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# HEALTHCARE SEEKING BEHAVIOUR WHEN SUSPECTING MALARIA

## AN ETHNOGRAPHIC FIELD STUDY OF INDIGENOUS PEOPLE IN UGANDA

ASTRID BAGEWITZ

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Malmö högskola
Hälsa och samhälle
205 06 Malmö
email: postmasterhs.mah.se

# HÄLSOUPPSÖKANDE BETEENDE VID MISSTANKE OM MALARIA

## EN ETNOGRAFISK FÄLTSTUDIE HOS URSPRUNGSBEFOLKNINGEN I UGANDA

ASTRID BAGEWITZ

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Malaria är ett globalt problem, som framförallt existerar i de tropiska delarna av världen. I Uganda uppskattas 25-40% av patienter som uppsöker statlig vård vara patienter som har relaterade malaria symtom. Eftersom Batwa är en minoritetsgrupp som skiljer sig från övriga Ugandier i sin historiska livsstil, undersöker denna studie hur denna grupp söker vård. Studien är kvalitativ och har använt sig av en etnografisk metod, därav tio intervjuer och en fokusgrupp diskussion för att samla data. Det teoretiska ramverket har varit *medicinsk antropologiskt*, där en hälsouppsökande modell har använts. Resultatet visar på en mängd olika hälsoalternativ för Batwa att söka vård inom. Dock skiljer sig Batwas hälsouppsökande beteenden från andra gruppers beteenden, enligt tidigare studier, och från det teoretiska ramverkets modell, som använts i uppsatsen. Batwa föredrar offentlig vård i högre grad, eftersom det är ett billigare och ett mer lättillgängligt alternativ att bli frisk på, i jämförelse med många andra alternativ.

*Nyckelord*: hälsouppsökande beteende, malaria, medicinsk antropologi, Uganda ursprungsbefolkning.

# HEALTHCARE SEEKING BEHAVIOUR WHEN SUSPECTING MALARIA

## AN ETHNOGRAPHIC FIELD STUDY OF INDIGENOUS PEOPLE IN UGANDA

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Malaria is a global problem that exists mostly in the tropical region of the world. In Uganda approximately 25-40% of the patients who are seeking governmental healthcare are patients with malaria related symptoms. Because Batwa is a minority group who differ from other Ugandans in their historical lifestyle, the present study investigates how this group are seeking healthcare. The study is qualitative and has used an ethnographic method, whereby ten interviews and one focus-group discussion to collect data. The theoretical framework has been *medical anthropology*, where a healthcare seeking model has been used. The result reveals a varied spectrum of healthcare option for Batwa too seek treatment within. However, Batwa healthcare seeking behaviour differs from other groups of healthcare seeking behaviour, according to earlier studies, and from the model used in the theoretical framework in the present study. Batwa prefer governmental healthcare in a greater extent, because it is cheaper and a more accessible alternative to get treated, compared to many of the other alternatives.

*Keywords*: healthcare seeking behaviour, indigenous people, medical anthropology, malaria, Uganda.

# CONTENTS

# TERMINOLOGY

Batwa- A group of indigenous people in Uganda
ECTS- European Credit Transfer and Accumulation System
GovHC- Governmental healthcare
Hc- Healthcare
ICN- International Council of Nurses
IP- Indigenous people
MCP- Malaria Control Program
MDGs- Millennium Development Goals
Mutwa- Singular of Batwa
NGO- Non Governmental Organisation
UOBDU- The United Organisation for Batwa Development in Uganda
P- Participant
PF- Plasmodium Falciparium
PopHc- popular healthcare
ProfHc- Professional healthcare
Ush- Ugandan shilling
WHO- World Health Organisation

# INTRODUCTION

The Declaration of Millennium Development Goals (MDGs) was adopted at the Millennium summit by the world national leaders in September 2000. One of the goals for this global commitment is to halt malaria by 2015 (UN, 2006). To achieve this goal one has to look at one of the most exposed groups in the world: the indigenous people. The African Commission of Human and Peoples´ Rights explain the situation of indigenous people as the most vulnerable groups. However, this group receives little attention from the responsible national health-authorities (Good, 2006). The International Labour Convention's definition of indigenous people are people who occupied the land before colonisation and after colonisation kept their own social, economic, cultural and political institutional structure (ILO, 1989). The convention underlines self-identification as the most significant recognition of indigenous people. The Batwa – the indigenous people of Uganda – fulfil parts of the Conventions definition (IRIN, 2006). The health situation is especially crucial in countries were the indigenous people do not have access to their natural resources for maintaining traditional livelihood, culture, and knowledge such as medical remedies. To summarise: in countries with increasing economic gaps the majority of the population can improve their health while the minorities are ignored when achieving the MDGs of improved health (IRIN, 2008).

Four years ago when I visited Kisoro- district in Uganda I observed how marginalised the indigenous Batwa people were compared to the non-Batwa people. Therefore, to further my knowledge of the situation of Batwa, as a future nurse, I would like to know what factors matters to them when seeking healthcare in their society. As a nurse working in a district with Batwa population, it is important to know their healthcare seeking behaviour in order to meet their needs. The aim of this study was therefore to investigate how Batwa in Uganda seek healthcare and experience the healthcare when suspecting the common disease malaria.

# BACKGROUND

This chapter will present background information about *Malaria, Uganda*, the situation of the *Batwa- indigenous people* and *Healthcare seeking behaviour*.

### Malaria

Malaria, a mosquito borne disease, is a major global problem. The Centers for Disease Control and Prevention (CDC, 2007) estimates 350-500 million people to be affected globally and that one million people die of malaria every year. Those who get infected are mostly children younger than five years of age, living in sub-Saharan Africa. In 2002 malaria caused 10.7 % of all children's death in developing countries. A major goal for the world is to halt the malaria disease and

to reverse the incidence of malaria by 2015 (Millennium Development Goals Report, 2007).

Malaria is mostly prevalent in the tropical regions of the world, and is caused by mosquito bites (Volk, 1996). A person becomes infected when an infected female mosquito injects the *sporozoite* into the blood. *Plasmodium falciparum* (PF) are one of several sporozoite that infect humans with malaria and causes 90-95% of sub-Saharan infections (Volk 1996). When the PF is active in human blood, the symptoms are chill and fever in more or less regular intervals, followed by an intensive sweating. An affected person can experience headache, muscle pain, anaemia, and complications as plugged capillaries, internal haemorrhages in the brain, the lungs and the kidneys. The incubation period is about 7-12 days. The symptoms appear in intervals. The sporozoite invades the liver where it undergoes one or more cycles of asexual reproduction before returning to the bloodstream to infect the red blood cells. When the red blood cell burst the person will get chilly and feverish. The PF in the liver continues to reproduce until the patient has been treated with an effective drug or died (ibid).

Repeated infections with PF can cause anaemia, especially in children and pregnant women (CDC 2006). To be able to treat the patient and prevent further spread of the infection the malaria must be diagnosed and treated immediately. The World Health Organization (WHO) recommends that anyone suspected of having malaria should receive diagnosis and treatment with an effective drug within 24 hours of first symptoms occurs. To diagnose malaria a blood sample is required to be able to visualize the parasite in the affected red blood cell (CDC, 2006). However in highly endemic areas the healthcare workers use “presumptive treatment”, without laboratory confirmations, to patients with undiagnosed fever. Different synthetic anti-malarial drugs are used to suppress the blood parasite. However, there are parasites that are resistant to some of these drugs. One way to prevent the disease is to use insecticide-treated bed-nets (ibid).

### *Malaria in Uganda*

According to Olupot M writing in the Ugandan newspaper *New Vision* 26th of June 2006 malaria kills 320 Ugandans every day. *President’s malaria Initiative* confirms that the risk of malaria infection exists in all 45 Ugandan districts (PMI, 2008). Over 90% of the population lives in highly endemic areas and the rest in low transmission areas. Malaria is the leading cause of illness and death in Uganda. Of all patients in Uganda that visit governmental healthcare 25-40 % are malaria patients. The Ugandan National Malaria Strategic plan and the Health Sector Strategic Plan II aim to distribute insecticide-treated nets. Particular efforts are put to distribute the nets in rural areas, both through health services and through home-based management of fever programs (PMI, 2008). At the time of the study home-based management of fever had not yet been implemented in the study village. In the district of Kisoro there are two hospitals, twenty health-units and four private clinics (Uganda Communication Commission, 2007). Governmental health facilities in Uganda are user fee free. However, Ugandan people claim cost as a hindrance to seeking medical attention at governmental health facilities (UN, 2008).

## Uganda

Uganda (see appendix 1) is one of several sub-Sahara African countries, bordering to Sudan, Tanzania, Kenya, Rwanda and Congo (Länder i Fickformat, 2003). Uganda was colonized by the British in 1896 and declared independence in 1962 (Utrikespolitiska Institutet, 2007). Idi Amin who was the dictator during 1971-1979 had more than 300 000 people killed. The present president, Yoweri Museveni, have held the power since 1986. In 2005 Uganda allowed multi-party system. However, in practice, the power is centred to president Museveni (ibid).

In Uganda there are about 40 different ethnic groups and several different domestic languages are spoken; Refumbira is one of the local languages spoken in Kisoro-district. The official language is English (Länder i Fickformat, 2003). Uganda has a population of 24.7 million people (Exportrådet, 2004). The country is dependent on agriculture being the main livelihood for 80% of the population. The policy since 1980 was to stabilize the economy with different economic reforms. Those reforms increased inequality in distribution of income. However, the present economic policy is no longer on a macroeconomic level rather instead on a microeconomic level, with the expectation to be able to eradicate poverty (Exportrådet, 2004). The Ugandan currency is called Shilling and 250 (Ush) is equivalent to 1 Swedish kronor (X-change, 2008).

