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**Exploring the role of nurses as
'intermediaries' in bridging the
gap between biomedical and lay
knowledge of disease: *A Case
Study of Malaria and HIV/AIDS in
Kisumu, Kenya***

This research report is submitted as partial fulfillment for the Degree of Masters
of Arts by coursework and research in the field of Health Sociology

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DECLARATION

I declare that this research report is my own unaided work. It is submitted as partial fulfilment of the requirement towards the completion of an MA by coursework and research in the field of Health Sociology. It has not been submitted before for any other degree or examination at any other university.

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Name and signature of candidate

_____ day of _____, 2011

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ABSTRACT

“Health”, “Illness” and “Disease” are multifaceted concepts and are perceived in a range of ways by different health care professionals. This study, using qualitative research, aims to understand nurses pre-existing and current perceptions of malaria and HIV/ AIDS two of Kenya’s most challenging public health problems. The study recognises that disease categories, beliefs attached to disease and explanations behind methods of help seeking behaviour as understood by nurses, originate from specific socio-historical, cultural and professional experiences. These experiences helped nurse’s traverse between meanings attached to the allopathic (biomedical), popular and traditional health care models and create a unique space in which a myriad of meanings can be used in line with each other, an outcome that can further inform local health practice. Though malaria and HIV/ AIDS were described within a biomedical framework by nurses, they understood that patients attached multiple meanings to the aetiologies and treatments of both diseases. Nurses stood as key informers for medical doctors and encouraged them to take cognisance of patients’ views- a difficult task. In doing so, nurses showed their ability to sensitively integrate non-biomedical and biomedical causalities in their everyday clinical encounters. Speaking in local dialects and reflecting on their views of disease before and after their professional training showed nurses as engaging in processes of “cultural mediation” and “cultural brokering”, two crucial aspects of their professional role. This study indicates the importance of documenting nurse’s knowledge in representing local biomedical and non-biomedical views of disease so as to better adapt health messages in such contexts.

ABBREVIATIONS

HIV/AIDS- Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome

SSA- Sub-Saharan Africa

CDC- Centre of Disease Control

UNDP- United Nations Development Programme

MOH- Ministry of Health

GLUK- Great Lakes University Kisumu

PLHA- People living with HIV/AIDS

ART- Anti Retroviral Therapy

WHO- World Health Organisation

WHA- World Health Assembly Resolution

NCK- Nursing Council of Kenya

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PREFACE

I remember growing up hearing Hassan our gardener and long time friend enter a verbal badminton game with my father, a Cardiologist and specialist in Tropical Medicine when the topic of malaria came up. Why did the two gentlemen never just stick to talking about Kenyan politics or football?

“*Daktari*¹!” Hassan would exclaim across our garden.

“All of us locals we have malaria. I have had malaria so many times, now it is in me. People don’t have to come to see you to get better! My grandmother taught me how to deal with these things. You know things Daktari but we also know things.”

The above comment by Hassan pushed me to question why him and my father held polarising views of malaria and its treatment and was a phenomenon I didn’t understand. My ‘innocent’ mind at the time saw my father as the omniscient clinician and Hassan as a ‘lay man’ who was unaware of the causes of disease and its treatment, as he had received no bio-clinical training. My studies in the Sociology of Health have shown that health professionals and patients from varying cultural contexts share diverse viewpoints around the concepts of health, illness and disease. Though a lot of attention has been paid towards the relationship between culture and health and how different cultural groupings understand disease and seek help, minimal attention has been guided towards how certain professionals, namely nurses in developing countries like Kenya, make sense of diseases and their causalities. This is despite their unique ability to traverse between the professional (biomedical) and lay context when disseminating health care information and treatment to patients.

What started and appeared as simple interactions between Hassan and my father pushed me to dig deeper ten years later and now serve as the basis of my fascination with the topic of disease perception. My interest in the topic has been related to nurse’s perspectives of malaria and more recently with HIV/AIDS and the role they play as ‘intermediaries’ in the health arena.

