that the blood smears were not well prepared and not well stained. The preparation and staining of the smears were carried out by the laboratory assistants at the public health facilities in the camp. The quality control results from both AMREF and LSHTM contradicted incidence of malaria recorded at the public health facilities in the camp, which were mostly diagnosed presumptively through signs and symptoms. Results from AMREF (2.6%) were lower compared to the incidence of malaria recorded at the public health facilities (Table 7.9) in the camp and results from LSHTM (26.6%) was higher, compared to the incidence of malaria recorded at the health facilities.

Over half of the participants' diagnosed by LSHTM laboratory as having malaria had complained of fever during the last three days of the survey and of these participants, only less than a quarter were diagnosed positive for malaria (Table 7.11). During the survey, seven participants reported using antimalarials and only one of these participants was diagnosed positive for malaria. No association was found between history of travel and malaria. Of the six participants who indicated having travelled out of the camp since their arrival, only one was found positive for malaria by both AMREF and LSHTM but the participant had travelled out of the camp and returned 12 month before the survey was conducted. The majority of participants' diagnosed positive for malaria lived in households (huts and tents) with clean and fairly clean surroundings meaning that they were free from grass, standing water or rubbish heaps or other factors that provide breeding sites for mosquitoes.

CHAPTER 8: GENERAL DISCUSSION AND CONCLUSION

8.1 INTRODUCTION

The public health burden of malaria in sub-Saharan Africa is enormous and over recent years the impact of malaria resulting from population movement in general, and forced population movement in particular, has increased markedly. As a consequence, in 1999, WHO established the Roll Back Malaria Complex Emergency Technical Support Network, to develop partnerships with non-governmental organisations, and assist them in the implementation of malaria control interventions in complex emergencies, and among refugee populations (WHO, 2000). In addition, with the rise in the number of complex emergencies, particularly in sub-Saharan Africa, several initiatives have been undertaken, and reports published to assist in development of standards and guidelines for the delivery of health care in general, and malaria control in particular, in these situations (Bloland and Williams, 2003; Meek *et al.*, 2000; Sphere-Project, 2000).

A minimum requirement for any malaria control strategy in complex emergency situations is the effective case management of the disease through prompt and accurate diagnosis accompanied by rapid treatment with an effective antimalarial drug (Bloland and Williams, 2003). However, while a significant amount of research has been undertaken on the factors affecting effective case management in stable (non-conflict) settings in sub-Saharan Africa, little is known about how the displacement experienced, and the complex political, social and cultural context which accompanies complex emergency situations, affects the case management of malaria.

This thesis attempted to investigate the factors influencing the effectiveness of a case management strategy in a displaced persons' camp (Kakuma) in Northwestern Kenya. The approach adopted in the study was to start with those who suffer from malaria, the refugees, and to explore the factors that were affecting their ability to access prompt diagnosis and effective treatment for malaria. This initially involved identifying and considering the factors that appeared to be influencing treatment-seeking behaviour in the context of the complex, social, political and cultural relations that existed among the displaced people of Kakuma camp.

An effective case management strategy depends not only on the promptness of diagnosis and treatment, but also on the accuracy of that diagnosis and the appropriateness of the treatment. A second concern of the thesis was, therefore, to determine the effectiveness of the case management of malaria patients by the health care providers at the clinical encounter. This was explored through investigating the quality of their management of patients and their diagnostic techniques, as well as the appropriateness of their prescribed treatments for malaria.

In this discussion, the results of the study are reviewed, and placed within the framework of the Piot model for malaria case management. As outlined in Chapter Two, this model can be used to provide a framework for analysing a malaria control strategy, and can be used to identify core issues that need to be addressed. The focus of this discussion is an attempt to apply this framework to the Kakuma data in order to help identify the core issues and actions that are needed for effective malaria case management in Kakuma in particular and in broader refugee camp settings in general.

8.2 BURDEN OF DISEASE

The Piot model states that the starting point for any strategy for the effective

management of a disease is an understanding of the relative burden of that disease. In Kakuma camp, the routine clinical data collected from each of the health clinics (see Chapter Three, section 3.8.1) suggests that the burden of malaria in the camp is high. However, despite the fact that each health facility employed a laboratory technician and assistants, the majority of the malaria diagnoses in the camp were presumptive, based on clinical features and history taking. In addition, while many of the clinical health workers said that they followed the IRC guidelines for malaria diagnosis, the results in Chapter Six (section 6.5.4.2) show that in practice, they were rarely observed doing so. The vast majority of those presenting with a fever appear to have immediately been diagnosed with malaria, even though in many cases the health workers did not take the patients' temperature. Furthermore, the clinical health workers reported that the burden of malaria in the camp was very high, and this perception may have influenced their clinical and diagnostic practices. Their diagnosis of malaria may also have been influenced by patients' demands as many of the clinical health workers said that patients sometimes asked for particular drugs such as SP.

The perception of a high burden of malaria in the camp was also commonly found among the refugees. Both the preliminary and the main studies found that the majority of refugee participants from all nationalities perceived that malaria in the camp was common, and created a high burden, but was different to the malaria they had experienced in their areas of origin, both in terms of severity, and response to treatment.

In spite of the evidence provided by the routine clinic data, and despite the perceptions of the clinical health workers and refugees, the health care services management of the camp appeared to either be unaware of, or not concerned with the problem. A parasite prevalence survey had been undertaken in April, 1999 by the IRC (See results in Chapter One, section 1.12), but no action appears to have been taken to try and prevent malaria transmission or to reduce the burden of the disease.

An alternative explanation for the lack of action is that the IRC health care services management did not fully trust the results of the parasite prevalence survey or the routine clinic data. The results from this study would tend to support the perception that the routine clinic data were unreliable (due to poor diagnostic practices), and the results of the parasite prevalence survey show that the technical skills of the laboratory technicians in the camp were insufficient. Furthermore, the location and surrounding environment of the camp, in a semi-arid area in the north west of Kenya, suggests that the burden of malaria in the camp is likely to be seasonal (See Chapter Three, section 3.8.1). On the other hand, the camp is characterised by poor and sub-standard shelters, inadequate health services and a continuous influx of refugees. So it is possible that the burden of malaria in the camp is greater than might normally be expected in such an arid environment.

While the true picture of the burden of malaria in Kakuma remains unclear, what is clear is the fact that the health system in place is not effectively functioning. The establishment of an effective health system is constrained in Kakuma (as in many other refugee camp situations) by: poor communication and cooperation between the agencies in the camp (including competition for funds); poor relationships and no feedback from the central management in charge of health services to the front-line clinical health workers; budgetary constraints; staff shortages and poorly trained staff (related to the difficulty of recruiting staff in areas of poor security and scarce resources), and by the on-going food and security crises that frequently afflict the camp.

The Kakuma camp has been established since 1992 and can no longer be considered to be in the acute phase of a complex emergency. The camp is located in a remote region of Kenya where there is very little food or water available for the local pastoralist communities, and where there is frequent fighting for these scarce resources among these local groups: a situation in which the Kenyan government, and even the police, prefer to stay out of the region and remove themselves from the local fighting. As described in Chapter

Three (section 3.7.10), this environment has resulted in a camp where the population is still primarily totally reliant on the NGOs for provision of food and shelter, and the means for life. Under such conditions, the NGOs are still principally concerned with providing food, water and shelter and are providing what amounts to emergency care rather than opportunities for sustainable development. It is, therefore, perhaps not so surprising that the establishment of an effective surveillance system has not been a high priority for the health care services management in the camp since much of the limited funding has been diverted into providing food, water and shelter for the refugees. However, the results from this study show that the consequences of not having adequate surveillance include spending a large proportion of the drugs budget on providing refugees with drugs that they may not need. While the first-line treatment for malaria is SP, this may not have significant budgetary consequences. However, with increased drug resistance (possibly hastened by the over use of drugs), and the change in policy to artemisinin-based combination therapy (ACT), which the Kenyan government has now pledged, the cost of the over estimation of the burden will be significant. In addition, treating all refugees with fever for malaria in an area where the endemicity is unknown may well result in refugees not being treated for the disease that is causing the fever.

Both the Sphere guidelines (Chapter One, section 1.8.1), and Bloland and Williams, (2003) have emphasised the need for an ongoing collection, analysis and utilisation of relevant public health data. They point out that a well designed surveillance system allows for rapid identification of increases in cases of communicable diseases in an affected area, signalling the need for a specific response. Bloland and Williams (2003), also point to the need for the provision of training in the use of surveillance information for all health care and administrative workers involved with surveillance and stress the importance of standardisation in case definitions. The data from Kakuma show that the front - line health workers have received little appropriate training in surveillance. Furthermore, they are receiving little feedback or support from the health care

management in terms of summarising an acting on the clinical data they are collecting. This lack of interest by the camp management may well be affecting not only the measurement of burden of disease, but may also affect the quality of care provided by the front-line health workers (see section 8.5 for a further discussion of this issue).

The data from this study reinforce the message that while in most refugee settings NGOs have many things to worry about, without an adequate, effective and functioning surveillance system, it will be difficult for them to target scarce resources appropriately. While the establishment of an effective and functioning surveillance system within the camp should be the goal of any camp health management team, local sources of information should not be ignored. An important source of information to assist NGOs in their efforts to understand what are the likely causes of disease in the camp is the local DHMT. In Kakuma, although there is already a formal relationship between the DHMT and the camp management as indicated in Chapter Three (section 3.7.3), it is not effectively functional in terms of sharing data on malaria and other disease burdens in the area. The need for liaising with the local DHMT for such data is important to enhance the surveillance system. If such data are not available locally, then the MOH may be an alternative (or additional) source of information. Should there be no data available at all, then involving the local and/or national authorities in the collection of such data, both within the refugee camp, and among the host population would be a valuable strategy. It would be helpful not only for the refugee population, but would also provide the opportunity for the strengthening of links between the NGOs running the camp and the local and national authorities, and would also provide the host country with important health data of their own.

An additional approach to building up an effective surveillance system in Kakuma camp (and in other refugee camps) is to ensure that those NGOs involved in the management of health care services in the camp improve their interaction with both the front-line health care providers (clinical and community), and with representatives of the various refugee nationalities.

Although in Kakuma there is already a mechanism for liaising between the NGOs and the refugees (described in Chapter Three, section 3.7.1) it is does not appear to be working effectively. Liaising with the community health workers is important because they spend much time in the community, and have detailed knowledge about the problems of the refugees. Both the health workers and representatives of the refugee communities can provide essential information on how the refugees themselves perceive the relative burden of various diseases, and how the burden may change over time (or between seasons). Understanding how the refugees themselves perceive the burden of malaria is essential in the development and design of appropriate and acceptable interventions to alleviate suffering from disease.

8.3 Step 1 - AWARENESS

As the Piot model states, the first step a person needs to take in order to effectively manage their disease is to recognise that they are ill. That is, a patient needs to be aware that they have a disease that requires treatment, they need to recognise a change in their health status and put a name to the reason for those changes (label the disease). Studies (reviewed in Chapter Two) undertaken in the countries of origin of many of the refugees suggest that for many of the people from these areas, symptoms such as fever, headache and body weakness are widely recognised as symptoms of malaria. That is, locally recognised signs of malaria broadly correspond to the symptom complex that is used in the clinical diagnosis of malaria. The results from this study (presented in Chapter Four) suggest that among many of the refugees in Kakuma camp, the recognition of the signs of malaria were similar to those of populations in their countries of origin. That is, while knowledge of the mode of transmission of malaria frequently did not correspond to the biomedical model, perceptions of the symptoms of malaria (fever, headache and body weakness) were very similar to those recognised by the biomedical notion of uncomplicated malaria. In other words, awareness of malaria as a disease that needed treatment was high.