Uganda has three levels of governmental hospitals: National Referral Hospitals, Regional Referral Hospitals and The District/Rural Hospitals. There are also Non Governmental Organisations (NGO) hospitals and private hospitals (Uganda Ministry of Health, 2007)

## Batwa- indigenous people

Approximately 257 million and 350 million indigenous people (IP) live in the world (Stephen, 2005). Indigenous people in general have a very wide definition of health. According to Durie (2003) the health definition encompasses three areas: the health of the whole community, for the individual and the health of the ecosystem which they live in. Because IP have a wide definition of health they also have a pluralistic and holistic solution to their health problems. The health situation of the IP can be categorised in four statements: genetic vulnerability, poor socio-economic situation, loss of resources, and political oppression. There is a close connection between national history of colonialism and poor health situation of indigenous people. A loss of self-determination, together with loss of land and resources create a material and spiritual oppression which increase risks for diseases and injuries. When the healthcare workers and the patient have different cultural background there is a risk of putting the wrong diagnose and a lack of agreement concerning treatment (Durie, 2003). IP all over the world are poorer, have poorer health and poorer access to governmental healthcare than the general population in their country (Stephens, 2005). This situation is more crucial in communities were the indigenous peoples' original lifestyle has been taken away from them or been destroyed (ibid).

Batwa are an indigenous people that inhabit parts of Uganda, the Democratic Republic of Congo, Rwanda and Burundi (Lewis, 2000). They are a minority group, estimated to be 6700 of the total Uganda population of 24.2 million people (UN, 2008). Batwa live in the South-Western part of Uganda, as in Kisoro (Lewis

2000). “Batwa” is plural and “Mutwa” is singular (Lewis, 2000). Batwa used to be hunters and gatherers in the forest, but they lost their land and resources, when The Mgahinga National Park and The Bwindi National Park were established 1990 in the region of Kisoro. Loosing land also affected their health in a negative way (ibid). Batwa was deprived their renowned herbal pharmacopoeia, which contains compounds active against malaria, when they lost access to the forest (Good 2006).

In all four countries with Batwa population it is estimated that less than 0.5% has a secondary education (Lewis, 2000). Because Batwa lack education and money for medical consultation they are dependent on their great knowledge of traditional medicine such as herbal remedies. However lack of access to the forests makes it even more difficult to treat illnesses by themselves. Batwa have reported cases of discrimination from governmental healthcare workers and non-Batwa patients when seeking governmental healthcare. The Batwa are regularly left out of health-programmes for such reasons as Batwa communities’ remoteness and immobility and the health-campaigns are preferentially directed to non-Batwa people (Lewis, 2000).

The World Bank cited in the year 2000 the situation in Uganda to turn much worse for Batwa health situation, compared to the last two decades (Good, 2006). When some Batwa were given land in Uganda the mortality rate of children younger then five years dropped from 59% to 18% which shows how crucial land is to their health situation. In Goods findings Batwa has reported, because they no longer live in the forest with access to traditional medicine, the most serious health problems to be malaria, diarrhoea, intestinal worms, and parasites (ibid).

### Healthcare seeking behaviour

In societies were a person feels ill or unhealthy there are number of different healthcare options available (Helman 1994). These are for example self treatment, get treatment by uneducated family members and friends, tradition- and religious health practice, school medicine, and complementary medicine. A person might seek treatment by all, some or only one of these options. The various healthcare options coexist, but they can be totally different in their origin. However, to the ill person the origin of a treatment is less important then the officiousness of it, as long as it relive suffering (ibid).

## AIM

The aim of the study was to investigate Batwa and their healthcare seeking behaviour, factors that influence this behaviour, and experiences of healthcare when suspecting malaria. To achieve the aim, the following questions were explored among ten Mutwa individuals:

* What treatment does a Mutwa believe to be the best way to treat her/him?
* What experiences does a Mutwa have from seeking healthcare because of malaria symptoms?

* Does a Mutwa experience difficulties to seek the healthcare she/he think will be the best for her/him?
* Does a Mutwa consider governmental healthcare as an option for seeking healthcare?

### Definitions and abbreviations

The following healthcare abbreviations will be used:
ProfHc when referring to professional health care
PopHc when referring to popular healthcare
GovHc when referring to Governmental healthcare
Hc refers to health care in general
"Hc-seeking behaviour" when referring both to their healthcare seeking behaviour and to their decision-making process.
"Batwa" when referring to more than one "Mutwa"
"Mutwa" when referring to one individual of the Batwa

### Limitation

The focus will be on the whole process from the first suspicion by a Mutwa of having malaria to the decision of seeking health care and their thoughts about the treatment. The aim was to find the Hc-seeking behaviour when suspecting malaria. It does not matter if the participants have been diagnosed with malaria at the ProfHc or not. Aspects of prevention are excluded from the scope of this study. The selection of village and participants was based on being a member of the Batwa ethnic group. Non-Batwa participants were excluded from this study. Only experiences of adults healthcare seeking behaviours was of interest for this study.

# THEORETICAL FRAMEWORK

At Malmö University, the Faculty of Health and Society's requirement, in order to achieve a bachelor degree in nursing, is to do an academic work of 15 ECTS[1]. I was granted a *Minor Field study* scholarship, which enabled me to conduct this study in Uganda to gather data for the essay. A theoretical framework of *Medical anthropology* was found to be suitable for the aim of this study. First of all a presentation of the *Essence of nursing and caring* is given.

### Essence of nursing and caring

A nurse has four responsibilities to act accordingly: promote health, prevent illness, restore health and alleviate suffering. In 1953 an international ethical code were adopted by International Council of Nurses (ICN), which was revised 2005 (ICN, 2006).

The nurse responsibilities according to the codes are to provide care to the individual, the family and the community and coordinate with related groups

[1] *ECTS-European Credit Transfer and Accumulation System*. European Commission 28-07-2004. (60 ECTS are equivalent to full time academic studies for one year.)

(ICN, 2006). When providing care the nurse should promote an environment were human rights, values, customs, and religious beliefs for the individual family and the community is respected. It is on the nurse's responsibility to ensure that the patient get sufficient information to base there informed consent on caring and related treatment. Together with the society the nurse has a responsibility to initiate and support action in order to meet the needs of health to the public. Special, attention needs to be taken to the most vulnerable groups in the society. The nurse also has a shared responsibility to sustain and protect the natural environment. The nurse has the responsibility to act appropriately to safeguard the health of the individual, family or community when a co-worker or any other has jeopardised those rights (ibid).

In Kirkevold (2000) Katie Ericsson, a nurse and researcher, has developed a theory of caring which will be used as a reference point in the present study. The theory is based on *Caritas,* consisting of three main components: the human, health and healthcare. The human is shaped and exists in its relationship to "the other", being the family and nurses, and "the abstract other", being God. Health is a state that characterise the human. However, health is continuously changing. The physical health is to obtain the possibilities of having fundamental life functions. To have health is to be whole and to have integration between body, soul and spirit. There are two different kinds of healthcare according to Ericsson, the Natural Healthcare and the Professional Healthcare. The Natural Healthcare is fundamental by consulting family and friends to achieve integration of bodily wealth, trust and satisfaction. The professional healthcare is the same as the natural healthcare in its essence, but takes other expressions. The professional way of caring should not only be technical but integrate a holistic approach to the whole patients aspects of health and life situations. The professional caring is needed when the natural healthcare is insufficient. The three main achievements of caring is to satisfy the patient's fundamental needs, to ease the suffering and to strengthen the care giving from "the others" such as the family and friends (Kirkevold, 2000).

The similarity between Ericsson's two different categories of healthcare and Kleinman's three categories of healthcare are evident. Below Kleinman´s model is presented.

### Medical anthropology

In the field of medical anthropology Helman (1994) explains that there are studies investigating how people in different cultures and social groups explain the cause of ill health, the type of treatment they believe in and whom they turn to when they get ill (Helman, 1994). The purpose with this approach is to have a holistic view to the human kind, which involves its origin, development, social and political organizations and religion. The investigator's aim is to discover the "actor's perspective" to be able to see how the world looks from the perspective of a member of that particular society (ibid).

Culture is a set of guidelines which the members inherit from that particular society they are in (Helman, 1994). The guidelines tell the member of how to view the world, how to experience it emotionally and how to behave in relation to others. All societies have more than one culture within their borders. Culture is

not the only factor that influences your life and health Helman (1994). There are also individual factors (age, genes, and gender), educational factors and socio-economic factors. Helman states that it is impossible to isolate "pure" cultural believes and behaviours from the social and economic context in which they occur. Members of a society may act in a certain way, not because it is their culture to do so, but because they are to poor or too discriminated to do otherwise (ibid).

All societies have a number of ways of helping sick persons to help themselves or to seek help from others e.g. they might try to cure themselves, consult friends, a religious authority, healers or a doctor (ibid). These healthcare options co-exist, but can in its origin differ from each other. However, the origin of the different treatments is less important then the
efficiency of curing their illnesses (Helman, 1994). See figure 1.

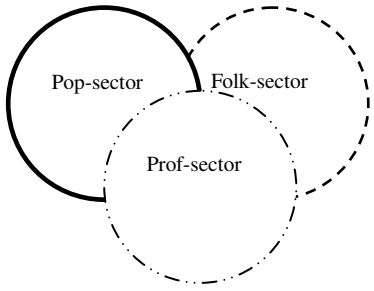



*Figure 1*. A figure of Kleinman´s explanation of three overlapping sector of healthcare used in societies, adopted from Helman page 55 (1994)

Helman (1994) refers to Kleinman and his book *Patients and Healers in the context of culture* where Kleinman describes a healthcare seeking model which also is the model that is used in this study (figure 1). This model is suitable to use when organizing and discussing the data results. The model consists of three overlapping and inter-connected sectors of healthcare (Helman 1994). *The Popular-sector* is a non-professional and non-specialist domain, were ill health is first recognized and defined and the first therapeutic activities are initiated. It includes all healthcare activities utilized without any payment as for consulting family, old women, healers, food can be used as a medicine, health believes of what will "attract good luck" or not (Helman 1994). All of these healthcare options are built on individuals own experiences rather then on education. The Pop-sector sometimes has negative effects on people's health, when the patient is not sharing the problem with an outsider of their cultural family (ibid).

*The Folk-sector* includes healers and herbalist, whom the patient needs to pay (Helman, 1994). Most healers share the basic cultural values of their patients, as for beliefs about the origin of treating ill health. Healers are common in societies were ill health are explained on supernatural causes. Because the healers most often share the patient culture and worldview and reinforce the cultural value, the healer has advantages over "Western doctors". Healers are often better to cure illnesses that are connected with social, physiological and moral aspects of illness and to explain the cause of the connection to the social and supernatural world.