¹ Kiswahili word for ‘doctor’. Kiswahili is a Bantu language whose transcription in this text has been directly translated by the author

INTRODUCTION

Malaria and HIV/AIDS are two of the world's most vicious infectious diseases. Malaria is a parasitic disease transmitted via the bites of infected mosquitoes, and HIV the virus that causes AIDS which damages the human immune system.

A third of the world's population—1.78 billion—lives where malaria once was reduced or eliminated, but the disease has returned and its control is unstable or deteriorating (Ijumba *et al.*, 2004). Most malaria cases and deaths occur in sub-Saharan Africa (SSA) and have plagued countries such as Kenya intensely. Among the countries where the *Plasmodium falciparum* parasite causing malaria, only those of Central America have not recorded resistance to the drug chloroquine. The rapid evolution of such resistance in SSA increasingly complicates malaria treatment. The Centre of Disease Control (CDC, 2008) estimated that 25 out of 39 million Kenyans are at a risk of contracting malaria. The disease is endemic (present in the community at all times) in the country and has occurred after major ecological or social changes, such as agricultural and economic exploitation of forests or socio-political unrest.

Furthermore, malaria stands as the leading cause of outpatient morbidity in Kenya, accounting for one-third of all new cases reported. Also, recurrent outbreaks of highland malaria and widespread emergence of drug resistance strains have aggravated the problem of malaria. High rates of the disease have justifiably made public health workers concerned about the severity of the condition, namely because till today, it is viewed as a relatively minor malady in the hierarchy of problems people face every day. Such problems include unemployment, hunger and social security (ibid). Malaria prevention has been a central public health activity in Kenya since the colonial regime in the early 1880's however, despite its longer disease history as opposed to HIV/AIDS it has shown very little sign of declining.

Comparatively speaking, HIV/AIDS can be understood as a relatively 'new disease' in Kenya as it was fairly unknown in East Africa until the early 1980's. According to the United Nations Development Programme (UNDP, 2008) the prevalence of HIV/AIDS in Kenya (total number of cases of the disease in the population) is just below that of the sub-Saharan African region overall (6.7% compared to 7.5%). Since its initial detection and subsequent peak in the year 2000 (13.4%), recent data between 2005 and 2008 indicate that the country's HIV prevalence rate may be on the decline in some areas. This has reduced the national prevalence rate to 6.7% (ibid). Studies conducted by the MOH between 2000 and 2008 show that Kenyans appear to be concerned about HIV/AIDS and that general awareness of HIV/AIDS amongst Kenyans is high. More than nine in ten (94%) say that HIV/AIDS and other epidemics are a "very big" problem in Kenya. Over four-fifths (89%) of Kenyans feel that HIV/AIDS and other infectious diseases are

the greatest threat to the world (MOH, 2008). Among young people in a study conducted by the MOH (2007) between the ages of 15 and 24, four in five (80%) young men and 74% of young women knew that a healthy looking person could be infected with HIV. Despite such encouraging results however, accurate knowledge of HIV is still relatively low, namely in rural Kenya, and significant misconceptions remain (CDC, 2008).

The lack of sufficient reduction in malaria prevalence over the last thirty years, and the gradual progression of HIV/AIDS make both diseases (despite decades of preventive and curative interventions) two of Kenya's most challenging health problems. Both diseases have existed alongside each other since the 1980s and their burden is not shared equally across the country. The national decline of HIV/AIDS rates in most of Kenya's provinces, do not reflect that in western Kenya. Githeko (2009: 23) in his extensive medical research in Kenya states that "certain pockets such as western Kenya, are standing on shaky ground in the fight against two of her greatest health challenges: malaria and HIV/AIDS."