However, the study also found that the impact of trauma and stress appeared to have had a considerable influence on the ability of the refugees who had been diagnosed with PTSD to recognise fever and headache as symptoms of malaria. The results in Chapter Five, indicate that study participants diagnosed with PTSD had difficulty in distinguishing the symptoms of malaria from those of stress since the somatisation of their stress resulted in physical symptoms similar to those of malaria (headache and fever). All of the refugees had undergone stressful experiences, both during their pre-flight and flight period, and were all living under similar stressful situations within the camp. It was beyond the scope of this study to investigate the factors that led to some individuals being better able to cope with these stresses than others (those diagnosed with PTSD). It was also beyond the scope of this study to question the PTSD diagnoses, but what the results of this study do show is that those diagnosed with PTSD had less 'awareness' and were less able to distinguish that they were suffering from a disease that needed treatment. Such a lack of awareness is of great public health importance, not only because they affect the individuals themselves, but also because an effective case management strategy for the control of malaria depends on the ability of those suffering from the disease to recognise that they have malaria and seek prompt treatment. The data from this study suggest that those refugees who had been diagnosed with PTSD were substantially more likely to take more than two days after the first recognition of the symptoms of malaria to seek treatment at the public health facilities than those refugees who had not been diagnosed with PTSD. It is, therefore, essential that, both in Kakuma as well as in refugee settings more generally, there is recognition that those diagnosed with PTSD are not only vulnerable because of their own suffering, but also need to be considered as a specific vulnerable target group in terms of their ability to recognise that they are suffering from another disease.

Another interesting and important feature of the results of this study was the finding that the long-term mixing of different nationalities in the camp appears to be affecting the name or label attached to the constellation of symptoms

recognised clinically as uncomplicated malaria. The results in Chapter Four suggest that the name 'malaria' or 'malariya' given by the dominant nationality in the camp (the Sudanese) to this constellation of symptoms was being adopted by the minority nationalities such as the Congolese and the Burundians to replace the name used for this disease in their place of origin. That is, there appears to be some sort of 'cultural assimilation' by the minority nationalities of the language of the majority nationality. The extent to which this causes conflict (as one culture tries to hold onto its identity in the face of the dominant or majority nationality) or promotes cultural inclusiveness is unclear, but it is an issue that warrants further investigation. It also raises the issue of knowledge transfer and the way in which knowledge about health and disease is constructed and transmitted. However, a more detailed discussion of these issues is beyond the scope of the current thesis.

The results of this study point to an urgent need for further studies on the impact of the refugee experience and response to stress on disease awareness. That is, while in stable (non-conflict) situations it is frequently suggested that the response to a lack of awareness should be more appropriate health education (Miguel *et al.*, 1998; Mumba *et al.*, 2003; Njama *et al.*, 2003), this study has shown that in refugee situations, an understanding of the impact of the refugee experience on awareness (particularly among those who are having the most difficulty in coping with their experiences) is as, if not more, important than traditional health education on the signs and symptoms of malaria. The recognition of this problem needs to take place at all levels including the community health workers, the front-line providers of clinical care, the camp health care management team as well as among the NGOs in charge of providing health care services at national and international level.

8.4 Step 2 - MOTIVATION TO SEEK TREATMENT

Once a person has become aware that they have a disease that needs

treatment, the Piot model suggests the next step that a person goes through in the management of the disease is the motivation to seek treatment from an appropriate source of health care. The literature reviewed in Chapter Two highlighted the factors that have been found to affect motivation to enable a person to seek treatment among stable communities in sub-Saharan Africa. These include: perceptions of severity, the availability of services and drugs, accessibility (including distance, cost, waiting times and the behaviour of providers towards patients), perceptions of quality of care, previous experience and the influence of any other people who need to be involved in the decision making process (the availability and influence of a therapy management group). The literature reviewed in Chapter One (particularly sections 1.9 and 1.11.1) suggests that the conditions experienced during complex emergencies are likely to have a considerable impact on many of these factors in a variety of ways.

One of the major factors that is likely to have an impact on motivation to seek treatment among refugees is their experience of stressful events and living conditions. Stress and trauma may affect awareness that a disease is present (as discussed above) but they may also affect an individual's perceptions of the relative severity of that disease (see Chapter Two, section 2.3.2) which in turn will affect their motivation to seek treatment. In Kakuma, some of the refugees diagnosed with PTSD were able to distinguish between the signs and symptoms of malaria and those of stress. However, the data from this study also show that those people who recognised that they might have malaria but had also been diagnosed with PTSD were less likely to think that the malaria was of sufficient importance (or severity) to require a visit to the clinic. That is, those diagnosed with PTSD who were able to recognise when they had malaria, often perceived that the malaria was of less importance than their over riding feeling of ill health due to stress. These refugees were, therefore, not motivated to seek treatment for the malaria episode. On the other hand, many of the refugees who appear to have coped better with the stresses they encountered (those not diagnosed with PTSD) said that they thought the malaria they experienced in the camp was more severe than the malaria they had

experienced back at home and this motivated them to seek treatment.

Even though the perceptions of severity may be motivating some of the refugees to seek treatment, the data also suggests that lack of choice of treatment providers may be delaying the treatment seeking process. The results from both the focus group discussions (Chapter Four) and the in-depth interviews (Chapter Five) suggest that, despite the fact that treatment at the public health facilities was free, and the distance to the facilities was rarely very great, the preferred first choice of treatment for the refugees would have been self-treatment (with drugs bought from shops) or traditional treatment. However, such sources of treatment were not readily available in Kakuma, and where they were available, they were expensive and few of the refugees had access to any source of funds. As a consequence, it appears that many of the refugees would wait a day or two to see if their symptoms resolved. If the symptoms didn't resolve, then despite the fact that the quality of care at the public health facilities was perceived to be poor and they had to spend a long time queuing to be seen by the staff, there was sufficient lack of choice to motivate them to seek care from the public health sector. While many of the refugees did not have jobs or the other calls on their time that they would have had in their place of origin (such as farming or herding), they often had to queue for food and water in the camp. Therefore, time spent queuing for health care meant time away from queuing for other vital necessities.

The perceptions of a poor quality of health service and long queuing times was confirmed by the results in Chapter Six (and discussed in greater detail in the following section). One of the major factors responsible for these problems was the fact that there were too few staff to deal with the number of patients. As a consequence, consultation times were very short. In addition, while few of the refugees complained that they had been discriminated against because of their nationality (see Table 4.11), the majority of the refugees said that the staff were rude and did not treat their ailments correctly. These are problems that are commonly found not only in other refugee camps but also across the public health system in much of sub-Saharan Africa. However, in refugee camps the

situation is exacerbated, not only by a lack of funds, but also by the lack of sufficient suitably qualified health care staff who are willing to work in the difficult and unstable conditions that are found in refugee camps. Furthermore, as was experienced in Kakuma, the availability of even these poorly regarded services may be limited as refugees may be faced with situations where curfews are put in place or staff are withdrawn, and health facilities temporarily closed due to a deterioration in the security situation. In such situations, the motivation to seek treatment may be high, but the availability of treatment may be non-existent.

While the availability of the public health services in Kakuma could be considered as insufficient (although probably greater than the availability of such services in the places of origin of many of the refugees), during the period of the study, the availability of drugs at the health centres was good. As described in Chapter Two, one of the primary factors that drives much treatment seeking behaviour for uncomplicated malaria in sub-Saharan Africa is the search for effective antimalarial drugs. The motivation to seek treatment from a particular source is the perception of the availability of the most appropriate drug to treat the disease. As the data from this study have shown, for refugees who have come from locations where SP is being used to treat malaria, the provision of CQ is considered to be inappropriate. This is likely to impact on their motivation to seek treatment from the public sector. During the course of the study, the treatment for most cases was switched to SP. Unfortunately, data on the impact that this had on motivation to seek treatment at the public health facilities was not collected. However, in Kakuma, as in many refugee camps in sub-Saharan Africa, refugees come from a variety of countries, and are familiar with the treatment regimes used in their country of origin. The provision of an unfamiliar drug or drug regime by the public health providers in the refugee camp may well impact on their motivation to seek treatment from that source.

The presence of many different nationalities in a refugee camp may not only result in many different views as to the most appropriate treatment for a

particular disease, but may also affect the ability of some of the nationalities or ethnic groups from gaining access to the public health services. That is, if the provision of services is the preserve of the dominant nationality or ethnic group (or members of the local population), then racism and discrimination may lead to some of the nationalities or ethnic groups being excluded from accessing the health services. For example, in Kakuma, the Rwandan and Congolese were in the minority, and none of the clinical health workers were from either of these nationalities. This could have led to a situation where refugees from these nationalities felt excluded from the health services. However, the data from the focus group discussions in this study suggest that discrimination at the health facilities on the basis of nationality was not considered by the refugees from Rwanda and Congo to be a major problem. Apart from the Rwandan and Congolese, the health staff were drawn from all the other nationalities in the camp. In addition, the health care providers were regularly rotated among the five clinics helping to ensure that all of the nationalities were sometimes able to access a clinical health worker of the same nationality. This process appears to have been successful in minimizing the effects of discrimination on the motivation to seek treatment. The broad lessons that can be drawn from this approach are that to reduce the effect of discrimination on treatment seeking in refugee settings; firstly, the providers of health care should be drawn from the same nationalities and ethnic groups as the refugees and secondly, that rotation of the clinical providers between the health facilities can help to prevent resentment building up between a specific group of refugees and a particular provider.

Another important factor that is distinctive of complex emergency situations such as refugee camps, which may affect motivation to seek treatment, is the disruption and frequent breakdown of nuclear and extended families, and the disintegration of communities. The literature reviewed in Chapter Two (section 2.2.2) has shown that decisions about when and where to seek treatment for a disease are rarely taken by the patient alone. The studies on stress suggest that the breakdown of these social structures can have crucial impact on health

and sense of well being. The data from Kakuma suggest that the disruption that study participants have experienced has resulted in a considerable breakdown in the therapy management and support groups that existed in their place of origin. Some of the participants in the study had established a new type of support group (often based on shared activities and friendship rather than family ties). These participants reported that they did ask some of the members of the support group for advice (motivation) on where and when to seek treatment. However, perhaps more importantly the majority of those who had been diagnosed with PTSD reported that they had not established any new form of support group in the camp and, therefore, received little support or external motivation to seek treatment. A few of those who had been diagnosed with PTSD were unable to motivate themselves at all, even when they recognised that they had malaria. As a result, treatment had to be imposed upon them. These data reinforce the data on awareness, and raise the concern that many of those diagnosed with PTSD are the most likely to not proceed through the steps of the Piot model. That is, they are the ones who are least likely to seek prompt treatment, and most likely to be 'lost' to the health care system. In order to address this issue, both within Kakuma and in refugee camps in general, the agencies in charge of delivering mental health services to the refugees need to work in close collaboration with the NGOs and front-line workers responsible for providing community health care and clinical curative services. This collaboration is essential, not only to ensure that those who are most vulnerable are receiving appropriate treatment when they become ill, but also as a vital component in an effective disease surveillance system.

While those diagnosed with PTSD should be considered to be the most vulnerable to being 'lost', all of the refugees have undergone experiences and are living in an environment that has reduced their capacity to make decisions and choices for themselves. That is, the majority of the refugees suffer from a loss of what Paul Farmer has called 'agency' (Farmer, 1999). As mentioned at the start of the discussion, because of the location of the camp, the refugees find themselves without freedom of movement, with few economic and

educational opportunities, and with almost no immediate prospect of finding a solution to their plight. In addition, as detailed in Chapter Three, the way in which Kakuma has been set up and managed has resulted in the inability of most refugees to do something for themselves. As a consequence, they suffer from the inability to make any meaningful choices or to influence the delivery of services on which they depend. This situation is impacting negatively not only on the health of the refugees, but also on their motivation to seek treatment for malaria.

To increase the motivation to seek care, the NGOs in charge of health care delivery among refugees need to consider mechanisms to provide the refugees' with a greater sense of 'agency'. A strategy that will contribute to developing a greater sense of control of their environment among the refugees is through the involvement of the refugees in decisions regarding health care provision. Such involvement will help to increase the sense of self-determination and ownership of the health services by the refugees. A mechanism to achieve this goal would be through the formation of 'community health committees' (CHC). These committees should be made of representatives of each of the refugee nationalities, representatives of the community health workers, clinical health workers, and other health care providers (such as the mental health worker) as well as representatives of the NGOs organising and managing health care and camp management. As described in Chapter Three (section 3.7.1), in Kakuma there is already a mechanism for liaison between the NGOs and the refugees. The camp health management team should build on this strategy to help develop a CHC containing representatives of all the nationalities. The committees could provide a forum in which the refugees' perceptions of the relative burdens they face could be put forward, and in which the refugees, together with the various health cadres, and members of the camp management, could discuss both issues of awareness and factors affecting motivation to seek treatment. Through this process the health care services management and health providers will be made aware of the concerns of the refugees and the health providers. In addition, the health care services

management can use the committee as a forum for explaining to the refugees the concerns they have, and the constraints they are working under. Greater involvement of the refugees in decisions about health care provision will not only help in the design of more appropriate and acceptable interventions, but will also help in the development of a greater sense of control and 'agency' among the refugees.