Healers' knowledge is often passed on from their parents, or discovered "healing power". Few have been trained by the Western medical school (Helman 1994). Some of the healer's treatment can be very dangerous to their patients. Sometimes healers are a part of the problem to why the patient does not get cured Healers are not preferable to consult when the patient are suffering from malaria, because their inability to cure this disease. (ibid).

*The Professional- sector* is the modern Western school medicine (Helman, 1994). In most countries of the world the Western school medicine only provide a small part of the healthcare options. In developing countries it is common that the Prof-sector is the least chosen of the healthcare options. This medical system is a reflection of its culture. The healthcare workers within the Prof-sector are arranged in hierarchies similarly to the social structure of the bigger society. The medical sector may reproduce the underlying prejudices of the society. Another criticism to the Western medicine is that its focus is on the individual, and sometimes forgets other factors as poverty, economic situations as part of their patient's illness (ibid).

Helman (1994) refers to Kleinman when stating that individuals seek treatment at several different healthcare options at the same time. This pragmatic way of using multiple forms of therapy is not only between the three different sectors. People make choices between diagnoses and treatment that makes sense to the patient and its beliefs. If they do not make sense they shift to another healthcare sector (ibid).

# METHOD

This chapter describes the relevant *Ethnographic method* and *Ethical consideration* based on the literature. In the following chapter there will be a thorough description of how the method was used in the present study.

## Ethnographic method

Healthcare seeking behaviour was explored by individual interviews, interview in a focus-group, and from fieldwork e.g interviews of different persons of health authorities, NGO for Batwa, and the Batwa community, observations of the participants' behaviour in various healthcare seeking situations. Data of individual experiences was collected by individual interviews, interview in a focus-group, and from fieldwork e.g observations of the participants in various situations. The method is a qualitative approach and the data was gathered systematically from empirical data interviews (Polit, 2006).

The *Ethnographic* method gives a holistic description and interpretation of the normative behaviour and social patterns of a culture (Polit, 2006). The method is suitable when one studies health beliefs and health-related practice of a culture or a subculture. The method is raised on the assumption that every human group develops a culture that guides the members´ view of the world and how to act and

structure their experiences accordingly. The ethnographic method includes a *fieldwork* where the ethnographer gets introduced to a culture and how to understand it (Polit, 2006). The second process is when the fieldworker with the help of the participants' communications and manifestations construct their culture in *graphic text*. Culture is not in it self visible and must be studied by the ethnographer to make him or her able to reveal the hidden meaning of the group member's words and actions. The present study is *microethnographic*, where it is investigating a narrowly defined group. This means it will study a small unit, such as the Batwa, within a bigger group and culture (ibid). An ethnographic approach was used as a method in order to describe and interpret cultural behaviour.

Ethnographic research seeks to learn from the cultural group, rather then to study it (Polit, 2006). The *emic perspective* is the insider's view of the cultural group members' action and their world. Expression of the group member's value and communication is studied. The investigator who is an outsider has an *ethic perspective* why she tries to interpret the group member's culture. However the researcher strives to get an *emic perspective* of the culture being studied. Therefore the researcher should be sensitive to cultural and linguistic variations of the study group. When the researcher is observing she is a tool in order to get the information (Kaijser 1999). The observer is a "professional subject" who participate, experience, note and sort out the material in a professional way. One way to reflect on the role which the observer takes is to describe and evaluate her own role in the field. It is important to become conscious of the different role the observer has in order to be able to characterise and evaluate the result (ibid).

### *Triangulation*

Data source triangulation is a way to put credibility to the data by using different data sources (Polit, 2006). Mays (1996) suggest it is a way to confirm the validity to the data collection by gathering data from a wide range of different independent sources. One way to confirm or disconfirm present results is to use references from literature searches. Another way is to use a pilot interview to give reliability to the study's questions as a reliable instrument (Polit, 2006)

### *Literature search*

A *PubMed* search in September 2007 identified eighteen studies[2] by search words: "healthcare seeking behaviour", "Uganda" and "malaria". Three of these articles was found as the most relevant to this study and are used in the present study. No studies were identified using "healthcare seeking behaviour", "sub-Saharan Africa", "indigenous people" as search words. An additional search was made in October 2008 in *MalariaJournal* search with search words: "treatment seeking behaviour" and "Uganda" witch resulted in total 37 studies[3]. Four of the articles are used in this study as a guidelines, the other articles were not found as relevant to this studies question, because their focus were on preventive measures and on whether the healthcare workers followed the guidelines for prescribing drugs, or not.

[2] Clark Sian, et al (2007), Kengeny-Kayondo JF et al (1998) and Magnussen et al (1994).
[3] Savigny Don de, et al (2004), Nuwaha F (2002), Malik E.M (2006), Makundi E.A et al (2006)

### *Interviews*

In order to get data saturation around ten face-to-face interviews are preferable, with time lasting from one to two hours. A purposive sample strategy with a maximum variation was chosen to get various answers to the study questions (Polit, 2006).

A semi-structured topic-guide is a list of pre-made questions concerning specific topics that the researcher wants to explore (Mays, 1996). During the process of gathering data the questions can be more detailed and also modified, but the topic-area must still be the same. This interviewing method gives different dimensions and deepens the understanding of how the participants view their world.

Focus-group is a group interview which purpose is to use group interaction as part of the method (May, 1996). The group's individuals are encouraged to talk to each other and exchange experiences. The method is not only investigating what people think, but also why they think in that way. Focus-group is a well used method to examine people's experiences of diseases and health services and to explore attitudes and needs of healthcare workers. This way of collecting data is sensitive to cultural variables, when they interact with each other in the discussion. A focus group discussion is appropriate to last from 45 minutes to an hour. Polit (2006) suggests that five to ten focus-group participants are appropriate to have in the same discussion, and a topic-guide is preferable to use.

There are two ways of recording interviews, either to write down the interview during the process of interviewing or to use a tape-recorder. Tape-recording might make the participant reluctant to speak freely and is also very time consuming. The transcribing is preferably made the same day as the interview takes place (Mays, 1996). The transcribed interview goes through in order to see patterns and notice differences in their answers.

To gain entrée to a researcher site, it is recommended in qualitative research to have a gatekeeper (Polit, 2006). The gatekeeper has the authority to enter the cultural group's world which is about to be studied.

## Ethical consideration

There are different ethical considerations a researcher needs to be aware of and act accordingly. The investigator needs to follow the ethical principals in protecting study participants (Polit, 2006). It is important to get each and every participant informed consent to be able to protect the participants' rights to self-determination. The researcher also has the obligation to give the participant understandable information regarding the research. To tape-record can make the interviewees more reluctant to talk freely (Mays, 1996). Further, the tape-recorder can also emphasis the economic differences between the investigator and the participants. It is preferable to have the interview in the participant's home surroundings to make the participant feel more comfortable (ibid).

The present essay will be send to the organisations that have taken part of the fieldwork and also to the participants of the study, as they were promised.

# FIELDWORK & DATA GATHERING

In this section the two main processes of *Fieldwork* and *Data gathering* will be presented. Based on the methodological chapter this chapter presents in detail how the method was used in the present study. The preparation work will in the following be called fieldwork. In ethnographic studies the researcher often uses herself as an instrument in analysing and interpreting a culture (Polit, 2006).

One way to reflect on the role which the observer takes in data collecting is to describe and evaluate her own role in the field. It is important to become conscious of the different roles the observer has in order to be able to characterise and evaluate the result (Kaijser 1999). Therefore, the investigator is visible in the following by "I".

## Fieldwork

I met my gate-keeper already four years ago during my first visit in Kisoro. During the present investigation he acted as an interpreter, and also in a sense he became my guide when it came to understand the structure of Kisoro and to get in contact with authorities and important people. Refumbira and English were used when translating between the investigator and the participants. In this case the interpreter did not only translate between me as an investigator and the participant, he also interpreted the implications of the studied area (Polit, 2006). Whereby, in this study he will be called interpreter, not just translator.

### *Orientation*

Before starting the individual interviews background information was gathered of the life situation of Batwa and the healthcare situation in Kisoro. The different data sources were collected from NGOs working with empowering Batwa, the Governmental Hospital, Health-unit, Health authorities' e.g. the person responsible of Malaria Control Program (MCP) in Kisoro, the Chairman for all Batwa in Uganda, two different Batwa communities and a special Missionary Hospital (Dr Scott) who is targeting Batwa especially. This information was used to evaluate the pre-understanding of the healthcare system and the situation of Batwa in Kisoro. Before getting to the actual Batwa-community another Batwa-community was visited, to get some pre-information of how they understood and answered to the study' questions. In that Batwa-community two pilot interviews were carried out, in order to change and reconstruct the semi-structured topic-guide (appendix 2) accordingly.

### *Permission*

After collecting pre-information I went to a NGO, called UOBDU (United Organisation for Batwa Development in Uganda) to discuss the project. They helped me to get in contact with another Batwa-community and prepared the people that I was coming. After arriving to Birrara-village I introduced myself and the purpose of the study thoroughly. The Batwa members told me about their history, their health-situation, showed me around in their community and the Chairman of the community gave his approval to do the investigation.

## Data gathering

Four different subheadings are presented of how data was gathered.

### *Sampling strategy*

Data was systematically collected from ten individual interviews and from one focus-group discussion. The same sampling was used for the focus-group as for the individual interviews. The participants were ten Batwa individuals who had in the last year suspected malaria symptoms. All were inhabitants of the same Batwa-community in south-western Uganda, in Kisoro region. Chairman hand-picked ten volunteers that could accept to participate in the study. The Chairman was informed of the criteria of maximum variation to participate according to age, sex, living condition and background. The age-span of the population was 18-70 years and half of them were women. Some of them was on malaria treatment or was about to seek malaria treatment at the time of interview.

### *Interviews*

All ten interviews took place in their own Batwa-community, some of them inside chairman's house and others outside there own houses. Two interviews were held each third day, lasting between one to two hours. I ensured orally, because Batwa are more or less illiterately, that everything said during the interviews were confidential. Emphasis was made on the participant's voluntariness before the Mutwa gave the consent. The topic-guide (appendix 2) was modified after four interviews. I made sure to cover the topics, but since they talked very freely I cut many of the specified questions to let them speak without getting too much interrupted.

A focus-group session was organised after the individual interviews, to clarify the possible contradictive data that had been gathered. In the focus-group all ten participants from the individual interviews participated at one time, lasting 45 minutes. The discussion was initiated using a topic guide (appendix 3).