Western Kenya and the Nyanza Province in particular have the highest malaria and HIV/AIDS transmission rates in the country. On average each inhabitant in this area receives 150-300 infective mosquito bites per year and the HIV prevalence rate sits at 15%- a figure higher than the national prevalence rate. Such a high presence of HIV/AIDS, according to the Ministry of Health (MOH, 2008) has been closely linked to long-standing cultural practices of widow cleansing and bride inheritance in the region. Though malaria remains the leading cause of morbidity and mortality in Kenya, the new found interest in diseases such as HIV/AIDS has somewhat shifted the attention paid towards the development of effective local prevention strategies and qualitative research around malaria in particular regions of the country.

While infection with either malaria or HIV/AIDS can cause illness and death, being infected with both diseases can cause detrimental effects for patients. HIV/AIDS can increase the adverse effects of malaria by increasing anaemia and placental malaria rates (Ijumba *et al.*, 2004). Additionally, malaria is not as stigmatised a disease in contrast to HIV/AIDS- a disease which questions people's behaviour. The adverse biological and socio-cultural links between malaria and HIV/ AIDS emphasise the need for public health initiatives in countries like Kenya to create a space that understands the ways in which messages between health personnel on the ground such as nurses, their medical colleagues and patients are expressed and interpreted. This is because nurses often assume multiple roles in the health care environment albeit being trained as biomedical professionals. Fighting malaria improves the lives of people living with HIV/AIDS. As a result of this, comprehensive malaria programmes must be a priority for malarious countries that also have a high prevalence of HIV/AIDS (Chatora, 2003). Both diseases have been selected due to the

difference in response each has received in Kenya over the last thirty decades. While HIV rates have decreased, malaria rates continue to increase. Numerous malaria interventions in Kenya have overlooked the social and cultural (non-biomedical) causes of the disease and subsequently the role played by nurses in its prevention.

HIV/AIDS has been treated differently to malaria in that considerable attention has been paid to the responsibilities assumed by primary health care workers and medical practitioners in the fight against the epidemic. Evidence suggests that HIV/AIDS rates in Kenya are reducing- despite its shorter lifespan in the country as opposed to malaria. A deep interrogation of why this phenomenon still prevails needs to be assessed (a task this study has aimed to fulfil) as high levels of research and funding have been invested in the reduction of malaria (MOH, 2008). Historically, malaria campaigns in Kenya have focused more on distributing comprehensible clinical information as opposed to HIV/AIDS campaigns whose prevention initiatives have paid attention to the clinical, social and cultural aspects of the disease (Koenraadt, 2003). Programmes such as these have influenced the ways in which perceptions of disease, patterns of help-seeking behaviour, the role of biomedical health personnel and the meanings they create around varying belief experiences have been researched not only in Kenya but in SSA.

The growing interest in the varying perceptions of malaria and HIV/AIDS from a nurse's perspective has initiated a new interest in multi-disciplinary public health research in Kenya, with the expectation of developing local interventions that have the potential to further reduce and control the rates of both diseases. This is because nurses have been acknowledged as playing a crucial mediatory role in fighting the challenges related to disease perception and meanings created around varying beliefs that explain different types of help seeking behavior (Walker, 1995; Wathen *et al.*, 2008). Through engaging in processes such as 'cultural brokering' and 'cultural mediation' both of which are not official characteristics of their professional job description, nurses exchange key information amongst themselves, their patients and medical doctors. Such interactions and perceptions are rooted within a complex social and cultural milieu (Helman, 2001).

There is full agreement amongst a range of authors that the causes of diseases such as malaria and HIV/AIDS cannot be solely explained by the biomedical approach as disease patterns and causes are also influenced by the socio-political, environmental and cultural context (Green, 1999; Ijumba *et al.*, 2004; Koenraadt, 2003; Gilbert *et al.* 2010;). Both biomedical and non-biomedical explanations and the way they are understood by health care providers have repercussions on the sustainability of health care programmes in their implemented fields. Studies interested in illuminating the dual role of medical experts such as nurses require greater collaborative knowledge in order for practices and interventions to be addressed as

connected instead of isolated processes (Winkleman, 2009). Understanding the fluidity associated with diseases such as malaria and comparing them to HIV/AIDS is important as both epidemics have altered the social, cultural and development framework of Kenya, as well as the role of health care practitioners and the responsibilities they assume within the medical hierarchy extensively.