8.5 Step 3 - DIAGNOSTIC PROCESS

Once a person has become motivated to seek treatment and accessed a health provider, the next step on the Piot model is the diagnostic process. As described in Chapter Two, the standard laboratory method for the diagnosis of malaria is through the microscopic examination of a blood slide for malaria parasites. However, even where adequate diagnostic facilities exist, the quality of the facilities and/or poor training of the technicians can produce unreliable results.

The health care facilities in Kakuma camp, unlike many in sub-Saharan Africa, had basic diagnostic facilities and laboratory staff. This suggests that the quality of diagnosis of malaria among the refugees should be good. However, the results in Chapter Seven suggest that the quality of the slide taking and reading was poor. This was as a consequence of a combination of the technical skills of the technicians, and the quality of the reagents and equipment used. The technicians themselves were very aware of their limitations, and of the limitations of the equipment they were using. There were policies in place to allow for on-going training and refresher courses for the laboratory technicians in the camp. However, due to budgetary constraints, lack of staff and high workload, few staff had ever attended such courses. In addition, while these constraints are common in many stable situations in sub-Saharan Africa, as mentioned before, the added concerns with security, allocation of funds to immediate needs (such as food), and donor fatigue all add to these constraints in Kakuma and most other refugee camps in sub-Saharan Africa.

While all of the health facilities in Kakuma had access to laboratory diagnosis for malaria, as in many other parts of sub-Saharan Africa, the majority of patients were diagnosed clinically. As the studies reviewed in Chapter Two have demonstrated, clinical diagnosis of malaria is very difficult, even for highly trained personnel and misdiagnosis of malaria is common in most countries in sub-Saharan Africa. The results from this study (presented in Chapter Six) suggest that this is also likely to be the case in Kakuma. In the majority of the consultations that were observed the diagnostic process was insufficient. The consultations rarely lasted more than five minutes and the majority was completed within three minutes. During this short time there was insufficient history taking and physical examinations were infrequent and inadequate. The data suggest that many of the patients are probably being misdiagnosed and the effective case management of malaria in Kakuma is severely constrained by the diagnostic process.

However, the data on the quality of health care (see Chapter Six) also reveals that health workers in the camp are faced by a heavy workload, work in poor environment and are surrounded by insecurity. This contributes to the stress felt by providers and contributes to their limited quality performance. The clinical health workers and laboratory technicians in Kakuma are offered little support, They are not frequently supervised, and are not given the opportunity to express their concerns to the camp health care services management. This in turn also contributes to feelings of stress and isolation. While recruiting more and better qualified staff, providing regular training opportunities and improving salaries would all help to relieve some of the pressure (and hence improve performance), the IRC, in common with health service providers in many other refugee camps, are constrained by their budgets, and the security environment in which they work.

The quality of clinical work and perception of too great a work burden may also be influenced by resentment about differentials in pay. As described in Chapter Three (section 3.7.6), the refugee clinical health workers were upset by the disparities in pay between themselves and the national health care providers.

For example, although the two national clinical officers had a higher standard of training than the 21 refugee medical assistants, their job descriptions were the same. Despite the similarity in job description, the national clinical officers were being paid almost twice what was given to the refugee medical assistants. Likewise, the national laboratory technicians in the main hospital in the camp were being paid almost twice the amount paid to the refugee laboratory technicians of the same standard in the outpatient health facilities. This pay disparity helped to create a bad working relationship between the national and refugee health staff, which in turn may have discouraged the refugee staff from putting in great efforts to improve their performance. This problem needs to be addressed either by decreasing the pay differentials or by better communication to explain to the refugees why the disparities in pay exist.

Bringing the refugee staff salaries in line with those of the national staff (who are on government controlled rates) may be beyond the budget for the health management team but providing feedback to front-line health workers and listening to their concerns does not incur a great financial cost, but can lead to improvements in performance (Bloland and Williams, 2003). Establishing a mechanism for regular communication (such as through the community health committees) would: a) help the management to identify the concerns of the providers, b) provide a forum in which the results of surveillance activities could be fed back to the providers (thus encouraging them to assist is better surveillance) c) help the community to understand the constraints that the providers work under, and d) help the providers to understand what the community want in terms of 'quality' care. This type of communication can help to re-establish a sense of control among the providers, and this in turn may have a beneficial impact on their quality of care.

An additional mechanism for improving diagnosis in Kakuma (as well as in many other refugee camps, particularly in areas of low or seasonal transmission) would be the introduction of Rapid Diagnostic Tests (RDTs). While SP is being used as the first-line drug for malaria treatment, NGOs on

tight budgets may feel that the introduction of this technology is not cost effective. However, as the results of this, and many other studies have shown, the quality of diagnosis of malaria is frequently insufficient. This not only has important consequences for the health of the patient, but when more expensive combination therapy drugs are introduced as a first-line treatment (as will happen in many countries in the near future and as are already being used by some NGOs), the over diagnosis of malaria will also have significant budgetary implications. However, while the introduction of RDTs may be advised, little is currently known about the impact of the introduction of these tests on either provider or patient behaviour. Research on the impact of the use of these tests, both in stable and areas of complex emergency such as refugee camps, is required.

8.6 Step 4 – STARTING THE CORRECT TREATMENT

Once the patient has been diagnosed, the next step in the Piot Model states that the patient needs to start the correct treatment (Mumba *et al.*, 2003).

As shown by the literature reviewed in Chapter Two, a major constraint in many parts of sub-Saharan Africa preventing patients from starting the correct treatment is the availability of drugs. Drugs may not be available where the patient is diagnosed, and patients may only receive prescriptions for drugs (Nsimba *et al.*, 1999). If they are given a prescription, they then may not be able to afford buy the prescribed drugs. In other circumstances, drugs may be available, but patients may not be able to afford a full course and so may be given half the dose prescribed. Supplies of drugs can also be problematic in refugee camps because of shortage of funds to purchase drugs, and due to security and logistical constraints in supplying drugs to remote refugee locations. Although in Kakuma refugee camp, drugs for malaria were available and dispensed according to the clinical health workers' prescriptions by the dispensers (the appropriateness of those prescriptions is discussed in step 6), the interviews and observations showed that most refugee patients were not

familiar with the treatment schedule that they were supposed to follow. The results in Chapter Six (section 6.5.4) show that insufficient treatment instructions were given to the patients by both the prescribers and by the dispensers. The drug dispensers said that language barriers and limited time were obstacles in giving adequate treatment instructions to patients and a few dispensers said they doubted if patients always understood instructions they gave on how to correctly administer the medication. Although some prescribers and dispensers indicated using symbolic instructions as a communication method to pass on information to patients who had limited language skills, they still doubted how helpful this was to patients. As discussed earlier, this issue of problems of a language barrier is common in many refugee settings where people of many different nationalities are gathered together in one location. In addition, as with initial visits to the health clinics, refugees of one nationality may be dissuaded from visiting the dispenser of a different nationality to collect their prescribed drugs if they feel that the dispenser will either treat them badly, or if they know they won't understand what they are being given. The results from this study suggest that refugees weren't being dissuaded from collecting their drugs due to differences in nationality, but they may have been having problems in then adhering to the correct regime (discussed in the next step) because of problems in understanding the limited treatment instructions given. Even where patients understand the treatment regime they are supposed to follow, they may be reluctant to start using the drugs they have been given. As mentioned in step two, in refugee situations, patients from different nationalities and locations may be used to different treatment regimes, and their previous experiences and expectations may well impact on their willingness to start treatment with a particular drug. The data from Kakuma camp suggest that the vast majority of the refugees were collecting their prescribed drugs, but the data from the FGDs suggests that many were not happy with the drugs they were prescribed. This may well have affected the timing of the starting of their treatment. The issue of correct drugs is discussed further in the following two steps.

The results from this study suggest that, during the period of this study at least, because drugs were relatively easily accessible (and free), the refugees in Kakuma had a good chance of starting the prescribed treatment. However, the study also highlights other factors which influence the starting of correct treatment in Kakuma camp, which are common in other refugee camps in sub-Saharan Africa. Principal among these is the need for recruitment of more (and better qualified) staff to relieve prescribers and dispensers from their heavy workload. The issue of the language barrier influencing the delivery of treatment instructions also needs to be addressed, either by having adequate translators, which means more money spent, or by considering representations of the different nationalities in the camp when recruiting health staff. Furthermore, supervision and monitoring of drug prescribers and dispensers is needed to strengthen the delivery of health service. As earlier indicated, there is need for establishment of a regular communication system between the communities, the health staff and the health care services management to help management to identify the concerns of the patients and providers. With the establishment of better communications, and a greater sense of 'ownership' by the community (through the community health committees), it might be possible to try to instigate a system of 'community volunteers' to help dispensers translate treatment guidelines to their patients. In addition, representatives of each of the nationalities should be involved in helping to develop written and pictorial guidelines appropriate for each nationality represented in the camp for the first-line antimalarial treatment used. These guidelines could then be displayed at the dispensing points, as well as being used by community health workers as part of their health education messages.

While the majority of refuges in Kakuma camp reported using the public health system, a few refugees in Kakuma did report using self-treatment with drugs bought from drug retailers. Recent global malaria control initiatives have highlighted the potential role of drug retailers to improve access to prompt

malaria treatment. Although the use of self-treatment with drugs from drug retailers was low in Kakuma, there is still need to identify the drug retailers and to train them on appropriate drug treatment policies. This is not only important for Kakuma but for refugee camps in general (Marsh *et al.*, 2004).

8.7 Step 5 – ADHERENCE TO THE TREATMENT

For the patient, the final step in the Piot model is the completion of the prescribed treatment regimen. That is, the patient needs to adhere to the prescribed regime not only to cure the patient, but also to help prevent the emergence of resistance to the drug being used (Mumba *et al.*, 2003).

Although this study did not focus specifically on refugee adherence to malaria treatment, the data presented in Chapter Four indicates that a good number of study participants with suspected malaria in Kakuma had used self-treatment with left-over drugs from a previous illness episode before visiting a health facility. These data would suggest that patients were not adhering to their treatment regimes by not completing the prescribed course of drugs. This is not surprising since many studies have shown that in many parts of sub-Saharan Africa, adherence to malaria treatment regimes is often poor (Depoortere *et al.*, 2004; Helitzer-Allen *et al.*, 1994; Phillips-Howard *et al.*, 2003; Vundule and Mharakurwa, 1996). The data reviewed in the previous section also suggests that many of the patients in Kakuma may not have completely understood the regime they were supposed to be following and so may have been unable to follow the instructions correctly. A recent study in Zambia found that insufficient explanation by the dispenser was identified as an important reason for non-adherence and recommended that for treatment regimens to remain efficacious on a long-term basis, specific and locally adapted strategies need to be implemented to ensure completion of the treatment (Depoortere *et al.*, 2004). As mentioned in the previous sections, the problems of sufficient explanation are magnified in refugee camp settings due to problems with language and previous experiences with different treatment regimes.

Experience has shown that more effective and better adherence of patients to treatment can result from home visits and follow-up of patients by community health workers (Botelho and Dudrak, 1992; Zimba and McInerney, 2001). This strategy requires adequate staff who are trained in the correct treatment regimes to follow up patients to enhance their adherence and understanding of the drug regimes. However, in addition to the patients needing to understand the correct drug regime, the health providers and management need to understand the reasons why patients may be reluctant to adhere to a particular drug regime. This may be due to a lack of understanding of the need to complete a treatment even when feeling better, but it may also be due to concerns about adverse side-effects or due to the belief that they have been given an ineffective drug. These problems may be increased in refugee situations where people may be introduced to new drug regimes or may be asked to take drugs that they have stopped using in their place of origin. In order to improve adherence to the chosen regime, the health care services management and providers need to understand and address the concerns of the refugees. This requires the use of a strategy to establish a forum in which these issues can be raised and solutions discussed. The community health committee could act as such a forum. In addition, a policy to ensure the recruitment of community health workers from each of the nationalities in the camp would help to facilitate the involvement of all nationalities in attempts to improve adherence.