The interviews were translated from Refumbira to English and back again, through my interpreter. I was in charge of guiding the interviews, but the interpreter, sometimes gave me some suggestions of how to go forward with the answers.

### *Recording and transcribing*

In accordance to Mays (1996) all that was translated during the interviews was written down. Field notes e.g if the interview was interrupted, what the participant had done a couple of hours before the interview, and whether it was easy to communicate or not. No tape recorder was used. The notes from the individual interviews were gone through in the same evening and transcribed into a Word-document during the next two following days.

To be able to see patterns and notice differences in their responses the individual interviews were transcribed according to Polit (2006). The transcribed interviews were then collated with the interpreter to ensure the understanding of the responses. The discussion with the focus-group was prepared from contradictive responses from individual participants. A couple of things were unclear and needed to be further investigated in the focus-group. The discussion in the focus-

group was also written down in a notebook and transcribed to a Word-document the same day. The following day the interpreter re-read the transcription and gave a few comments.

### *Data analysis*

When all data had been collected in order to organise the written transferred data a category scheme was developed (Polit, 2006). *Kleinman´s* model in Helman (1994) of healthcare seeking behaviour was used: "Pop-sector", "Folk-sector" and "Prof-sector". One category, "healthcare seeking process", was added to Kleinman´s model. The transferred interviews were re-read each suitable part of the data was put under each category. The categories was later on underlined by three different codes (Polit, 2006) originating from various parts of the interviews marked as "similar" or "unsimilar" to the group and "concrete examples" of what they tried to explain. From this a compilation of the result was developed.

# RESULTS

In this section the responses to the study questions of ten Batwa individuals will be presented as a description of Batwa healthcare-seeking behaviour, factors influencing their behaviour and statements of their experiences of seeking healthcare when suspecting malaria. The results are based on data collected from the individual interviews, from the discussion in the focus group, from fieldwork with the given community setting and by observing the ten participants (P). The quoting is not grammatically correct, in order to give authenticity to the participants' voices, and to be truthful to the interpreter's translation. The method used to categorise the data is appropriate for qualitative data (Polit, 2006). The categories are differentiated according to Kleinman´s Healthcare-seeking model; *Popular sector, Folk sector* and *Professional sector* (Helman, 1994). These are also the subheadings of this chapter as well as *The community setting* and *Healthcare seeking process* are.

## The community setting

The village is placed on a top of a hill, one hour drive and three hours walking from Kisoro-town (see figure 2 below). Birrara-village consists of Batwa and non Batwa inhabitants. The Batwa-compound, within Birrara-village, consists of 40 households, which is comparably bigger than most other Batwa-community. Within 15 minutes walk is a centre were bars, market and a health-unit are placed (see figure 2 below). Near to the village is a swamp where the participants believe they get many mosquito bites from. This particular Batwa-community is part of projects run by different NGOs. These projects have given them contributions e.g. for land, a water tank, and opportunity for at least one person to study for free on primary level. None of these things are common for a Batwa-community to have, but nor are they really uncommon either. Before the Batwa-community received land by a NGO four years ago, the members of this Batwa-community were scattered around Kisoro. The Batwa-community has built their own houses, have pigs, goats, chickens and have their own small plots to grow things at. There are

opportunities to earn money or get paid in exchange for e.g. food or soap by working for non-Batwa, mostly by digging on their plots. The majority of Batwa-adults are working by digging at others, from 8 am to 7 pm. The Batwa-community also earn money by having dance shows for tourists or when hired for special occasions. One NGO project is to help the community to use a saving account, for money. The figure 2 describes the Batwa-community location to its different healthcare options.

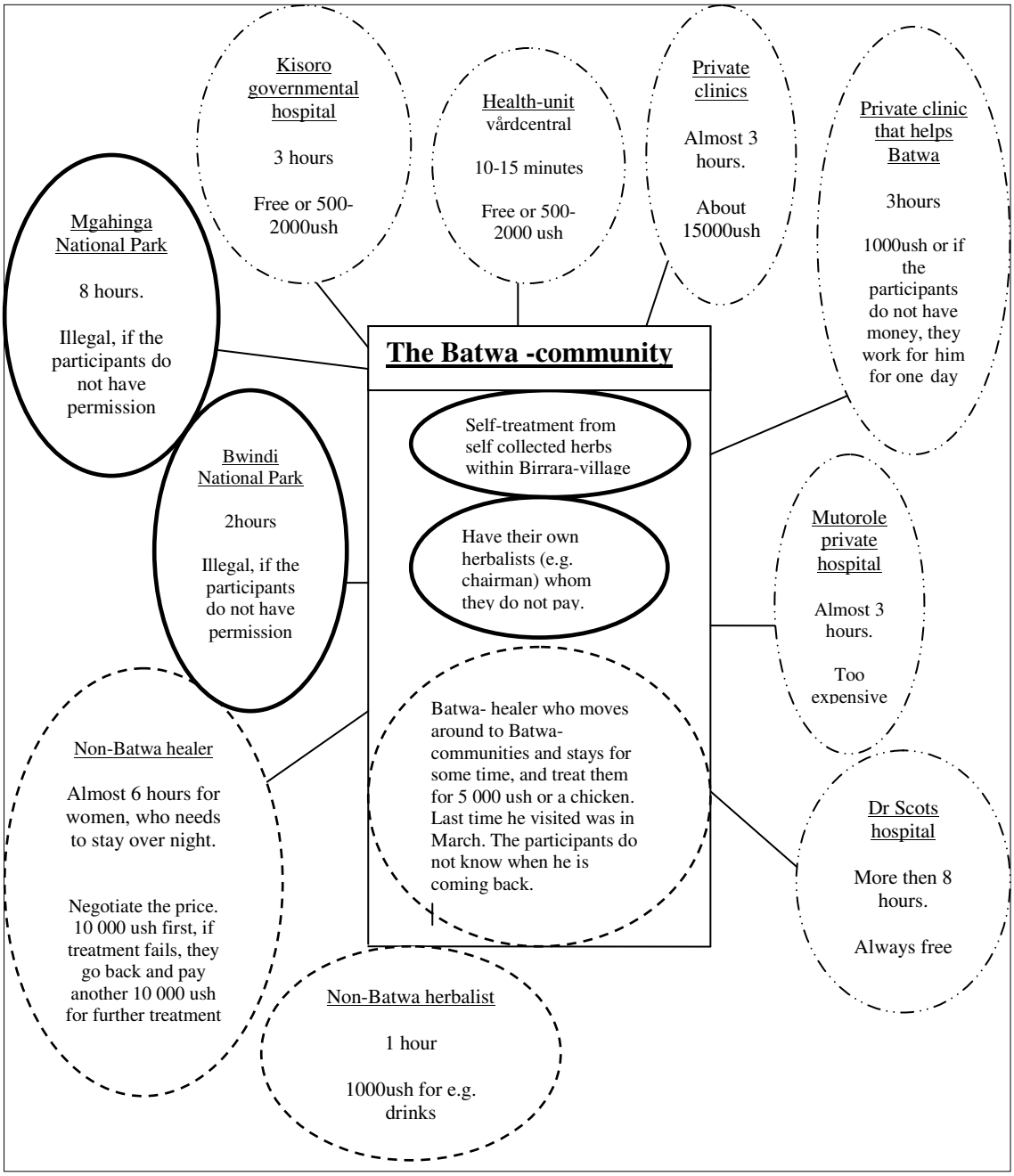



*Figure 2*. Walking distance, one way and fees to different healthcare option from the Batwa-community.

Popular sector: _____
Folksector - - - - - - - -
Professional sector: _

## Healthcare seeking process

From fieldwork and interviews in Birrara-village it is obvious that Batwa are aware of that mosquito bites can cause malaria. Some believe they can get malaria from bad water or old food. Batwa seem to have a wider definition of malaria symptoms then Western school medicine has. The symptoms the participants account are headache, cold, shivering, fever, running nose, joint pain, miscarriage, weakness, faintness, vomiting, and "malaria in the stomach" and sweating. According to other studies (Kengeya-Kayondo, 1994 and Ndyomugyenyi, 1998) non-Batwa also relate to malaria in this way. Even the word malaria covered a broader symptoms complex that did not consistently correspond to the clinical case definition of malaria. It covered all different fever symptoms, which also could be related to food drinks, environmental conditions and mosquitoes (Kengeya- Kayondo, 1994).

### *Herbs*

If the participants have slight malaria symptoms most of them treat themselves with herbs, either by their own knowledge or with the help from a family-member. The only exception is P1 who always get the herbs from an herbalist.

If the herbs do not help within some hours Batwa know if it is useless to cure malaria or not. Most of the participants wait 2 hours to evaluate the effect of the herbs, but some of them wait more than 48 hours. At times the herb seems to cure malaria then there is no need to seek additional treatment.

### *Different healthcare options*

The three first healthcare sectors chosen by each individual participant is shown below in table 1. In general the first option is to turn to Pop-sector and to use herbs, as the second option the choice the Prof-sector, and a few turn to healers or herbalists. The third choice differ more between the participants. Some are seeking further treatment within the Prof-sector, while others return to use herbs. However, to collect herbs themselves is not as frequent in the third option as in the first option. Instead they turn to herbalists to buy stronger herbs. One of the participants always goes straight to the Gov-hospital without taking any herbs if the malaria is serious. She thinks it takes too much time to go and look for herbs and it might even spoil the medical treatment**.**

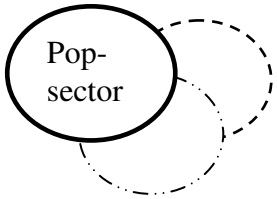
*Table 1.* The three first Healthcare-sectors chosen by each participant

| | **Healthcare option 1** | **Healthcare option 2** | **Healthcare option 3** |
|---|---|---|---|
| P 1 Man, in his 40 years | Popular sector | Professional sector | Folksector |
| P 2 Man, in his 40 years | Popular sector | Folksector | Professional sector |
| P 3 Man in his 30 years | Popular sector | Professional sector | Folksector |
| P 4 Woman, in her 60 | Popular sector | Professional sector | Folksector |
| P 5 Woman, in her 40 | Professional sector | Professional sector | Popular sector |
| P 6 Woman, in her 45 | Popular sector | Professional sector | Folksector |
| P 7 Woman, in her 30 | Popular sector | Professional sector | Popular sector |
| P 8 Man, in his 20 years | Popular sector | Professional sector | Professional |
| P 9 Woman, in her 20 | Popular sector | Popular sector | Professional sector |
| P 10 Man, in his 20 years | Popular sector | Folksector | Popular sector |

### *Consultation*
If the participants have serious malaria symptoms they consult family-members about treatment options. Even the chairman can be part of that discussion. P1, P3 and P9 sometimes send their family-member or chairman to talk to the doctor about treatment. The family-member or chairman can sometimes get medicine after meeting the doctor on behalf of their sick friend.