Key aims of the study and rationale

The key aim of this study was to gain insights into the meanings, complexities, possibilities and constraints related to malaria and HIV/AIDS. This has been achieved by focusing on one of group of health care practitioners- nurses in mitigating their role as ‘intermediaries’ in the health space at Great Lakes University (GLUK) in Kenya’s Nyanza Province city of Kisumu². Studies on nurses have documented them as performing multiple roles within the health space, some of which include them engaging in informal conversations with patients, interacting with domestic staff in their areas of practice, working side by side with medical doctors and carrying out various biomedical tests on patients (Bern *et al.*, 2007). All these aspects of their profession further expand their skill base some of which are not components of their formal clinical description- a primary reason they were selected as the primary informants for this study. A key aim of this study is to understand the complex ways in which nurses negotiate meanings around malaria and HIV/AIDS and attaining a comprehensive picture of nurses themselves. The effect mediation has on the nursing role will also be explored.

Nurses selected in the study came from different provinces in Kenya; including Central, Western, Nyanza and Rift Valley Provinces. Each nurse had either come to the university to obtain a second degree and/ or further training in Emergency Medicine or Intensive Care Studies. Nurses from all regions worked in district or private hospitals and engaged in the distribution of medication, health education and examinations of patients for ailments such as malaria, typhoid, HIV/AIDS and its related opportunistic infections- namely tuberculosis (TB), cholera, various congenital disorders and varying types of cancer. While there is a substantial body of knowledge on lay and professional conceptualisations of the concepts of “Health”, “Illness” and “Disease” and how they are perceived by different professional and cultural groupings, the importance of how and why health personnel-in this case nurses-can function as ‘intermediaries’ in the context of malaria and HIV/AIDS in Kenya has not been interrogated at all.

It is of great importance to have a nuanced understanding of all aspects related to the transfer of health knowledge in relation to malaria and HIV/AIDS and the reasons behind this, in this context. The prime intention of this study was to gain an in-depth understanding of the processes nurses engage in when

² Map of Kenya attached in the appendices below (1)

disseminating health information on malaria and HIV/AIDS to their patients as a means of contributing towards literature on the nursing profession. How all of these aspects around the creation of meaning by nurses, how they traverse between the lay and professional space and the impact the information they disseminate is personalised within the professional setting are essential components of this study. Nurse's perceptions around the causalities and treatment of malaria and HIV/AIDS, the relations they share with medical doctors and patients and how nurses view their role as 'cultural brokers' and mediators have also been further examined in this study. This study is based on following the trend in Health Sociology and Public Health which encourages aspiring health care practitioners to expand their knowledge base by moving beyond the clinical doctrine and encompassing aspects of the psycho-socio-environmental model to holistically power relations that produce and shape disease (Trostile, 2005).

Literature that has aimed to contextualise the above mentioned concepts encourage health practitioners and researchers not to view and define them purely as biomedical phenomena. This is because so called 'commonsense' views, or lay beliefs as much as biomedical perspectives constitute themselves upon understandings within expert paradigms. Aggleton sheds light on this assertion (1990: 16) by stating that "local beliefs about health, illness and disease are a consequence of people's attempts to make sense of the various sources of information to which they have access". Aggleton's work (1990) accentuates the idea that people (in the case of this study-nurses), use a variety of professional and lay knowledge from within their context, to help them make sense of their personal and patients perceptions of health, illness and disease. Moreover, the concept of 'intermediaries' has only recently made an appearance in public health and sociological literature.