There is also need for production of effective information, education and communication (IEC) materials to improve adherence. That is, if people understand both what they are meant to do as well as why they need to do it, then they are more likely to be able to adhere correctly to a treatment regime. In refugee camps, particular attention has to be paid to the needs of the various nationalities and language groups. The involvement of representatives of each of the different nationalities within a camp in the development of IEC materials is essential if adherence is to be improved. In addition to IEC and better instructions, the introduction of pre-packaged antimalarial tablets has also been

found to be helpful in improving adherence (Ansah *et al.*, 2001; Kilian *et al.*, 2003; Qingjun *et al.*, 1998; Yeboah-Antwi *et al.*, 2001). However, blister packaging does involve extra cost and getting adequate and regular supplies of blister packaged drugs, particularly in refugee camps, maybe a logistical challenge. On the other hand, as mentioned in Chapter One, in many refugee camps, the drug resistance patterns may be unknown, the use of combination therapy including an artemisinin derivative may be recommended for first-line treatment. Where this is the case, particularly if the combinations are not co-formulated, the use of blister packs could be considered to be particularly important to help in increasing adherence to a new treatment regime, which will be unfamiliar to many of the refugees.

8.8 Step 6 – DRUG EFFICACY

The final issue in the Piot model to analyse the effectiveness of a malaria case management strategy is a consideration of the drug chosen as first-line treatment to treat the disease. The model emphasises the importance of drug efficacy if the RBM goal on accurate diagnosis and prompt and effective treatment is to be achieved. Studies reviewed in Chapter One (section 1.3) indicate that most of the antimalarial drugs used as first-line treatment in many sub-Saharan countries are not efficacious. Although several countries have shifted their first-line treatment to SP or combinations of SP with other drugs such as CQ or amodiaquine, resistance to SP is also becoming widespread. As a result, the need for more effective drugs such as artemisinin derivatives is now being considered. In some countries such as South Africa, artemisinin combination therapy has already been introduced.

The literature reviewed in Chapter One also indicates that, although it is important to follow (where possible) the national drug policy of the host country when implementing health services in refugee camps, drug policies of the host country may not reflect the drug resistance patterns found in the area in which the camp is situated (Bloland and Williams, 2003).

The results from this study suggest that during the initial phase of data collection, the first-line treatment policy for refugees in Kakuma was different to the Kenyan national policy. Despite the change in policy in Kenya for first-line treatment of malaria from CQ to SP in 1998, in Kakuma the IRC policy in 2001 was for the use of CQ as first-line treatment. The reason for the continuous use of CQ according to IRC was that it was still effective in treatment of malaria in the camp as most of the refugees came from countries that still used CQ as their first-line treatment. It was not until early 2003 that the IRC abandon the use of CQ as the first-line treatment. While the delay in changing policy in Kakuma may have been influenced by the perception among the IRC management that CQ still worked in the camp (although the refugees clearly felt differently), the reluctance of the IRC to change may also have been influenced by two other factors. Firstly, an awareness of the difficulty in implementing change in drug policy in Kenya which had actually taken about 2-3 years, and secondly, budgetary constraints and the need to use up stocks of CQ. However, it is also clear from the observational data that, despite the IRC guidelines, many of the refugees were actually being prescribed with SP.

These results raise the issue that is a key concern in the case management of malaria in a complex emergency situation. That is, knowledge about current resistance patterns, both in refugee camps as well as in the refugees' countries of origin, and area of transit before arriving the camp. It is extremely difficult to make an appropriate selection of a first-line drug without such information. On the other hand, gathering this type of information in a complex emergency is almost impossible. The Kakuma results show that choices about the first-line treatment were probably driven more by logistical and budgetary constraints rather than based on any reliable evidence about levels of resistance. In addition, they show that decisions about the policy within the camp were made independent of the Kenyan national policy guidelines. While in the acute emergency phase of a complex emergency where mortality is high, it may be necessary to use the newest and most effective drugs (such as artemisinin combinations, even if this does not coincide with national policy) when a

situation stabilises, then the host county should also be involved in decisions about first-line treatment policy within a camp. Kakuma was a well established camp, and yet its policy was failing to keep up with the changes agreed at the national level.

Policy change at the national level is a complex process but it should at least be based on an analysis of the levels of resistance to the currently used antimalarial drugs. While there are obviously huge logistical and security constraints, where a country is host to a large population of refugees settled in medium to long term camps (post emergency phase), attempts should be made to include such locations in national or regional drug resistance surveillance networks (such as EANMAT). The inclusion of such sites would not only improve the likelihood that the refugees receive effective drugs based on reliable evidence, but the national policy makers will also receive information essential for drug policy decision making. Regular surveillance is of particular importance where there is either a steady influx of new refugees from new locations (possibly spreading new resistance parasite), or where there is regular movement in and out of the camp by refugee populations (possibly facilitating the spread of resistance parasites to new locations).

The need for establishment of a drug resistance surveillance system and an ongoing monitoring of first-line antimalarial drug efficacy, both in Kakuma camp as well as in refugee camps in general, is essential. The system should be integrated into the health management system to ensure that the results get fed back to the health care providers and the refugees. In addition, the health staff and administrators involved in the drug resistance surveillance system need to be trained in the use of surveillance information. The provision of such information will not only help to improve provider practice, but should also help the refugees understand the need for adherence to a particular drug regime and so improve their willingness to adhere to such a regime. Case definitions and reporting forms used by all agencies involved in the surveillance systems also needs to be standardised. Furthermore, the refugees themselves need to be involved in the system, particularly in relation to feedback about adverse drug

reactions and concerns or problems with the use of new drug regimes. Community health committees could be an important forum for the feedback of anecdotal information that could then be followed up in a more systematic manner.

As well as the involvement of the refugees, a drug surveillance system that is linked to the national and/or regional system would help in the establishment of regular communication among the camp health care services management and the Ministry of Health of the host country. It will also provide important information for international bodies such as WHO. While the setting up of such a system would be politically, logistically and economically challenging, with the increasing cost of first-line drugs and the rapid spread of resistance, such an approach needs to be given serious consideration.

8.9 OVERALL STRENGTHS AND CONSTRAINTS OF THE STUDY

The preliminary study based on focus group discussions provided information on the range of opinions found among the different groups within the camp, and provided an overview of the various malaria treatment-seeking behaviours of these groups. The results from this preliminary work enabled the development of a larger but more focused and detailed study on the problems related to treatment-seeking behaviours and the factors affecting the effective case management of malaria in the camp.

The aim of the study was to determine the factors influencing effective case management of malaria in Kakuma, including understanding the factors affecting treatment-seeking behaviours for malaria. The approach was to provide a broad perspective of the issues including the perceptions and behaviours of different nationalities represented in the camp as well as taking account of the effects of PTSD on these behaviours. One of the problems with this approach was the possibility of cultural and linguistic biases during data collection. However, the translators involved in the study were selected from among the refugees who had participated in surveys before and they attended a

one-week theoretical and practical training in research techniques. In addition, the translators were selected to represent the different nationalities and ethnic groups in the camp and their own backgrounds proved essential in investigating sensitive issues related to culture and traditions. A further concern was the issue of dealing with participants who had experienced severely traumatic events and had been diagnosed as suffering with PTSD. The method that was devised to help deal with this problem was to encourage the participants to tell their own stories and to ensure that back up and referral to the appropriate support organisations was available if and when required. While the interviewers did not probe into these traumatic events, the fact that many of the team were refugees themselves who had undergone similar experiences helped them to empathise with the interviewees which allowed the interviewees to tell their stories more freely. Further interviews by interviewers with more training in dealing with PTSD would be required to investigate the impact of specific traumas in greater detail.

In this study, the investigation related to the issue of PTSD was limited to adults. While this is a limitation in terms of malaria, the majority of those diagnosed with PTSD in Kakuma were adults, and therefore, to study the effect of PTSD on treatment seeking behaviour, it was necessary to restrict participant selection to the adults.

The use of both qualitative and quantitative methods in this study was important since it allowed for quantitative comparisons between groups (such as those affected and not affected with PTSD), as well as allowing for a more in-depth investigation of the reasons for the differences between the groups. It is possible that participants in the FGDs withheld essential views about the topics under discussion due to lack of confidentiality but the informal individual interviews were helpful in eliciting detailed chronological descriptions that were used to complement data from the FGDs. In addition, the principle investigator spent about 2 year living with the refugees in the camp, developing relations and building trust with them. This allowed for freer expression of views in the FGDs and interviews and allowed the investigator to gain a greater insight and

knowledge of the most suitable ways in which to raise and investigate sensitive topics. In addition, as a consequence of spending an extended period of time living in the camp, anecdotal data and insight into the problems and issues related to refugee life and their experience with diseases was collected and explored. These data were very helpful in complementing and understanding data obtained through the more formally recognised methods of data collection.

The study assessed quality of care from both the users' and providers' perspectives. This allowed for the triangulation of the data and gave a better insight into the constraints on the system.

One of the major limitations of this study was the quality of the parasite prevalence survey. Involving the laboratory personnel from the IRC public health facilities as part of the research team for the malaria prevalence survey was an effective way of assessing the quality of their work, but this affected the reliability and accuracy of the results from the parasite survey. The validation teams found that many of the blood slides were unreadable due to inappropriate preparation of the smears and staining of the slides. This meant that the assessment of the malaria burden in the camp could not be validated parasitologically. Furthermore, while the parasite surveys had been planned for the dry and rainy seasons, to assess seasonal variation in parasite prevalence, the first survey actually took place during the early dry season, while the second survey took place during the late dry season as the rains were very late. Even if the slide taking had been reliable and the slides readable, the data from the surveys would not have reflected seasonal variation of malaria prevalence in the camp.

A final limitation was the fact that the participants with PTSD who took part in the interviews and FGDs were both purposefully and self-selected. That is, only those participants with no history of aggressive behaviour and who agreed to take part, were selected as participants. It is unclear the extent to which these participants were representative of the rest of the refugees who were diagnosed with PTSD, but the fact that they agreed to take part in the study suggest that

they were likely to be more socially engaged than those who refused. This in turn could be used to assume that these participants were possibly more likely to seek outside help and be less vulnerable that their counterparts who refused to be involved.

The aim of this study was to help the IRC to investigate the state of the case management of malaria in the camp and to provide suggestions, where necessary on ways to improve the system. The sample size, while large enough to draw conclusions about the situation in Kakuma, is probably not large or sufficiently detailed to allow for sweeping generalizations. To allow broader conclusions to be drawn, further research among refugees in a variety of camps would be required. However the study does raise some important issues and concerns that may well be applicable in other malaria endemic refugee settings.

8.10 SUMMARY OF RECOMMENDATIONS

8.10.1 Summary of recommendations

The summary of discussion and recommendations has been presented in Tables 8.1 below.