### *Healers*
None of the participants seek malaria treatment from healers. However the participants usually turn to healers for diagnose whether they have malaria or are poisoned. The healer can not treat malaria, but is the only one they trust when being poisoned. P2 differs with his healthcare seeking behaviour. He explains he first tries herbs that he has collected himself. If that does not help he seeks treatment from a healer, and if that also fails he turns to governmental hospital and then back to the healer if he has not been cured. But if he is very sick then he seeks treatment immediately at the governmental hospital.

## The popular sector
*The popular sector* is a non-professional and non-specialist domain, were ill health is first recognized. Healthcare (Hc) options without payment are included in this sector, as for consulting family, old women, herbalist and eating prescribed food (Helman 1994). This part has six subheadings.




### *Poor access to the National Park*
Members of the Batwa-community have permission once or twice a year to take herbs from the National Park to use as medicine or to plant them (see figure 2). The problem is that the herbs they have access to are too weak, since they have not been able to grow secluded in a forest. This Batwa-community has its own land and the people have applied for permission to plant a forest later on to be able to take herbs from the National Park to grow in their own forest. P7 explains in the interview:
*"Before we could treat ourselves with herbs /…/ Nowadays many of us die, because we can not get any treatment".* P7

P2 once tried to collect herbs illegal in the National Park at night, but did not get the right herbs because it was too dark. Access to the National Park would help them to differentiate the diagnose malaria by using honey from the forest. Today they can not treat themselves, they are referred to expensive and inaccessible treatment in the professional sector.

### *Consultative advice*
All of the participants say that they consult their family, neighbours or friends when they suspect malaria symptoms. P8 and P10 consult old women. Because

Batwa in Birrara-village work for other non-Batwa they also get information from them on what to do, concerning malaria. Either they can ask for advice, money for treatment or extra work to earn money for treatment.
"*The non-Batwa that we have started to get to know here, they do not all hate us any longer and they often help me. If I am sick or my children are sick, I can go to non-Batwa and ask if they can contribute with money for the treatment and later on I work as a payment.*" P7

P3 explains that the advice given from Batwa comparing to advice from non-Batwa can differ from each other. The non- Batwa he is working for do not know so much about herbs and advice him not to work when he has malaria and to seek treatment at the professional sector while the Batwa he consulted advised him to take the herbs.

NGO help and support with money, medicine, transport, food, and coffins for dead persons.
"*If I don't get help at the governmental hospital I go to the private clinic. Then I will consult the UOBDU and see if they can contribute to pay for the medicine. But they can not always contribute with money. UOBDU tells us that we should grow herbs if we can not afford to buy the medicine. The healer should continue to get access to the herbs since some day UOBDU might not be working any longer."* P2

### *Cheap and efficacious*

In general the participants think that herbs are a good option because it has been used for a long time and cured many Batwa from malaria in the past. They collect the herbs themselves in the nature or buy it for money or work from an herbalist (see figure 2). To use herbs as the first option is a way of trying to put a diagnose. Most of the participants also use herbs when they have failed to get treatment or failed to get cured at the professional sector. As participant 9 explained, she used herbs when she was refused to receive treatment at the health-unit because she could not afford to buy a new medical journal.
*"If we had access to the herbs in the forest we would not burden the hospital, but at the same time we would not die."* P2

Another reason to choose herbs is that with medicine it takes some days before the fever drop which makes it difficult working. Herbs cool the fever quicker.

### *Disadvantages with herbs*

P5 is different from the others when she listens to the advice of the healthcare workers at the hospital. They have told her that it is not preferable to combine herbs and medicine. She always tries to go straight to the professional sector when suspecting malaria symptoms. Most of the participants agree that herbs can be dangerous.
*"You might cure wrongly since you do not know the diagnose /.../ When you get medicine or an injection you know the dose."* P8

Almost all of them stated that herbs could kill them if they got too strong dose. P1 is the most careful one because once he almost became mad by a too strong dose of herbs**.** The female participants stated that herbs are not preferable to take if you

are pregnant because it can cause damage to the foetus or lead to miscarriage. However some of them take herbs anyway, but then they consult someone that knows a lot about herbs, instead of getting the herbs themselves. P4 can not always take herbs because she has no one that can help her to collect it and because she has nothing to eat in the morning.

### *Relief of symptom*

P9 is the only one explaining using a knife to stop the headache caused by malaria. The enormous pain in the head forces her to let an herbalist or a healer cut her around her temple. After the pain has released she turns to the professional sector for further treatment. She knows that the knife is not curing her, but she needs a painkiller. There are no rituals or believes that says that this method is advisable. She does it because she lacks other options.
*"If I have symptoms in the evening when the health-unit is closed, and I can not stand the pain until the next day, then I use this method with the knife."* P9

She thinks that it has some down effects, since it gives her scars, which could develop diseases. P7 is the only one explaining to cool the clothes in cold water as a method to reduce the fever.

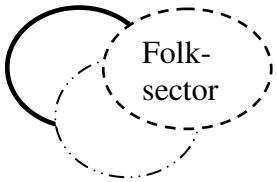
### *Believes*

P10 declare that he is sick from malaria during the interview, but it is not serious enough to seek treatment at the hospital because he can still work. It is necessary for him to work to get food for the day and it is better to work instead of just lying. By working he forces the malaria out of the body.

People from the village come to pray for the sick person. P4 declares that she gets help from God when she lacks other options:
*"When I am really weak and no one takes care of me, the only thing for me to do is to pray, because there is no one who can collect the herbs or medicine to me."*
P4

## The folksector

*The folksector* includes healers and herbalist, whom the patient needs to pay (Helman 1994). In this part there are four subheadings.




### *Differential diagnostics*

In the focus group the participants declared that they do not seek treatment from a healer, because the healer do not have a cure for malaria. They only use the professional sector and herbs for treating malaria if the participants suspect being poisoned instead of/ or while having malaria they turn to healers as the first option. By taking a special herb at a healer they get the answer if they are poisoned or not. If they have malaria the healer sends the patient to the hospital. If they are poisoned they will not take the injection at the hospital, but they do take

the medicine that the Hc-workers give them at the hospital. All participants also declared when being poisoned that they have a fear for injections given by the Prof-sector.

### *Healers divineness'*

The participants sometimes prefer to seek treatment at a healer because they explain better about the sickness. The doctors can not tell if you are poisoned and have no cure for it.

*"Sometimes the healer tells me if I will live for a long time or not. That is why I like to go there. I go there when I have problems /.../ because they tell you HOW to understand the problems."* P10

In the focus-group they also explained why they sometimes seek healthcare at healers even though they usually do not turn to healers when having malaria. They gave an example of one of the participant who thought she had malaria for 4 month, because the doctors at the hospital told her so. Later on when the woman sought treatment to a healer, she was told that she was bewitched. After the visit to the healer she became well.

### *Collaboration*

Both P2 and P4 thought it would be a good idea for the hospital and the healers to work together. With such collaboration the healer would learn to diagnose and have knowledge of both herbs and medicine. There had been one healer who collaborated with Mutorole hospital, but he had died.

### *Disadvantages with healers*

In the focus-group there seemed to be an agreement on that everyone in their village goes to healers. However, since the church does not approve of them to visit healers or "small Gods" some participants did not want to admit it during the individual interview that they do go to healers.

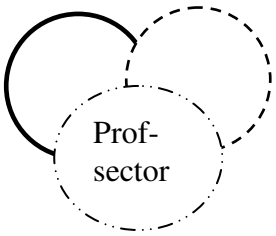
The female participants seemed more reluctant than the men to seek treatment from a healer (see table 1). Reasons for that are the distance but mostly the high price and fear from revenge in case of not being able to pay (see figure 2). P8 differs from the other male participants when not believing in the healer's method.

"*I do not want to go there. I have been there but did not get treated, but yet I had to pay for it. The healers give you herbs that are smashed. They cut in your body and uses stones and meat. I don't think that can treat. I need to pay the healer with money, and that is a lot. /…/ I do not like healers and their animal-skin.*" P8

His wife had been molested by a healer who had forced her to have sex with him. He just does not believe in the healer's method and think healers are deceiving people.

## The professional sector

*The professional sector* is the modern Western school medicine (Helman 1994). There are various professional healthcare options for the Batwa-community to choose between. Three subheadings emerged when categorising the data: *Health-unit, Kisoro governmental hospital and Private health initiatives.*




### *Health-unit*

The Hc-workers at the health-unit closest to the Batwa-community are two nursing assistances (see figure 2). The Hc-worker at the health-unit in Birrara-village thought in general that Batwa patients have malaria every third month. He explained that the Batwa-patient often share the Hc-workers opinion of diagnosing malaria. The Hc-worker explained that Batwa do visit the health-unit often and Batwa-patients do seek treatment at the Gov-hospital. However, there is a problem of explaining to the Batwa patient when and how to take the medicine.

All of the participants had sought treatment from malaria at the health-unit the last year. Those participants, who think that the health-unit is a good option when seeking treatment, have experiences of getting treatment and receiving education about malaria and how to prevent it. However, most of the participants expressed that if they had money they would not have bothered seeking treatment at the health-unit they would prefer to seek it in the Gov-hospital.

#### *Poor education*

In general the participants think that the Hc-workers in the health-unit have poor education. Some participants express that the health-unit is worthless because they do not make a thoroughly medical check-up. For example: they do not measure the temperature with a thermometer. P8 summaries her experiences of seeking treatment at the health-unit:
*"If I tell the health-unit how bad I am feeling, then I can get good medicine. But it is only if I get to talk to someone that really knows what he is doing. Like a doctor. Sometimes you are lucky and then you get to talk to someone that has a good education. Otherwise you can get something just for the headache"* P8

#### *Lack of strong medicine and to diagnose*

The Hc-workers at the health-unit reported that they sometimes do not have anti-malaria drugs. Last year they did not have any anti-malaria drugs for five months. In those cases the Hc-workers advice the patients to visit the hospitals. There are no blood samples taken at the health-unit to diagnose malaria. The healthcare workers can give the patient injections to treat malaria. The prescribed medicines are written down in the medical journal.