Due to the dearth of research on this topic particularly in the African context, a crucial aim of this study, has been to contribute towards filling in the gaps in the literature in relation to nurses in the context of their professional role as 'intermediaries', in the health care arena as a means of informing public health practices (Wathen *et al.*, 2008). There has been a greater focus on health experts' views in rural areas of Kenya in contrast to health professionals practicing in urban regions of the country due to the higher manifestations of malaria and HIV/AIDS in these areas. Key to understand is that health experts whether biomedical or traditional medicine have two very different perspectives of the world. Both function around particular power structures, out of which biomedicine and medical doctors in particular (still) hold a dominant position (Bury, 2000). Due to this occurrence, studies representing the voices of front line health care practitioners such as nurses and their belief systems have either been misrepresented or sidelined. Analysing disease and interpreting its associated symptoms, conceptualising the ways in which diseases are classified and understanding the complex network of explanations related to treatment are deeply informed by one's cultural context (Helman, 2001; Trostile, 2005).

The long and differentiated history between how the biomedical health care model and traditional-indigenous healing systems understand health and disease has been actively debated in the public health arena over the last fifty years. Literature in this field suggests that biomedical and traditional perceptions of disease have often been studied separately as each health care model and its practitioners have their own intrinsic views of health, illness and disease, which continue to occupy polarising seats (Lewis, 1981; Helman, 2001). Both paradigms hold different views around causality, treatment and prevention and function according to their own cultural and symbolic system of norms (Gilbert *et al.*, 2010). Such a situation has encouraged health researchers to analyse the spaces in which instances of ‘cultural brokering’ and ‘cultural mediation’ take place amongst health care practitioners as a means of establishing mutual corroboration between both paradigms- with the hope of improving health practices and policies.

Recent public health studies (Helman, 2001; Chatora, 2003; Trostle, 2005) have called for a mutual point to be created between both schools of practice and has prompted this research project to bridge this gap and work with nurses to ascertain further insights of their views. Conducting this research has elucidated the multiple roles held by nurses in disease interpretation and ultimately in treatment implementation. The latest literature on the nursing profession has noted the group as a prime component of front line health personnel in many countries (Bern *et al.*, 2007; Walker, 2008; Denny *et al.*, 2009). This has been attributed to the ability nurses have- which is to simultaneously interpret biomedical and traditional practices in terms of their own, and their patient’s socio-cultural context.

Nurses, more than medical doctors have the ability to see how their patients’ cultural background may influence their expectations, their approach to health services and how they interact with service providers (Walker, 1995). Such aspects are often not documented and take away the role played by nurses in the health field. It is important that health service providers, including government and the biomedical school respect and recognise the role of nurses as ‘intermediaries’ as a legitimate aspect of the nursing profession as such a process is not easy to administer. More than giving credence to ‘folk’ explanations of malaria and HIV/AIDS or rejecting them, nurses understand the importance of enabling patients to voice their understandings as a prelude to facilitating both prevention and treatment. Moreover, they spend more time with patients and realise that patients themselves actively navigate and negotiate across medical models and the treatment protocols that they authorise (Colloton, 1999).

Gaining an in-depth analysis of the ways in which nurse practitioners mediate between formulating meanings attached to malaria and HIV/AIDS is crucial when assessing their role as intermediaries, a key reason that makes this study sociologically significant. In addition, this research has the potential to improve the framework in which nurse’s work in relation to future public health programmes at a primary

health care level (see general discussion and conclusions below). Previous research on nurses by authors such as Walker (1995), Wegner (1995) and McElroy et al (2000) have shown that nurses occupy a unique space when negotiating meanings around disease despite their relative low position in the medical hierarchy and the fact that most of the time they are recruited from local communities and trained to provide care in these communities.

Research questions and objectives

This study used the psycho-socio-environmental model of health and disease which advocates for a broader/macrosopic approach to understanding disease so as to further make sense of the processes undertaken by nurses in malaria and HIV/AIDS perception (Gilbert *et al.*, 2010).

The main research questions posed in this study were:

- 1) What are the local perceptions of malaria and HIV/AIDS and their origins? How do they apply and/ or compare to the predominant biomedical understanding?
- 2) What are nurse's interpretations of the causalities of malaria and HIV/AIDS in the clinical and non-clinical setting?
- 3) How do nurses disseminate clinical information to patients?
- 4) How do nurses incorporate their own experiences and perceptions of malaria and HIV/AIDS to their method of practice?
- 5) What processes of mediation do nurses engage in when explaining symptoms, prospective prevention and/ or treatment strategies related to malaria and HIV/AIDS?