Table 8.1: Summary of core issues and major recommended actions at different steps using the Piot model to improve malaria management and control in Kakuma camp and in other post emergency refugee camps

Steps	Core issues	Major actions for Kakuma refugee camp	Major recommendations for post emergency refugee camps
Burden of the disease	Prevalence of malaria is not known because: -lack of adequate and functional surveillance system -limited data available -insufficient health information system -poor quality of parasitological diagnosis	Establish adequate, functional and effective surveillance system: -establish community health council/ committee (CHC) to liaise with front-line health providers and representatives of refugee nationalities to obtain data needed -liaise with local authority for data -improve HMIS through involvement of CHC -train laboratory staff in slide preparation and reading techniques and introduce rapid diagnostic tests (RDTs)	Adequate and functional surveillance system essential and facilitated by: -establishment of community health council or committee (CHC) -data collected by and fed back to front-line health workers and representatives of refugee nationalities -working closely with the local and national health authorities to obtain relevant data
Step 1: Awareness	-Most refugees have knowledge about malaria and they relate fever to malaria, although knowledge about malaria transmission is low. -Malaria awareness among refugees diagnosed with PTSD is lower	-Conduct research on impact of refugee experience and response to stress on disease awareness -Use CHC to help develop appropriate health education messages and identify channels for delivery -All community health workers to be aware of refugees diagnosed with PTSD in their area and develop register of those 'at risk' of being unable to distinguish signs of malaria.	-Use CHC to: a) identify refugees' knowledge about disease signs and symptoms b) help develop appropriate health education messages -Delivery of curative and mental health services needs co-ordination to assist in identifying and targeting those less likely to be aware of illness (the most vulnerable) e.g. active case detection among those diagnosed with PTSD

Step 2: Motivation to seek treatment	Motivation to seek treatment is low and affected by: -psycho-social stress and trauma, particularly among refugees diagnosed with PTSD -limited choice for treatment -perceived low quality of service -perceived drug ineffectiveness -loss of agency -insecurity and harsh camp conditions	-Form CHC to involve refugees and providers in decision-making about health care -Develop a sense of self determination and ownership of the health services by the refugees -Help support and motivate providers -Help develop and disseminate appropriate health education -Train clinical providers in patient management as well as clinical care -Improve access by improving security in the camp	-Involve refugee in activities that will provide them with greater sense of agency. E.g. form CHC to promote self determination and ownership of health services -Ensure training of providers in patient as well as clinical management -Recruit staff according to nationalities of refugees and rotate staff through the clinics -Ensure availability of effective drugs and develop health education messages for all nationalities -Develop awareness among camp management staff that security affects access to health care
Step 3: Diagnostic process	Poor quality of clinical and laboratory diagnosis: -inadequate history taking and physical examination -necessary equipment available but rarely used -staff over worked and poorly motivated -lack of technical laboratory skills -poor slide preparation, staining and reading -lack of good quality microscopes	-Provide more staff training opportunities and refresher courses -Use CHC to enhance communication between management and staff, and between providers and refugees -Increase support to providers -Decrease pay disparity between refugee and local staff -Provide efficient medical equipment -Strengthen supervision and monitoring of staff performance, including positive feedback -Introduce RDTs	-Ensure adequate training, supervision and support to staff -Ensure there are sufficient numbers of staff of the relevant nationalities to cover need -Ensure pay differentials between refugee and local staff do not cause dissatisfaction -Use CHC to provide forum for feedback and communication to support staff (from management and patients) -Ensure supply of equipment -Introduce RDTs, particular in areas of low transmission

Step 4: Starting correct treatment	-Initially inadequate supplies of appropriate drug (SP) -Patients are often not prescribed appropriate treatment -Patients not given adequate instructions -Perceived lack of effectiveness of antimalarial drugs discourage patients from starting treatment immediately	-Train staff and provide refresher courses to improve diagnostic and prescribing skills -Ensure supply of adequate and effective antimalarials -Train dispensers and monitor dispensaries for adequate treatment instructions -Recruit dispensers to represent each nationality or employ translators to assist in giving instructions in the appropriate language	-Provide regular staff training and refresher courses in prescribing -Recruit adequate and qualified staff from representative nationalities to give instructions in the appropriate language -Ensure adequate availability of effective drugs -Use CHC to develop appropriate health education messages for drug use -Where shops are used for drug purchase, train the drug retailers
Step 5: Adherence	-Patients may not to understand treatment instructions -Few patients self treat with drug from drug shops but do use left over drugs from previous episodes -Actual extent of drug adherence not known	-Recruit dispensers to represent each nationality or employ translators to assist in giving adequate instructions in the appropriate language -Involve CHC in developing appropriate health education messages in the each language -If (when) combination therapy is introduced then use pre-packaged drugs -Conduct research on adherence to identify problems and possible solutions	-Ensure recruitment of dispensers to represent each nationality or employ translators to assist in giving adequate instructions in the appropriate language -Involve CHC in developing appropriate health education messages in the each language -If (when) combination therapy introduced then use pre-packaged drugs -Conduct research on adherence to identify problems and possible solutions

Step 6: Drug efficacy	-Although SP is supposed to be used as the first-line treatment for malaria in the camp, CQ was still being used as well -Resistance to common antimalarials used such as CQ and SP is widespread in Kenya -Efficacy of SP in Kakuma is unknown	-Liaise with national and local authorities to undertake drug resistance survey in Kakuma -Liaise with local and national authorities to establish Kakuma as part of the drug surveillance network -Camp management needs to ensure that Kakuma is ready for the next drug policy change – plan for provider training, development of health education messages and identify a reliable source of drugs. -Use CHC to obtain data on refugees perceptions on drug efficacy and concerns about drug use (e.g. side effects)	-Liaise with local and national authorities to ensure that camp management is aware of current resistance information and drug policies. -Liaise with donors and national and local authorities to undertake a drug resistance survey in the camp -Maintain contacts with national authorities to keep up with MOH thinking on drug policy -Investigate possibility of camp acting as sentinel surveillance site for monitoring of drug resistance -Use CHC to obtain data on refugees perceptions on drug efficacy and concerns about drug use (e.g. side effects)

8.11 LESSONS LEARNT

This study looked at the factors influencing treatment-seeking behaviours for malaria in a refugee setting in Northwestern Kenya using an epidemiological, anthropological and health services' perspective. These various perspectives provided a useful framework for the investigation of the impact of experiences, beliefs, and social support, as well as the quality of malaria diagnosis and treatment on both the treatment-seeking behaviours of refugees and effective case management of malaria in a refugee setting. Eliciting narratives on what people do during malaria illness when they have experienced traumatic events in the past was an important part of the study and highlighted the usefulness of involving ethnographers in such studies.

This study has not only been helpful in examining factors influencing effective management of malaria in Kakuma camp, but it has also broaden my knowledge and understanding about life in displaced peoples' camp. The experience of staying with the refugees in the camp for two years has shown me just how much difficulty the refugees had in coping with the stress caused by life in the camp as well as the stress caused by their experience during the pre-flight and flight period. This difficulty reflected negatively on their health, and in some cases on their ability to cope with ill health. However, although refugees are vulnerable (and some are vulnerable than others), my experience staying in the camp also showed that most refugees actively seek care and are not just passive recipients of care. Their decision to seek care is based on previous experience before coming to the camp as well as their experiences and options available to them in the camp.

The experience also brought forward the fact that working in refugee camps requires additional skills. During my stay in the camp, I witnessed a high

turnover of staff among the NGOs caused by the difficult working environment in the camp. The important lesson here is that working in areas of complex emergencies such as refugee camps is not the same as working in stable environments. There are a lot of challenges in refugee camps, which can have an effect on work performance. Therefore, staff working in refugee camps need additional skills and support to overcome the challenges of working in areas of complex emergencies such as in refugee camps, and this is very important to improve quality of health services.

While in Kakuma, I interacted with the refugees and the front-line health care providers, as well as with the health management staff of the camp. My experience with the health management staff showed that the relationship between them and the front-line providers was fairly formal, and many of the management staff felt that, while they were trying their best to provide refugee health care providers in the camp with training, the low educational standard of many of the providers contributed to the difficulty in developing effective training programmes.

The informal relationship between the health management and the front-line health care providers was lacking. Although a few of the health management staff in the camp were very flexible and friendly, not only to the front-line health care providers, but also to the refugees, the majority of the management staff had little time for any informal interaction with either the front-line health care providers or with the refugees.

The relationship between the refugees and the local population was poor. As well as the bad relations caused by the difference in paid incentives between the refugee and national front-line health care providers, the majority of refugees complained about how they were being attacked, and how their property in the camp was being looted by the locals. On the other hand, although I did not get a

chance to interact with the locals, they appeared unhappy to see all the relief services being offered to the refugees. Despite experiencing many similar problems, they were excluded from the services provided to the refugees.

The burden of malaria in the camp was not the only problem faced by the refugees in Kakuma. My experience interacting and talking to the refugees showed that they had several other concerns, which to them were more important than malaria in the camp. One of their major concerns was the issue of resettlement abroad (America). Finding ways for resettlement through UNHCR to them was their major concern. Even during informal talks, each time I tried to discuss with them about health problems in the camp, they would change the topic to resettlement issues abroad. Although a few refugees were successful in being resettled in America based on their individual cases, for the majority in the camp, this looked impossible. This is one of the problems that is contributing to the stress of the refugees in the camp, which in turn is impacting negatively on their health and in some cases, on their ability to cope with ill health. For others, their concern was returning to their original areas of settlement where they had left their families, relatives, businesses and properties. A few refugees, however, were much more concerned with the living condition in the camp, and complained about the quantity and quality of food in the camp, the poor housing, and the hot and dusty weather of Kakuma.

I found my experience staying in the camp helpful in both collecting and interpreting the research data. For example, it would have been difficult for me to carry out the interviews and discussions with the refugees without interacting with them and knowing their problems. At least by knowing what they are going through in the camp as well as having known their experience during the pre-flight and flight period, I had to always be sensitive and adjust the way I asked them questions and handle the discussions. My experience in the camp also

helped me analyse much of my raw data, providing the context for interpretation of my results.

Although it is difficult to assess exactly how I was assessed by the interviewees, initially during the preliminary stage of the study, a few of the refugees thought I was a new health coordinator for IRC and was trying to familiarise myself with the problems of the camp. As a consequence, they were very free in relating to me their problems, with the hope that I would be of great assistance to them. On the other hand, the health care providers thought I was sent by the IRC to evaluate their performance, and so I could feel that they were trying to be careful in what they said and did. However, after my interaction with them during the actual study, both the refugees and the health care providers at the front-line came to accept me as a student. Surprisingly, as being a Sudanese, all the nationality, and not only the Sudanese, perceived me as one of them who could lobby on their behalf with the management to help solve their problems. This might be because I interacted with all of them in the same manner and tried my best to listen, learn and be accepted as a member of the community by spending many hours visiting, sharing stories and interacting informally. Nevertheless, there were a few refugees who, although they did not refuse to participate in the study, complained that they were fed up of research and assessments in the camp as they were not seeing any positive results coming out from the previous research, assessments and surveys conducted in the camp.

8.12 CONCLUSION

Applying the Piot model to analyse the case management of malaria in Kakuma camp has proven useful in helping to identify the critical challenges faced in a complex emergency situation in managing diseases. The model distinguishes the various steps (from the onset of malaria to the cure of patients) that patients

have to take when they are ill, and this provided a framework for the analysis and interpretation of the data on treatment seeking behaviour. Thinking about the factors influencing the movement of a patient through the steps has helped to identify and highlight the additional complicated contextual issues that refugees and providers of health care face in complex emergency situations.

Among the important issues raised by using the Piot model in this study, is a lack of motivation among refugees to seek treatment due to a loss of sense of 'agency'. To increase the refugees' motivation to seek care, there is need to involve the refugees in decisions regarding health care provision so as to increase the sense of self-determination and ownership of the health services by the refugees. This could be helped by the formation of community health committees made up of the representatives of each of the refugee nationalities as well as of the community health workers, clinical health workers, other health care providers and representatives of NGOs organising and managing health care and camp management.

The model has also been helpful in highlighting the need for an adequate and functional surveillance system in the camp to establish the disease burden and levels of drug resistance. The study have emphasised that for a surveillance system to be effective in Kakuma, as well as other refugee camps, there is need for the NGOs involved in the management of health services in the camp to liaise with local and national authorities as well as with front-line health care providers, and with representatives of the various refugee nationalities. Such alliances can contribute not only to the collection of valuable epidemiological data on malaria and other disease burdens in the area but are also essential to developing an understanding of the critical contextual factors that contribute to the disease burden and spread of drug resistance.

Overall, this study on the treatment-seeking behaviour of refugees in Kakuma

camp in Northwestern Kenya has highlighted the impact that the refugee experience and context has on treatment-seeking behaviour and the management of disease. While the disease, malaria, is the same in stable and complex emergency situations, this study has demonstrated how the social, economic and political context of being a refugee helps to shape both the 'illness' as well as the patients' and providers' abilities to manage malaria. The study has clearly illustrated that the management of malaria in a refugee camp is not merely a technological issue. It cannot be separated from the overall context in which the disease exists.