The participants reported that the health-unit rarely do have medicine for them and if they have they are too weak. They get unsealed medicines, that are out of date and they do not get full dozes. Two of the participants declared that they had received painkillers for headache instead of anti-malaria medicine.

### *Stigma*

The participants also complain about that they have to wait in line until the non-Batwa patients are finished. The participants do not think they get good assistance or the best treatment from the Hc-workers. However it is not entirely an ethnicity problem. Non-Batwa who is able to pay can get sealed medicine, when the Batwa and other poor people do not. The participants have been told by Hc-workers at the health-unit that they are not prioritised with treatments before non-Batwa, because these Batwa get support from NGOs helping them with different issues. An advice the participants gets from the Hc-workers is to find herbs to treat themselves instead of getting medicine for free.
"*I don't like their suggestions. Do they tell me that because I am a Mutwa? The herbs might not be strong enough*." P4

### *Closeness and free*

In spite of all the negative experiences all ten participants seek treatment at the health-unit. It is the nearest treatment they can get from the Prof-sector and treatments are supposed to be for free (see figure 2). These two factors are the most important reasons to why they choose the health-unit.

### *Kisoro Governmental hospital*

Five different subheadings are presented under Kisoro Governmental hospital: *Education, Lack of free medicine, Stigma, Integration in the community,* and *Distance.*

### *Education*

P5, P7 and P8 express that Gov-hospital is the best option, because they trust the Hc-workers. They know if the participants have malaria and not e.g. AIDS. They can tell because they look at the temperature, use a special machine and they make an exact dose according to the severness of their conditions. The participants get instructions of how to take the medicine. P7 believes the healthcare workers have a lot of knowledge about malaria and they treat her like a non-Mutwa, not as in the health-unit.
"*If I die in Kisoro hospital, then it was meant to be.*" P7

On the other hand the non-Batwa director of the Kisoro Gov-hospital who had worked there for 13 years, explained that he very rarely meet Batwa patients at the hospital, not one in every six month. He found it difficult for the Hc-workers to reach out with their message to the Batwa-communities. He explained that Batwa as a group is conservative which makes it more difficult to treat them or prevent illnesses. A possible explanation to why Batwa do not seek treatment at the hospital he believes is that Batwa culture looks more easily upon death then non-Batwa do.

### *Lack of free medicine*

The participants have experiences of insufficient treatment from the Hc-workers at the Gov-hospital demanding them to bring money for treatment (see figure 2). *"It feels pointless to go to the governmental hospital, because it is to difficult getting tablets for free."* P1

The Hc-workers often send the participants to buy the tablets in a private clinic, which they usually can not afford. The paying-system is not the same as to the herbalist were they can negotiate the price and they have the possibility to work as a payment.

### *Stigma*

Another problem is to bring all things to the Gov-hospital that are needed, such as madras, clothes, food, shoes, blankets, sheets, washing equipments. If they do not have those things they can get badly treated. If they are really sick they will treat them, but P5 declared:

"*They treat me, but they don't want the hospital to be dirty and smelling. When I lay in their bed, lay in their sheets, the healthcare workers do not let me stay with the others. They do not want the other patients to be sick* [my marks: from me]."

P5

### *Integration in the community*

P5 whished to be able to work more for non-Batwas to be able to pay for treatments, but also as a way to be included in the rest of the community. Another whish is to have a hospital were an educated Mutwa-nurse could be working. In that case the Mutwa would ensure that the Batwa patient received tablets for free. Furthermore, she said that Batwa as a group lack knowledge and education and in general do not have much experiences of seeking treatment in the Prof-sector.

### *Distance*

The biggest problem of seeking Hc at the Gov-hospital seems to be the distance (see figure 2). It is difficult to be sick and walk three hours to reach the hospital, especially for pregnant women. If a person gets really sick a stretcher will be used to carry him or her to the Gov-hospital. The possibility to stay in a bed for the night at the Gov-hospital is an advantage compared with the health-unit. However P4 think this could be a problem if she has things that need to be taken care of at home, if she want to be close to her family when she is sick and do not want to worry them.

The distance to Gov-hospital is also a problem if you need a blood-transfusion. Neither the health-unit nor the herbalist can administrate a transfusion, which they consider is a good treatment. In the focus group they said that if the hospital would be closer, they would have a closer contact with the doctor who also would be able to follow how the patient is progressing. The relatives and neighbours could also take more responsibility, like bringing food and to look after the sick person.

### *Private health initiatives*

Four different subheadings are presented under Private health initiatives: *Distance, but free and good reception, Expensive, but strong medicine, Strong medicine and use credit,* and *Expensive.*

### *Distance, but free and good reception*

Dr Scott is an American who built a missionary hospital that is targeting Batwa especially. The hospital is placed within the north part of the district witch Kisoro belongs to. Not all participants know about Dr Scotts clinic. But those who know about his clinic are impressed and would like to have a clinic like his, but closer. At Dr Scotts hospital they know about the problem of Batwa and have treatments free of charge to Batwa patients. The tablets they are getting from his clinic are strong and his Hc-workers are good educated. The downside is the distance (see figure 2), which takes them eight hours one way to walk. It is too far away to walk to the clinic and they do not know the way. P8 say that she always feels welcome at Dr Scott's place.

### *Expensive, but strong medicine*

Everyone knows that they can get sealed and strong medicine at different private clinics. But there are participants who never managed to pay for treatments at private clinics. In private clinics they never run out of medicine, have educated Hc-workers and they treat the participants well, if they have money. But it is too expensive and it is impossible to reduce the price or to work as a payment (see figure 2). Most of the women explain that they never go to private clinics because they can not afford the treatments. P5 explains that she has been helped by UOBDU with money to be able to afford private clinics.

*"I do not like the private clinics because they take the medicine from the governmental hospitals, were the medicine should be for free. If there were not private clinics the governmental hospital would be functioning."*P1

### *Strong medicine and use credit*

Almost everyone has sought treatment at the private clinic that helps Batwa. This private clinic the participants find as a good alternative, because they always have tablets, and can pay on credits or work as a payment (see figure 2). When they can not pay immediately, two participants explain they take a family member or someone with credibility to ensure that the Mutwa will pay later on. But the oldest participant were sceptical about getting strong medicine, because she was afraid they were too strong and she might die of them. P5 said that the clinic had its own agenda of helping Batwa, because the doctor wants votes from Batwa.

### *Expensive*

None besides P7 had sought treatment at Mutorole hospital because of its high costs (see figure 2). P7 has once been to Mutorole hospital when she had earned money from working and could pay for the treatment. She stayed at the hospital when her child was sick from malaria. But the child died there.

# DISCUSSION

In this section there will be a discussion of and reflection on the method that was chosen, data gathering and selection, ethical considerations and a discussion of the results.

## Discussion of method

There are different methodological difficulties with this study. One of them is the role the researcher needs to take as an outsider to the culture, while observing (Polit, 2006). The researcher needs to be highly aware and conscious about the role as a professional while interacting with the participants of the study. At the same time the researcher needs to have a certain level of intimacy with the members of the cultural group to get entry to their cultural world. It was difficult to get this level of intimacy with the group and it would had been better if I on the day of introduction had been clearer on the value of not only interviewing them but observing the participants in their daily life. When the researcher interprets the cultural manifestations and the behaviour of the cultural member it might be difficult to avoid the researchers' own pre-understanding to interfere (Polit 2006). There is also a risk of interpreting everything as culturally related instead of also observing other factors, influencing the members' action (Helman, 1994).

To have a translator can be problematic, because he might put other words and other understandings to what was said. During the fieldwork, before getting to the Batwa-community I had many discussions with my interpreter about the purpose of the study and what his assignment would be. Probably, this made him understand and act more professional in a way that was beneficial to the study purpose, when the interviews with the ten Batwa were carried out. The ten interviewees spoke very freely and explained with patience their healthcare-seeking behaviour.

To add credibility to the data of this study the triangulation method was used (Polit, 2006). Information has been collected not only from this particular Batwa-community. Before starting entering the study sight, data was collected from healthcare workers, different Batwa-communities and different authorities which gave their views on the purpose of the study. Data has been collected both from single interviews, a focus-group, observations, and from medical journals. As the results of the present study are in accordance with other studies the triangulation method is fulfilled also in that matter (Polit, 2006).

The interviews were semi-structured using a topic-guide. A questionnaire was made of areas that needed to be covered to be able to fulfil the aim of the study (Polit, 2006). With pre-set questions the participants were guided to talk about their healthcare-seeking behaviour. This might be problematic, but Polit (2006) states that a pilot-study gives a hint of what questions are appropriate to the study's purpose. For an inexperienced interviewer it is easier to have a topic-guide (see appendix 2) to follow; instead of having a free conversation were the interviewer finds relevant questions to ask during the interview.

## Discussion of data selection and gathering

The first attempt to get interviews with a Batwa community fell out badly because they demanded gifts to participate in the study. The problems were discussed with UOBDU who selected a more assisting community. This Batwa-community has pieces of land and consequently they have more money than the average Batwa and might in that matter not be the most representative community. However this is probably of minor importance because there are many other factors related to the result.

Polit (2006) emphasise the importance of the researcher to give the participant understandable information regarding the research. Therefore, the first day at the Batwa-community there was a long introduction were we got to know each other. I wanted them to be very clear on why I was there, why I wanted to do this special investigation and the purpose of the study. I told them that this study only could contribute with knowledge and that it would not bring them any money or change their situation. Polit (2006) state there is a risk of getting a nurse- client relationship during the interviews which needs to not be emphasised. There might have been a risk that the participants associated me with an authority and responded in a way that they thought was expected. Therefore I was very clear on the day of the introduction to tell them who I am and what I represent. I was very clear to tell them that I did not belong to UOBDU, since many Batwa do not have much trust in them. I found it even more important since OUBDU had been the one to arrange the meeting and had told the village that I would come. Because of this mistrust between Batwa and UOBDU, the chairman for all the Ugandan Batwa joined me on the day I introduced myself to the village.