Answering the above questions helped achieve the study's objectives to:

- 1) Gain a deeper understanding of the logic underlying nurses perceptions of the biomedical, traditional and lay perceptions of malaria and HIV/AIDS
- 2) Understand how nurses process and create knowledge attached to malaria and HIV/AIDS
- 3) And how this knowledge is translated by the nurses to their patients and the wider community.

LITERATURE REVIEW

The following literature review engages the published work of health theorists who have focused on the topics of and/or associated to disease perception, nurses and their role in the medical arena, culture and health and the biomedical and psycho-socio-environmental model. Their research is analysed and various issues and concerns that contribute to this study have been presented here. The literature reviewed in this section highlights the body of work that this study has been built on and will draw attention to gaps within the literature that this research intended to fill.

In order to grasp whether nurses did indeed fulfil their role as ‘intermediaries’ within the health space key aspects such as a) the processes underlying disease recognition by patients and health practitioners; b) varying treatment strategies of both diseases; c) the pathways taken to seek help when ‘ill’ with malaria and/or HIV/AIDS; d) adherence to treatment regimens and e) mechanisms underlying behaviour change need to be considered. These have been documented within the literature (Walker, 1995; Helman, 2001; Koenraadt, 2003; Denny *et al.*, 2009; Wathen *et al.*, 2009; Gilbert *et al.*, 2010). Content within the literature has also noted a number of factors that have been identified as contributing to negative social responses to diseases like malaria and HIV/AIDS. Some of these factors include the antagonistic ways in which the biomedical and psycho-socio-environmental models understand the concepts of health, illness and disease and how information on both diseases is disseminated by different health care professionals.

Biomedical and lay definitions of ‘illness’ and ‘disease’- the biomedical and psycho-socio-environmental model

Content within the literature has noted a number of factors that have been identified as contributing to negative social responses to diseases like malaria and HIV/AIDS. Some of these factors include the antagonistic ways in which the biomedical and psycho-socio-environmental models understand the concepts of health, illness and disease and how information on both diseases is disseminated by different health care professionals and understood by each approach (Bury, 2000; Blaxter, 2004; Gilbert *et al.*, 2010).

The biomedical model asserted its autonomy in the mid 19th century during the era of the scientific revolution. During this period, due to scientific and technological advancement, medicine was established as a science and therefore assigned greater power and authenticity upon which individuals came to rely. The starting point for the biomedical approach is the assumption that disease or illness can be reduced to a pathological lesion and that in order to address the illness it is therefore necessary to identify and treat the lesion (Armstrong, 2000). In order to accomplish this said objective the biomedical approach relies upon the “doctrine of specific aetiology” (Dubos, 1992:5) whereby each lesion is believed to have a specific

underlying cause that is biological in nature (otherwise known as the germ theory of disease). In order to uncover the specific biological cause the biomedical model relies partly on patients' accounts of physical symptoms and mostly on clinical testing and examination. The patient's body is therefore viewed as a machine which must be clinically examined and treated by either removing the lesion or reducing the negative effects by prescribing the appropriate medication. The patient is passive during the treatment phase and the success of such treatment is in no way accredited to any psychological position, action or behaviour of the patient outside of his administration of the prescribed medication. In terms of the consequence and effect of the illness on the patient, the biomedical approach simply considers the individual biological changes that occur in the patient and does not take into account the effect the illness has on the patient's social status and role. The biomedical model is reductionist in its approach as it adopts a microscopic view of disease and illness and reduces such to specific biological causes. This model overlooks any link between the mind and the body in the cause and treatment of illness and focuses purely on medical intervention in the treatment of illness (Blaxter, 2004).