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APPENDICES

APPENDIX 1: MAIN SURVEY

INTERVIEW GUIDE: PERCEPTION OF MALARIA, EXPERIENCES OF TRAUMA AND SOCIAL SUPPORT: IMPACT ON TREATMENT SEEKING,

1. SOCIO DEMOGRAPHIC DATA

Code No:
Sex:
Occupation:
Tribe:
Country:
District:

Age:
Education:
Marital status:
Ethnic group:
Region:
Duration of stay in the camp:

1. INTRODUCTORY DISCUSSION

(To give information on possible support groups that existed in place of origin and have survived displacement)

- When did you first arrive in the camp?
- Which members of your direct family, close relatives and community members from your clan arrived with you

Family members

Age	Sex	Relation

Close relatives

Age	Sex	Relation

Clan members

Age	Sex	Relation

Which members of your direct family, close relatives and community members from your clan joined you later in the camp? (If none, write none on each box).

Family members

Age	Sex	Relation	Arrival year

Close relative/Clan members

Age	Sex	Relation	Arrival year

2. PERCEPTIONS ABOUT MALARIA AND STRESS

A. Perceptions on malaria burden in the camp

- What are the common diseases in the camp?
- What are the most leading diseases of great burden?
- Have you experienced febrile illness in the last three month?
- Have you heard about the disease called malaria? (If not, probe on febrile illnesses)
- Have you experience malaria before (has the participant ever been sick with malaria)
- Is malaria a health problem in the camp?
- Is malaria a health problem in your area of settlement?
- What is the difference between malaria in the camp and in your original area of settlement?

B. Knowledge about malaria and recognition of signs and symptoms

- What are the signs and symptoms of malaria?
- Are you able to recognise when you have malaria?
- If yes, how do you usually know you have malaria?
- What signs and symptoms helps you recognise malaria
- How long does it take you from the time you first recognise malaria to the time you seek treatment

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C. Knowledge about stress and recognition of stress

- Have you heard about stress ('Zehij)? Do you know what it means to be stressful?
- Do you knows of someone who has been stressed?
- Have you ever been stressed? If so, what signs and symptoms did you experience that made you think it was stress?
- What are the differences between signs and symptoms of malaria and stress? (Probe if suffered or knows about stress)
- When you have malaria, do you have some of the signs and symptoms you usually experience when you are stressed?
- Are there similarities between signs and symptoms of malaria and stress? (Probe)
- What are the difficulty in distinguishing between signs and symptoms of malaria and stress?

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3. TREATMENT-SEEKING BEHAVIOURS FOR MALARIA AND USE OF SUPPORT GROUP IN THE CAMP

- Is there any difference what you do in the camp here compared to what you used to do while in your country of origin or settlement with regards to malaria treatment?
- How long is it between the time you first feel sick and the time you seek treatment? Is this different to time to treatment in your home village?
- Is it more difficult or easier to get treatment for malaria here in the camp? Why?
- When you first recognise malaria, do you take any sort of treatment in the house before seeking other treatments? If so, what treatment do you start at home?
- Where do you first go for treatment outside the household? (Allow to tell story) (record type of provider e.g. shop, herb seller, health facility)
- What is the usual treatment/medicine you take in the camp here when you have malaria (record if it is anti-pyretics e.g. panadol, antimalarials or herbs, or other traditional treatment or a combination)? What does it cost?
- For this first treatment outside the household do you get help, advice or encouragement from others before seeking treatment or do you decide to seek treatment yourself?
- If you got help from others in making the decision to seek treatment, what help did you get and who were involved in providing the help/advice/support?

- Are any of the people you mentioned before available to help you give advice/decision for treatment when you are sick?
- If some, then who are they and do you still use them in the same way? If you don't still ask their advice then why not?
- Do these people you mentioned give you the same type of help, encouragement and advice you used to get while back home when you were sick? If not then how and why is it different?
- Who do you turn to for advice in times of need for decision to seek treatment when sick with malaria?
- What now happens if the first treatment outside the house didn't work? What do you do then, who is involved in the decisions and why?

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4. TREATMENT-SEEKING BEHAVIOURS FOR MALARIA AND USE OF SUPPORT GROUP IN PARTICIPANTS' AREAS OF ORIGIN

A. Household composition in area of origin

- When you were living in your place of origin, what was the composition of your household (who did you live with)?
- What was your relationship to the head of household?
- Which household members or community were involved in decision-making? For example: If you needed to make choice on food, treaument, education, etc whom did you consult before making decision.

People involved	Relation	Reasons for involving them

B. Treatment-seeking behaviour and use of support group

- When you were back home at your place of origin, what did you do when you feel ill, e.g. got a fever. (Allow to tell story & record verbatim)

- Did you ever seek advice from others during the course of the illness?
- Did you ever have an attack of malaria (or fever) before coming to the camp?
- When you had an attack of malaria before coming to the camp, did you ever seek treatment within your house
- When did you first seek outside your household?
- Where did you first seek treatment outside the household? (record type of provider e.g. shop, herb seller, health facility etc
- What was the usual treatment/medicine you took when you had malaria (record if it was anti- pyretic e.g. panadol, anti- malarial or herbs, or other traditional treatment or a combination)?
- What did it cost?
- For this first treatment outside the household did you get help, advice or encouragement from others before seeking treatment or did you decide to seek treatment yourself?
- If you got help from others in making the decision to seek treatment, what help was provide and who else was involved?

People involved	Relation	Stage of illness	Reasons for involving the person

Further verbatim responses in use of support group (to be asked for both experience in the camp and area of origin)

- Why were the people mentioned involved (Probe) in the decision to seek-treatment
- What sort of help did they provide? (probe for: money, advice etc) – [this is to provide a check on the previous answer]
- Was it necessary for them to be involved? If yes then why? If no then why not?
- Were they always involved or only if they were readily available?

- How long after the onset/symptom of the disease did you wait before asking advice?
- What treatments were you frequently advised to go for when sick with malaria?
- Were you always satisfied with the decision for seeking treatment they gave you?
- Did you follow the advice?
- What used to happen if the first treatment outside the house didn't work? What did you do then, who was involved in the decisions and why? Etc

NB: All process of decision-making throughout the course of the illness should be recorded.

Date of interview: ---------- Interviewer's name:----------

Comments on interview by interviewer if any_____

APPENDIX 2: MAIN SURVEY

TOPIC GUIDE: INFORMAL DISCUSSION WITH HEALTH CARE PROVIDERS RESPONSIBLE FOR MALARIA MANAGEMENT IN THE CAMP

Socio demographic data

Name of clinic:
Gender:
Education level:
Qualification/s:
Nationality:
Duration of service in the camp:
Provider's code No:
Age:
Religion:
Duration of training
Ethnic group:

General perceptions of all health care providers involved in the study about malaria in the camp

- General perception of health care providers about malaria situation
- Malaria as a common disease
- Burden of malaria in the camp
- Treatment-seeking behaviours of the refugees in the camp
- Reasons for delays in treatment-seeking

General perceptions of clinical health workers about malaria in the camp

- Opening hours of health facilities
- Common diseases presenting with fever
- Number of malaria cases seen in a day.
- Existing *Plasmodium* species and their intensity
- Known pattern of malaria transmission and factors influencing it
- Seasonality and limiting factors of endemicity (e.g. geographical/climatic factors)

Case management of malaria at the out patient facilities
Participants: Clinical health workers

Guidelines

- Knowledge on guidelines in case management of malaria
- Use of guidelines in case management of malaria in the camp

First encounter with patients

- Patients greeted
- Patient offered a sit
- Details of patient recorded

History taking

- Present history taken
  e.g. main complaint that brought patient to facility
  duration of complaint enquired, inquiry on details of fever (If patient mentioned having fever), enquiry on other symptoms
- Past history taken
- Patients asked if encountered similar complaints before, how problem was managed

Physical examination (Probe)

- Physical examination of patients conducted
- Examination of patients in relation to complaint
- Patients examined explained reasons and procedure for examination

Diagnosis (test ordered for malaria)

- Process in reaching a diagnosis in patients presenting to the facilities with fever of suspected uncomplicated malaria,
- Common diagnostic method used for malaria cases in the camp
- Types of tests/examinations ordered when malaria is suspected
- Reason for particular tests/examinations mentioned
- Perceptions on reliability of tests/examinations mentioned
- Use of laboratory facilities and decision for laboratory test
- Type of laboratory test frequently ordered for when malaria is suspected
- Type of patient referred to the laboratory for malaria test
- Perceptions on reliability of laboratory tests.

Treatment

- Anti malarial treatment prescribed
- Other treatment prescribed
- Treatment instructions provided

Health education

- Brief education on diagnosed disease
- Preventive methods emphasised

Laboratory diagnosis of malaria at the outpatient health facilities
Participants: Laboratory assistants

- Perceptions on laboratory diagnosis of malaria at the health facilities
- Types of laboratory test for malaria carried out
- Perception on accuracy and reliability of results
- Laboratory results in relation to seasonality
- Number of patients received in a day for laboratory blood test
- Total number of smears examined for laboratory test in a day
- Total number of positive slides for malaria parasite
- Common malaria species
- Supplies and equipment

Drug dispensing at the outpatient health facilities
Participants: Drug dispensers

Dispensing practice

- Receiving prescriptions and crosschecking
- Interpreting prescriptions
- Preparation of drugs to be dispensed
- Administration of drugs
- Dispensing process
- Type of anti malaria dispensed

Health education programme carried out in the camp as a control measure
Participants: Community health workers

- Perceptions on health education as a control measure in the camp
-

- Health education activities carried out
- Perceptions on role of health education in malaria control

Date of interview: ---------- Interviewer's name:----------

Comments on interview by interviewer if any_____

Appendix 3: Main survey

CHECKLIST: OBSERVATION OF CLINICAL HEALTH WORKERS' PRACTICE IN CASE MANAGEMENT OF MALARIA AT THE PUBLIC HEALTH FACILITIES

Provider's Code No: ---------- Name of Clinic:----------

Observer's name---------- Date:----------

A. FIRST ENCOUNTER WITH PATIENTS AND HISTORY TAKING

Use the symbol below when filling the checklist
✓ means Yes X means No

NO	Characteristics and anamnesis	CODING CLASSIFICATION
1.	First encounter with patients	Patient greeted [ ] Patient offered [ ] Name recorded [ ] Address recorded [ ] Patient's age recorded [ ] Patient's sex recorded [ ]
2.	Duration of consultation	<2-3 min [ ] >3-5 min [ ] 6-10 min [ ] >10 min [ ]
3.	History taking	Present history taken [ ] Past history taken [ ]
4.	Questions asked by Clinical health workers during history taking included:	Enquiry on duration of illness [ ] Enquiry on onset and nature of fever [] Enquiry on previous treatment [ ]
5.	Further enquiry made	a) Headache [ ] b) diarrhoea [ ] c) Vomiting [ ] d) Nausea [ ] e) Cough [ ] f) Current treatment [ ] g)Diarrhoea [ ] Others (mention) ----------

B. PHYSICAL EXAMINATION

NO	Characteristics and anamnesis	CODING CLASSIFICATION
5.	Physical examination carried out to patients	i) Examination carried out a) Yes [ ] b) No (If No, move to 6) ii) Pallor: Eyes checked [ ] Mouth checked [ ] Hands checked [ ] iii) Dehydration checked for [ ] iv) Abdomen for enlarged spleen/liver [ ] v) Respiratory tract checked [ ] vi) Temperature recorded using thermometer [ ] vii) Chest examined with stethoscope [ ] vi) Others(mention) ----------
6.	Reasons for examination explained to each patient.	Reasons explained [ ] Reasons not explained [ ]

C. DIAGNOSIS & TREATMENT

NO	Characteristics and anamnesis	Coding classification
7.	Method used for diagnosis.	a)Clinically [ ] b) Laboratory Test [ ] c)No diagnosis made [ ] d)Others (mention) ---------- -
8.	If laboratory test is ordered, type ordered.	a) Blood smear for malaria parasites [ ] b) Haemoglobin for anaemia [ ] c) Full blood count [ ] d) ESR [ ] e) Urinalysis [ ] f) Others (mention) ----------
9.	Diagnosis reached (mention)	---------- ---------- ----------
10.	Patients Informed about diagnosis reached	Patient informed about diagnosis [ ] Patient not informed of diagnosis [ ]
11.	Type of treatment prescribed.	Mention: ---------- ----------
12.	Patient given instructions on:	Drug administration [ ] Drug side effects [ ] Health education [ ]