The ideal situation would have been to interview one participant per day. Because of lack of time and of the remoteness of reaching Birrara-village instead two interviews per day were held. It was not idealistic for me and the interpreter to work under those circumstances. It might have affected the alertness during the interviews. The participants were informed not to talk to each other about topics and answers with the others until all the interviews was finished.

When it was time to do the focus-group several problems appeared. It was difficult to gather all ten participants at the same time and when they finally were together they had just found out an internal problem to discuss. Because of this the situation was not ideal, to make them talk about the questions of the study. Although they had been instructed it was difficult for them to focus on the actual subject, to speak up for themselves, and to get an opinion from each of them. However, they did contribute with some clearness to some of the things they did discuss. It might have been better to have two focus groups with five participants in each group. It would hade been easier to gather together and for all of the ten Batwa to speak more freely.

## Ethical considerations

There are different ethical aspects of this study which I as a researcher and the reader need to be aware of. The fact that my appearance and background differ very much from their situation I might have behaved inappropriate to there expectations, and if so, it might have influenced their answers to the questions.

To my knowledge no one refused to participate in the study when the chairman made inquires. There might have been participants that did not want to participate but felt anxious to the chairman's reactions. However, before each interview it was emphasised that the interview was voluntary, which is of great importance according to Polit (2006). Furthermore, some of the interviews took place in chairman's house. That could have put the interviewees in an awkward position, to being unable to answer the questions freely. However, most of the time the chairman and chairwoman were not in the house. They were mostly working in the field during the times of interviewing.

Some participants answered the questions expecting that I had the power and money to help them to solve different problems in their life situation. One example is that many of the participants told me they did not have a stretcher, to carry the sick person to the hospital, because they thought I might give them a new one. But in fact, they did have a stretcher. There were examples were I thought they answered me in a certain way since they thought it was not appropriate to tell the truth, e.g. some told me that they did not see healers since they thought that was an unchristian thing to do. Some of these situations I could see through and discuss with them later on, but probably not all of them.

## Discussion of results

In this section the discussion of the results from the individual interviews and the focus group will be from a caring point of view. The results will be discussed from the responses of the four questions of the present study, in the light of the theoretical framework, other scientific studies and data gathered from non-Batwa during fieldwork.

### *Healthcare-seeking behaviour*

Helman (1994) refers to Kleinman that the healthcare-system consists of three different sectors were the patient move freely. From the first sector, consisting of consulting family, friends and neighbours, the patient move to the second sector including healers and herbalists with which the patient later on valuate and consult others for further advice in the light of their knowledge and experiences. The third sector is treatment of the professional which usually is valuated by the last performance together with what other people have experienced, in relation to what the sick person expect the healthcare-workers to do. There has to be a choice of treatment between different therapies which partly depends on diagnose and advices that complies with the sick person (Helman 1994). Table 2 and 3, on the next page, are summaries of the participants' healthcare seeking behaviour and their reasons for their choice of healthcare sector. The themes are the same as the subheadings from the results. When generalising the participants three first chosen healthcare options, the participants follow this order: popular-sector, professional-sector, folk-sector. This order is slightly different from Kleinman´s model.

*Table2*.The participants decision-making foundations of *why* to seek the three different healthcare-sectors.

| **1. Pop-sector** | **2. Prof-sector** | **3. Folk-sector** |
|---|---|---|
| Cheap and efficacious | Close and free | Differential diagnostic |
| Relief of symptoms | Educated | Healers divineness' |
| Believes | Integration in the community | Collabora-tion |
| Consult-ative advice | Distance but free and good reception | |
| | Expensive but strong medicine | |
| | Strong medicine and use credit | |

*Table 3*.The participants decision-making foundations of *why not* to seek the three different healthcare sector.

| **1. Pop-sector** | **2. Prof-sector** | **3. Folk-sector** |
|---|---|---|
| Dis-advantages with herbs | Poor education | Disadvant ages with healers |
| Poor access to the National Park | Lack of strong medicine and to diagnose | |
| Consultative advice | Stigma | |
| | Distance | |
| | Distance, but free and good reception | |
| | Expensive | |
| | Distance but free and good reception | |

As shown in tables 2 and 3 that are emerged from the results, the first healthcare-seeking option of the majority of the participants is the popular sector, consulting family-members and neighbours, followed by self-treatment such as herbs. They have several other ways of self-treatment or reducing symptoms such as washing their clothes in cold water, in the belief that it will reduce the temperature. This behaviour is in accordance with a common action in Tanzania (Manduki, 2006). If very severe symptoms occur their first option is to go straight to the hospital. In Malik's study in Sudan it was concluded that the main healthcare-seeking behaviour is to consult the nearest health facility together with using traditional medicine or herbs (Malik, 2006). In the present study (see tables 2 and 3) the second healthcare-seeking option for the majority of the population is professional healthcare especially governmental healthcare were they try to get treatment for free. If that fails their third step (see tables 2 and 3) is to try to seek further treatment within the professional sector or try herbs again, but at an herbalist were they can get stronger herbs. Savingny (2004) suggest that this multiple-care-seeking behaviour, switching between modern care and traditional care, can be a factor in the delay of receiving effective care (ibid).

This present study of healthcare-seeking pattern is slightly different from that described by Kleinman and by two other Ugandan studies (Kengeya-Kayonda, 1994 and Ndyomugyenyi, 1998) were after self-treatment, the sick person buy drugs at a drug shop, private clinic, seeking treatment by a friend or a healer, and last followed by seeking treatment from the professional sector if not the previous actions did cure them efficiently (Kengeya-Kayonda 1994, Ndyomugyenyi 1998). However, in the present study Batwa do not buy medicine as the second option which probably is because they cannot afford it (see tables 2 and 3).

*What treatment does a Mutwa believe to be the best way to treat her/him?*
Strong herbs from the forest that are administrated and dosed by an herbalist are one of the optimal options. Sealed strong medicine from an educated healthcare-worker from the professional sector, such as Dr Scott and governmental hospital, were they do not need to pay to get a thoroughly medical check-up, a correct diagnose and the correct drug is another optimal way to be cured from malaria (see table 2). From the results of another Ugandan study it is fairly common by non-Batwa in Uganda also to use herbs as a drug treatment (Ndyomugyenyi, 1998). However, Batwa are renowned by non-Batwa in their region for their great knowledge of using herbs as a medical treatment (Lewis, 2000).

The participants of the present study clearly expressed a whish to have a clinic as Dr Scott's closer to them. They knew that they were to be cared for, because they feel supported by their healthcare-workers to seek treatment there. They also want a clinic close with healthcare-workers that are aware of the problems Batwa as a group is facing, but most preferable a Mutwa-nurse working at the clinic.

The professional healthcare-system reflects the values and social- and hierarchy-structures of the bigger society (see table 3). This sector reproduces many of the bigger society's prejudices (Helman, 1994). The director of Kisoro hospital was not aware of frequently receiving Batwa-patient in his hospital. There seems to be no compliance between the participants' whish to easier receive treatment at the Kisoro hospital and the director's explanation of why Batwa generally did not seek treatment based on Batwa conservativeness.

*What experiences does a Mutwa have from seeking healthcare because of malaria symptoms?*
Since herbs are a quick way to ease the symptoms of malaria some of the participants prefer using them before medicine. It makes it easier to work during the time of treatment when they use herbs. The participants think it is very important to have knowledge about what kind of herbs they should use since some of the herbs can make them hallucinate as some of them actually have experienced.

From their own experiences the participants also know that healers can not treat malaria and refer the sick person to professional healthcare. These findings are in accordance with a study of Makundi et al (2006). However these participant believes that the healer is the only one who has the capability to decide the diagnose whether it is malaria or poisoning, and to heal a person that is bewitched (see table 2). In Makundi´s study the healthcare-seekers in Tanzania could not associate specific malaria conditions with malaria, believing that they are bewitched because of evil spirits and should only be treated by a healer (Makundi et al, 2006). Some of the participants in the present study have trust in the healer's knowledge while some of them do not believe in their methods or feel cheated by them (see table 3). The women seemed more reluctant too seek treatment at healers which goes in line with the findings of Savigny´s study made in Tanzania. In that study the females were statistically more likely to be kept home to receive traditional medicine and the males were more likely to seek healthcare at a healer (Savigny, 2004).

Governmental hospital is distant to Birrara-village, why the transport is a problem when seeking treatment as well as the eventual payment to the healthcare-workers, the food costs together with the inconveniences of being at a hospital and to have to bring all things that are needed during the stay (see table 3). However, when the participants receive treatment at the governmental hospital most of the times they are satisfied with the results (see table 2).

### *Does a Mutwa experience difficulties to seek the healthcare she/he think will be the best for her/him?*

The participants experienced difficulties when seeking the healthcare they thought would be the best to get cured. Strong herbs for treatment were difficult to find and to collect themselves because they do not have access to the National parks (see table 3). UOBDUs fourth Batwa Work plan Priority is Forest Access and Benefit Sharing (Zaninka 2004). The organisation states that Batwa need access to the forest to secure herbs and medicine because they rely on these medicines even though Batwa have access to other alternatives (Zaninka 2004). The herbs from the herbalist are strong, and are given in doses, but they need to pay or work as a payment.

In the professional sector the healthcare-option which they thought were the best is very distant, for example Dr Scott's hospital. Private clinics were they know they can get strong medicine are often too expensive (see table 3). It should be user fee free to seek governmental healthcare (UN 2008). Although, it sometimes feels pointless to seek healthcare in the governmental hospital because they could be obliged to pay the healthcare-worker to get anti-malaria medicine, to get medicine that is strong enough, sealed, and not only relief symptoms (see table 3). Lack of anti-malaria drugs at professional healthcare was also found in the scientific study of Ndyomugyenyi (2006). It was also observed that some patients got a presumptive diagnosis of malaria with anemia and were treated only with heamatinics without any anti-malaria drugs. It was concluded that even when patients seek treatment at the professional sector, there are no guarantees of receiving a prescription of an efficacious anti-malaria drug or a drug with the correct dosage (Ndyomugyenyi 2006).

Deressa (2007) found in a study with 12 225 Ethiopian participants that although symptomatic diagnosis for malaria was reported, 23% of the individuals were not taken to health facilities because of mild illness (41%), financial constraint (37%), distant health facility (18%), shortage of time due to work overload (3.5%), and the perception that anti-malaria drugs were expensive (0.5%) (ibid). Deressa´s findings why the participants choose not to seek healthcare can be compared to the findings of the present study (see table 3).

### *Does a Mutwa consider governmental healthcare as an option for seeking healthcare?*

All participants of the present study have experiences of being cured from malaria by the governmental healthcare and consider it a good treatment. Although the participants know that the medicine is supposed to be for free they often think it is pointless to seek governmental healthcare without money to pay for strong medicine. The health-unit is the closest and the most frequent healthcare option sought. However, the health-unit has poor facilities, have rarely sealed tablets, the

healthcare workers are not well educated and sometimes they discriminate towards Batwa (see table 3).

Helman who is referring to Kleinman states that the structure of the Western school medicine reflects the bigger society's hierarchy and prejudices (Helman 1994). Stephen (2005) states that indigenous people in general has poorer access to professional healthcare then non indigenous people in their countries, partly due to their physical isolation (see table 3) and lack of influencing the national priority-setting. The amount of money that the government spent on healthcare on indigenous people compared to non indigenous people is significant less. Furthermore, the health services accessible are often inappropriate to the needs of indigenous people (ibid).

The distance makes it difficult for family members to contribute to the sick person's needs of food, prayers and familiarity (see table 3). The participants miss that they do not have as close contact with the healthcare workers in the governmental hospital as in health-unit. Kirkevold who is referring to Katie Ericsson's nursing theory states that the three main achievements of caring is to satisfy the patients fundamental needs, to ease the suffering and to strengthening "the others" way of caring (Kirkevold 2000). However in the present study the participants apparently think that the governmental hospital has failed to include and strengthen "the others" supplementary way of caring.

These negative experiences of seeking governmental healthcare (see table 3) are also found in Ndymugyenyi (2006) study from Uganda. That study found various reasons to why the patients did not use the professional sector: economic factors, lack of drugs, long distance, long waiting time for treatment, and personal preferences for self-medication. Though the main reasons why the patients did not seek treatment at the professional sector-sector were lack of money and absence of drugs. Drugs are often very likely to be out of stock in the professional healthcare sector and it is easier for the patient to get the drugs from a shop or other places. It is concluded that patients visit the professional healthcare sector as the last option, when the others have failed (Ndymugyenyi, 2006). Nuwaha´s study in Uganda is in agreements with that long waiting time, health workers abusing patients and being given tablets instead of injections are important barriers to seek professional healthcare (Nuwaha 2002).

# CONCLUSION

The participants of the present study move freely between the various healthcare options despite the different origin of the treatments, as the healthcare-seeking model by Kleinman. It is the efficiency of curing their illnesses that the participants base their decision-makings up on. The participants have various healthcare options to choose between. However the participants are mostly referred to the cheaper and closer alternatives although they believe other options would cure them more efficacious. Those are most certainly the reasons to why

the participants do not follow the most obvious pattern of seeking treatment for malaria; first popular-sector, then folk-sector and later professional-sector. There are various reasons not to choose these steps of healthcare-seeking, e.g. poor economy, long distance, age, access to food during treatment, severity of symptoms, needing to stay at home working, and discrimination. These factors are important to know as a nurse working in regions with Batwa-population in order to be able to fulfil the four responsibilities of promoting health, preventing illness, restoring health and alleviating suffering in an environment were human rights are respected (ICN 2006). Together with the society the nurse has a responsibility to pay special attention to initiate and support action in order to meet the needs of health to the most vulnerable groups in the society. The nurse also has a shared responsibility to sustain and protect the natural environment, to act appropriately to safeguard the health of the individual, family or community when a co-worker or any other has been jeopardised peoples right to health (ICN 2006).

My suggestion of how to relate to the results of the present study is to be clear on the participants' wishes to have hospitals with educated healthcare workers closer to them. Most of the participants wanted to have an educated healthcare worker from the Batwa-community in the hospitals, a person they could rely on. Or, as at Dr Scotts hospital where there are high knowledge and friendly receptions toward Batwa patients, but only non-Batwa healthcare workers. The trustworthiness of caring everyone equally and having access to efficient medicine in the governmental healthcare must be a matter to develop in order to make the participants feel safe of getting the best accessible treatment at the governmental healthcare.

Healers are rarely an option for the participants when suspecting malaria. Furthermore the participants are not all in favour for the healers' method of curing and their paying systems. Health authorities need to listen to the experiences Batwa have on healers and not oppose healers upon them, as a lack of other health options. Whereby not said that healer should not be an option at all.

To have real use for the herbs Batwa needs to have access to the herbs in the forests and not only to weak ones growing outside. The lack of access to the forest is linked to a treatment option of malaria that is taken away from Batwa. The forests have not only herbs that are connected to curing malaria but also other remedies, as honey, that are of value for Batwa.

It is important to remember that few scientific studies have been made on Batwa and their healthcare seeking behaviour which clearly is in need for further investigation in order to meet their needs of how they want to be cared for. Suggestions of how to go forward is for the health authorities to be aware of the needs of healthcare of this special group and to take their experiences and wishes of being cured from malaria as a demand of their equal right to health.

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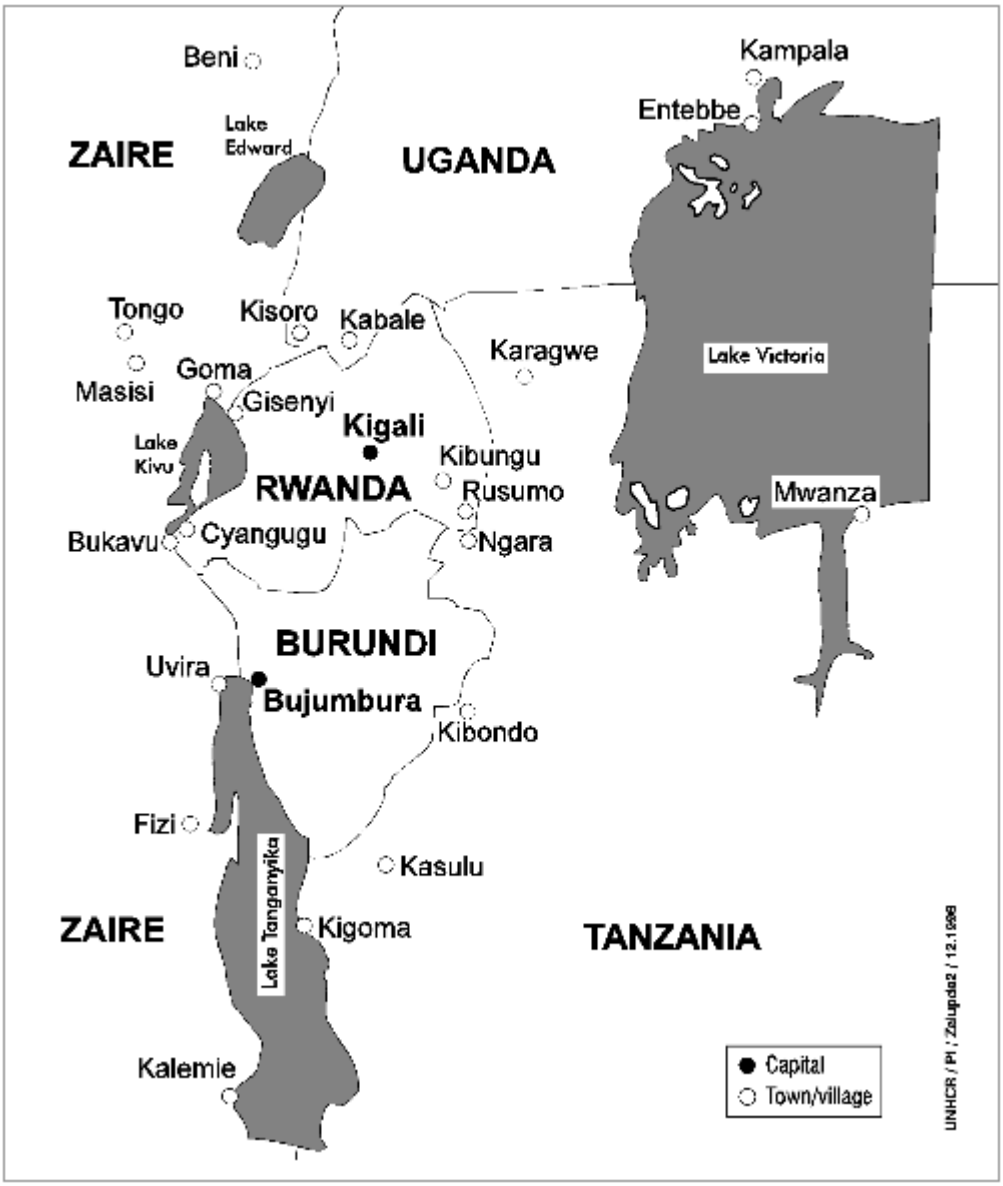
# APPENDIX



**Appendix 1**

Map provided by ReliefWeb <http://www.reliefweb.int/>
Source: United Nations High Commission for Refugees (UNHCR)
Date: 9 Dec 1996



## Appendix 2

**Semi-structured topic-guide, individual interviews**

Background: sex/living condition: family, does for a living/How often do you get malaria? What are the symptoms?

1) What are the different healthcare options you have chosen for treating your malaria?
(Herbs, herbalist, healer, health-unit, GOV hospital, Dr Scotts clinic, NGO private clinic, private clinic that helps Batwa?

2) which of these options do you think gives you the best malaria treatment?

3) Tell me about the process from getting the first symptoms and consulting different treatment options, to the time when you get cured?

4) What are the advantages of seeking treatment at the different healthcare options?

5) What are the disadvantages of seeking treatment at the different healthcare option?

## Appendix 3

**Semi-structured topic-guide, focus group**

Can you discuss the five most important things you take into account when you decide what health-treatment you seek for curing malaria?

For how long do you wait until you turn to any other healthcare option than herbs?

The healer is the most expensive treatment option and very fare away. Why do you prefer healers instead of any other healthcare option?

What would you think of having a healer that is collaborating with the hospitals?

Can you get access to food at Kisoro governmental hospital?

Is the access to food something you take into account when you decide what treatment you should seek?