D. OBSERVATION OF HEALTH FACILITY STRUCTURE

NO	Structure	Coding classification
1.	Physical structure	General structure of the outpatient health facility buildings Good [ ] (Concrete building building, tidy, enough Space available, good ventilation) Fair [ ] Accommodating but temporary building constructed from poor materials, ventilation inadequate, too small, not tidy) Poor [ ] Building constructed from poor materials, almost falling apart, cracks on the wall, dirty, poor ventilation.
2.	Rooms	Number of rooms ---------- Division and use of the rooms ----------
3.	Furniture (where possible indicate how many available)	Chairs [ ] Tables [ ] Coaches[ ] Cupboards [ ] Others (mention) [ ]
4.	Availability of basic equipments (Where possible indicate how many available)	Thermometer[ ] Stethoscope[ ] Sphygmomanometer[ ] Microscope[ ] Dressing trays[ ]

Date of interview: ---------- Interviewer's name:----------

Comments on interview by interviewer if any_____

APPENDIX 4: MAIN SURVEY

CHECKLIST: OBSERVATION OF DISPENSERS' PRACTICE AT THE PUBLIC HEALTH FACILITIES

Dispensers' code No: ---------- Name of Clinic:----------

Observer's name---------- Date:----------

Use the symbol below when filling the checklist
✓ means Yes X means No

NO	Characteristics and anamnesis	CODING CLASSIFICATION
1.	Dispensers understood and could translate prescription	-Prescription clear and readable [ ] -Prescription Partially readable and needs to be crosschecked [ ] -Prescription unreadable [ ]
2.	Dispensers correctly identified prescribed drugs	-Availability of drug checked [ ] -Expiry date checked [ ] -Old drug stock used first [ ]
3.	Dispensers correctly interpreted prescription	Name of drugs clearly labelled Dosage indicated as prescribed Duration indicated as prescribed
4.	Dispensers communicated the correct way	-Communicated exactly as prescribed -Symbolic instruction used incase of illiteracy -Warning and caution provided to enhance compliance
5.	Dispensing time	1-2 min [ ] >2-3 min [ ] >3-5 min [ ] >5-10 min [ ] >10 min [ ]
6.	Drugs dispensed	Antimalarials (Mention) ---------- Others: ----------

Appendix 5: MAIN SURVEY

QUESTIONNAIRE: CROSS-SECTIONAL MALARIA PARASITE PREVALENCE SURVEY, KAKUMA REFUGEE CAMP

Kakuma: ---------- Community:---------- Date: ----------

Interviewers name: ---------- Lab assistant's name:----------

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Socio-Demographic data

Code No ..... Age .....

Sex ..... Education .....

Occupation ..... Marital status .....

Tribe ..... Ethnic group.....

Antecedents

1. Location of respondents' residence: Phase ..... Group ..... Zone.....

2. Number of people in the household: .....

3 (a) Details of household members are to be illustrated in the table below.

Name	Slide code	Sex F/M	Age	Occupation	Duration of stay in the camp	*Fever in last 3 days* (Yes/No)	*On anti malarial drug*

- If blood smear is not taken, right the sign dash (—) against the name in the slide code column.
- Write 'Yes' if there is fever in the last 3 days (72 hours) and 'No' if no fever.
- For Sex, write F for female and M for male.

3 (b) Details of **absentees** to be filled later when the interviewers return for them. Only names should be recorded in their absence during first visit.

Name	Slide code	Sex F/M	Age	Occupation	Duration of stay in the camp	Fever in last 3 days Yes/No

4(a) **Family movement:** Number of times family or its members travelled out of the camp since arrival in the camp, place travelled to and duration spent.

Names of family/members who travelled out the camp and came back since arrival in the camp.	No of times travelled out the camp	Places travelled to (not >2)	Last time travelled out of the camp	Duration spent, (days /wks/month)

4 (b) Details of movement of absentees to be filled later when the interviewer returns for them. Only names should be written in their absent.

Names of family/members who travelled out the camp and came back since arrival in the camp.	No of times travelled out the camp	Places travelled to (not >2)	Last time travelled out of the camp	Duration spent (days wks/month)

5. Sanitation/drainage around the residence (observation)

a) Very clean [ ] (No grass/rubbish hips/standing water around or within house compound)
b) Fairly clean [ ] (Few grass, or rubbish or standing water seen but easily unnoticed)
c) Poor [ ] (Grass/rubbish hips & standing water around and within the house compound)

6. Are you currently on any malaria drug a) Yes [ ] b) No [ ]

7. If yes, which malaria drug are you taking?
a) Mention/show _____ b) Don't know [ ]

8. Have you been on malaria drug in the last 7 days
a) Yes [ ] b) No [ ]

9. Smear for laboratory investigation of malaria parasite taken
a) Yes [ ] b) No [ ] If yes, Number of smears taken from this household _____

APPENDIX 6: PRELIMINARY SURVEY

TOPIC GUIDE: FOCUS GROUP DISCUSSION, MALARIA KNOWLEDGE AND TREATMENT-SEEKING BEHAVIOURS, KAKUMA CAMP

Date: ---------- Code number: ----------

Kakuma: ---------- Community:----------

Socio-demographic data

Age (yrs):	Gender:
Nationality:	Country of origin
Education	Religion
Occupation	Marital status

Malaria Burden

- The common diseases in the camp
- The most leading disease of great burden in the camp
- Malaria as a health problem in the camp
- Malaria as a health problem in the refugees' original area of settlement
- Difference between malaria in the camp and in the original area of settlements

---

Malaria knowledge

- Causes of malaria
- Common signs and symptoms of malaria
- Perceptions on malaria transmission
- Perceptions on malaria complications
- Perceptions on malaria prevention
- Common drugs used for treatment of malaria in the camp
- Administration of the drugs
- Reasons for any left over drug

- Treatment-seeking behaviours
- Experience of fever/malaria in the last 3 month
- Malaria self-recognition
- Recognition of malaria signs and symptoms
- Difficulties encountered in recognising malaria
- When malaria is recognised, first actions taken in seeking treatment
- How decision was reached for the action taken
- If no action taken, reasons for not taking any action?
- Who decides where to seek treatment?
- Sources of treatment used and reasons for preferences
- Time taken to seek treatment after the onset of the first signs and symptoms of malaria/febrile illnesses
- Incase of failure of recovery of particular treatment, next action taken.
- Malaria treatment-seeking behaviours in original area of settlement and differences if any compared to treatment-seeking in the camp
- Use of health facility in management of malaria in the camp

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Date of interview: ---------- Interviewer's name:----------

Comments on interview by interviewer if any_____

APPENDIX 7: Checklist: Background information, Kakuma camp

Size of population

- Estimate of total population
- Number of men: women
- Percentage of under-five

Social characteristics of the population

- Nationalities
- Ethnic groups
- Language spoken
- Culture/traditions related to malaria treatment

Literacy

- Proportion of men and women estimated to be literate
- Literacy rates between nationalities in the camp
- Formal education in the camp

History of the community

- When the camp was established
- Setting of the camp
- Migrants and population movement

Climate (describe)

- Seasonal variations
- Seasonal variability in malaria

Environment

- Water
- Sanitation
- Hygiene

Economic background

- Occupation

- Women and men's work
- Out-migration and in-migration

Political organisation

- Organisation within the camp
- Is there a head?
- How is the head elected?

Security camp

- How secured are the refugee in the camp
- Ethnicity problem in the camp

Host community

- How do the host community interact with the refugees?
- What sort of tension exist
- How free is the refugee among the host community
- Is there anything they share in common

Health services available in the camp

- Available health programmes in the camp
- Number of health facilities
- Type of service provided
- Malaria morbidity and mortality in the camp
- Epidemiological characteristics of malaria
- Malaria and seasonality in the camp
- Vulnerable groups
- OPD attendance rates
- Any malaria control programme in the camp

Date of interview: ---------- Interviewer's name:----------
Comments on interview by interviewer if any_____

APPENDIX 8

TOPIC GUIDE: MALARIA, PSYCHO-SOCIAL FACTORS, BREAKDOWN SOCIAL NETWORK AND TREATMENT-SEEKING BEHAVIOUR

Principal Investigator: Olivia Lomoro, C/O IRC-Kakuma health programme

INFORMED CONSENT FORM FOR " CASE" AND "CONTROL"

I am a student from a university in UK (abroad) called London School of Hygiene and Tropical Medicine and I am coming to carry out a study on a disease called malaria (febrile illness) under the guidance of IRC. I don't know if you have heard about the disease. It usually causes fever. The disease is said to be very common here in the camp and IRC are looking for a better strategy to control it. Most of the patients visiting the health facilities in the camp are diagnosed for malaria but it is not known if they know about the disease and if they visit the clinics when sick with the disease. If some people don't visit the clinic when sick with the disease, we would like to know how they treat the disease when sick and where they go for treatment. Secondly, most of the refugees have undergone violence and persecution that have affected them. So we would like to know how the effect of the trauma they have undergone is affecting their treatment-seeking behaviours when sick with malaria.

Since you have experienced/**not** experience (case/controls) trauma due to the violence and persecution following your displacement, your participation in the study is very important. I (the principal investigator) will be responsible to see to it that all information you give is strictly used for the purpose of the study only and kept confidential. We shall not indicate your name in our forms but will use codes instead. Preliminary findings of this study will be given through a community meeting facilitated by IRC health staff. Your participation in the study is completely voluntary and would not affect you in any way. Likely inconvenience the study might cause is the time you will need to take off your normal duty to answer questions that will be asked. Where possible, we shall try to limit inconvenience likely to be caused. If you have any questions about this study or have any doubt, I will answer them for you.

This study was approved by the ethical Committee of the London School of Hygiene and Tropical medicine and the International Rescue Committee Organisation, in consultation with UNHCR.

.....

This form has been read by/I have read the above to: _____
In a language that she/he understands. I believe that she/he has understood what I explained and that she/he has freely agreed to take part in the study.

Signature / thumb print of study participant: _____ Date: _____

Witness name and signature:_____ Date: _____

Name and signature of interviewer: _____ Date: _____

APPENDIX 9

CONSENT: MALARIA MANAGEMENT IN THE PUBLIC OUTPATIENT HEALTH FACILITIES IN KAKUMA CAMP IN NORTHWESTERN KENYA
(Principle investigator: Olivia Lomoro, C/O IRC Kakuma)

INFORMED CONSENT FORM FOR HEALTH CARE PROVIDERS

Malaria (febrile illness) is a major public health problem in sub Saharan Africa. The clinic records have shown that malaria is a major health problem here in Kakuma camp. The London School of Hygiene and Tropical Medicine in UK, and the International Rescue Committee, Kenya programme are trying to identify appropriate ways to control malaria in the camp. The main aim of the study is to determine factors influencing malaria treatment-seeking behaviours in Kakuma refugee camp in order to recommend strategies for malaria improvement and control. This involves looking into the quality of malaria management at the health facilities.

Your participation in the study is very important because it will generate insight into the problems affecting you and your colleagues when managing malaria and will help IRC design better strategies to control malaria in the camp. We would like to interview you by asking some questions related to your job descriptions in management of malaria in the camp. We shall also later come back to observe your practice during management of malaria/dispensing of drugs if you accept (only to clinical health workers and drug dispensers).

I (principal investigator) will be responsible to see to it that all information you provide (and the practice we observe) is strictly used for the purpose of the study only and kept confidential. Your name will not be indicated. We shall use codes instead. Preliminary findings shall be communicated to you through a workshop at the end of the study. You are free to decide whether you would like to participate in the study or not. You can refuse to participate or you can even withdraw at any time without giving reason. This will not affect you in any way. Likely inconvenience the study might cause is the time you take off your normal duty to answer questions that will be asked. We shall try all possible ways to be brief.

This study was approved by the ethical Committee of the London School of Hygiene and Tropical medicine and the organisation (International Rescue Committee) you work for in consultation with UNHCR. If you have any questions about this study or have any doubt, I will answer them for you. If you agree to participate in the study, then you need to sign this form. (Applies for clinical health workers and dispensers: we shall inform you in advance when we shall come for the observation).

This form has been read by: **Study participant** _____
In a language the participant understands and has freely agreed to participate in the study.

Signature of study participant: _____ Date: _____

Name and signature of interviewer: _____ Date: _____

Appendix 10

CONSENT: CROSS-SECTIONAL MALARIA PREVALENCE SURVEY IN KAKUMA REFUGEE CAMP IN NORTHWESTERN KENYA
Principal Investigator: Olivia Lomoro, C/O IRC-Kakuma health programme

A. Information sheet

I am a student from a university in the UK (abroad) called London School of hygiene and Tropical Medicine. I have come to carry out a study on a disease called malaria (febrile illness) under IRC. Have you heard about the disease? The health staffs at the clinics here in Kakuma camp have reported that most patients visiting the facility present with fever due to malaria, but it is not known how many people generally in the camp here suffer from the disease as not every one with malaria visit the health facilities. Some people are likely not to have any symptoms when sick with malaria and so they don't visit the facility. Others with malaria symptom can decide to look for treatment outside the facility. Some of the refugees here have also mentioned that malaria is a common disease of great burden in the camp. Therefore, the London School of Hygiene and Tropical Medicine is trying to know approximately the rate (prevalence) of malaria in the camp. This information will be used by IRC to design better strategies for control of malaria in the camp.

We would like you (include children if available) to participate in this study. This means we shall be asking you some few questions about your health (and child' health) and we'll take a blood specimen for malaria parasite test. This will involve a prick in your finger that might cause discomfort to you (and your child). The persons that will be taking the blood are trained persons and they will try their best to avoid much discomfort where possible. The materials that will be used to take the blood sample are new and will not cause infection. The needle (lancet) that will be used to prick one person will not be shared with any other person. For each person we prick, we shall use a new needle. I (principal investigator) will be responsible to see to it that all information given and blood specimen taken is strictly used for the purpose of the study only and kept confidential. Results for the test shall be communicated to you and if any of you are found positive for malaria parasite, we shall ask you to visit the nearest clinic for treatment. You are free to decide whether you would like to participate in the study or not. You can refuse to participate or you can even withdraw at any time without giving reason. This will not affect you in any way.

This study was approved by the ethical Committee of the London School of Hygiene and Tropical medicine, the International Rescue Committee and the UNHCR body both in Nairobi and here in Kakuma camp. If you have any questions about this study or have any doubt, I will answer them for you. If you agree to participate in the study, then you need to sign the consent form attached.

MALARIA PREVALENCE SURVEY IN KAKUMA REFUGEE CAMP IN NORTHWESTERN KENYA

B. Consent form for all adults above 18 years

Date: DD/MM/YY
Participant's code:

I have read the information sheet concerning this study and have understood it/The information sheet have been read to me and I understand it.

I understand what will be required for me and what will happen to me if I take part in the study.

My questions and doubts concerning this study have been answered and clarified by _____

I understand that at any time I may withdraw from this study without giving a reason and without affecting my normal care and management.

I agree to take part in this study

.....

This form has been read by/I have read the above to: _____
In a language that she/he understands. I believe that she/he has understood what I explained and that she/he has freely agreed to take part in the study.

Signature / thumb print of study participant: _____ Date: _____

Witness name and signature:_____ Date: _____

Name and signature of interviewer: _____ Date: _____

MALARIA PREVALENCE SURVEY IN KAKUMA REFUGEE CAMP IN NORTHWESTERN KENYA

C. CONSENT FORM FOR PARENTS/GUARDIANS OF CHILDREN AND PARTICIPANTS LESS THAN 18 YEARS OLD

Date: DD/MM/YY
Participant's code:

I have read the information sheet concerning this study and have understood it/The information sheet have been read to me and I understand it.

I understand what will be required for my child/son/daughter/etc and what will happen to him/her if asked to take part in the study.

My questions and doubts concerning this study have been answered and clarified by _____

I understand that at any time my child/son/daughter/etc may withdraw from this study without giving a reason and without affecting his/her normal care and management.

I agree that my child/son/daughter takes part in this study

Signature / thumb print of study participant: _____

.....

This form has been read by/I have read the above to: _____
In a language that she/he understands. I believe that she/he has understood what I explained and that she/he has freely agreed to take part in the study.

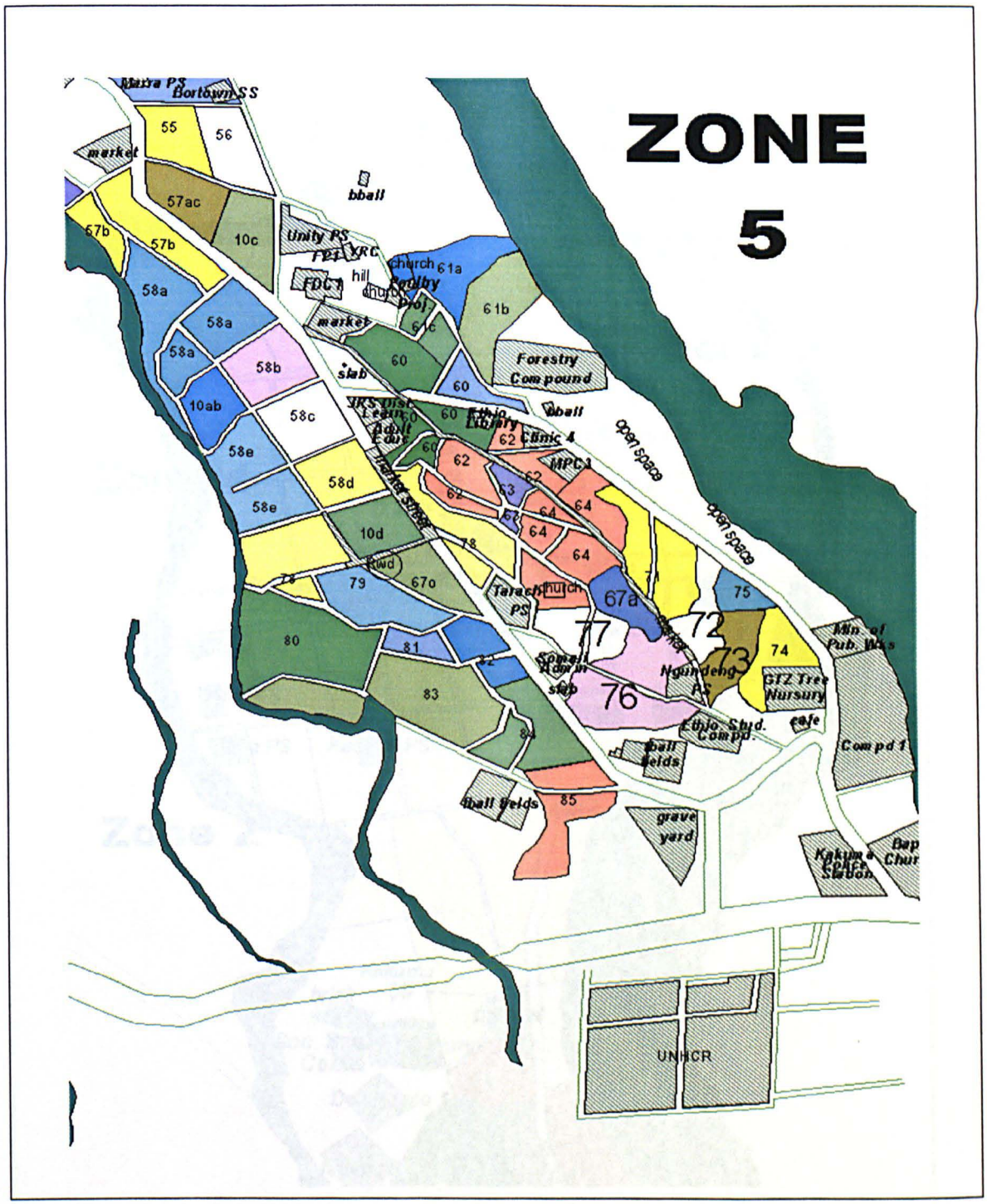
Name and Signature of Parents/Guardian:_____ Date: _____

Witness name and signature:_____ Date: _____

Name and signature of interviewer: _____ Date: _____

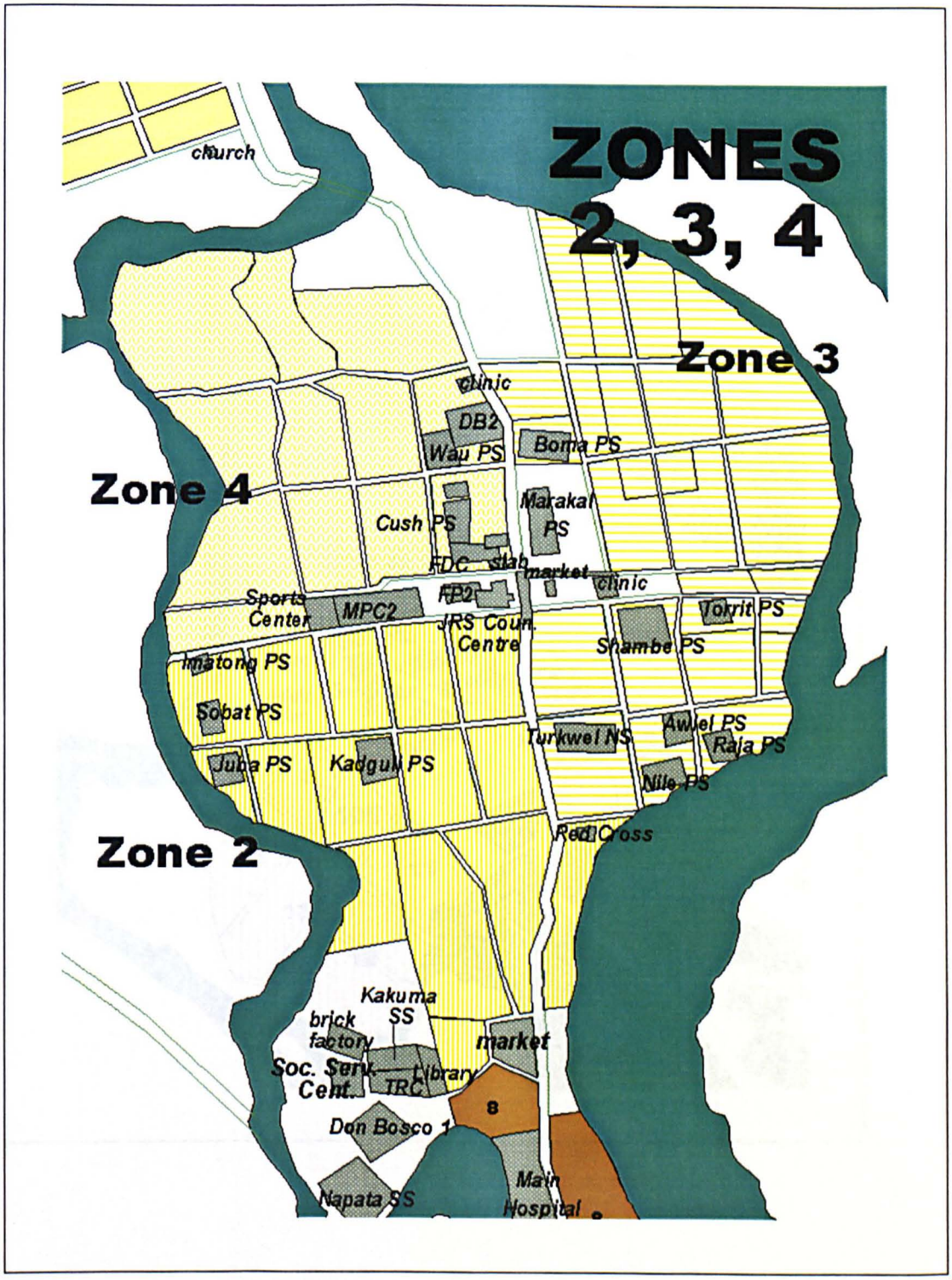
Appendix 11

Map illustrating division of groups within zone 5 in Kakuma Refugee Camp



Appendix 12

Map illustrating the location of Primary schools within Kakuma camp



Appendix 13

Map illustrating zone one and six in Kakuma refugee camp