Disease, according to the biomedical model is caused by a specific agent as opposed to the psycho-socio-environmental model, which understands disease as being multi-causal (Bury, 2000). In the case of this study, malaria was understood as an infectious disease transmitted by female *Anopheles* mosquito which houses, the parasite *Plasmodium falciparum*. Though HIV was known to cause AIDS (see section titled 'Nurses perceptions on causality, prevention and treatment of malaria and HIV/AIDS' below) various risk factors- referred to as social causalities, such as polygamy, infected needles and various cultural practices were also discussed.

Though the biomedical model continues to dominate the medical realm it is increasingly being challenged by advocates of a social approach to health and illness. The social model differs significantly to the biomedical model in various ways. It highlights a different understanding of the nature and cause of health and illness, the appropriate intervention methods, the role of the patient during treatment and the consequence of illness. While the biomedical model relies on causes of disease that are purely biological in nature, the social approach identifies multiple causal factors of disease and illness. This approach emphasizes the role that social factors play in causing (or preventing) disease i.e. the behaviour and mindset of individuals, their type of employment, their geographical location and how they live their daily lives (Fitzpatrick, 1986; Nettleton, 1995; Gilbert *et al.*, 2010). In this way, the social model offers more of a 'macroscopic' view of health and illness and offers solutions that are dependent on the examination of the patient within his/her broader social context.

Unlike in the biomedical model the patient within the social model is regarded as an active participant in the treatment of disease. Furthermore, while the biomedical approach focuses primarily on treatment and

cure of disease the social approach extends its focus to care and disease prevention whereby healthy lifestyle becomes imperative (Tarlov, 2002; Herek, 2002). Additionally, the biomedical model regards impact of illness simply in terms of the individual status of the sick; the social approach considers impact in terms of the wider social identity of the patient (Armstrong, 2000). While the social model does not deny the links between disease and specific aetiology it seeks to determine the various social conditions which would allow this germ or parasite to flourish and to address these conditions.

Helman (2001) suggests that if various perceptions around illness and disease are to be understood, it is vital for lay beliefs and behaviours in everyday settings (provided by the non-biomedical approach) to be studied. Social and cultural frameworks play an instrumental role in dictating the modes of expression of illness behaviour. Lay knowledge of disease is rooted in analysing the 'wholeness of human beings' postulates Aggleton (1990: 13) in contrast to the medical sciences, which views the body as an anatomical and functional structure. Some lay believers may or may not agree with biomedical definitions of disease indicating that lay beliefs are derived from a complex network of beliefs, perceptions and constructs and are products of peoples attempt to put together their own conceptions.

Denny *et al* (2009: 24) state that as “actors, people use common sense knowledge and scripts to guide their everyday lives and to produce explanations or accounts of their actions”. This view came across in the interviews when nurses reflected on their views of diseases before and after training (see section ‘The world of nurses’ below). Such attempts, in my view, consequently impact the ways in which help seeking behaviour is managed and studied. Aggleton’s work (1990) on lay beliefs about disease is helpful for this study, in that it highlights the significance of local knowledge derived by health care practitioners, namely nurses and patients from their socio-cultural contexts and how health care practitioners make sense of this. Lay beliefs refer to the idea that different social and cultural groupings make sense of their experience of disease and illness differently. Their views are extensively informed by the access they have to health information and health services. The socio-cultural environments and roles assumed by health care practitioners influence the way they make sense of the health knowledge and services they have access to (Nettleton, 2006).

Crucial to understand is that the psycho-socio-environmental model does not negate the biological causes or attributes of malaria and HIV/AIDS- however challenges the biomedical model to understand the importance of culture, geography and the environment when analysing both diseases and their distribution. Malaria and HIV/AIDS, according to the psycho-socio-environmental model are occurrences that don’t exist in a vacuum, but are a component of a broader social, spiritual, cultural, environmental and historical framework. Gaining a sense of how malaria and HIV/AIDS are interpreted by nurses can point out that it is

inappropriate to regard one model as superior to the other. This is because each functions within its own doctrines of methodological practice and understanding (Semali, 1999). Both models must not be viewed as existing on opposite ends of the spectrum rather, they must be accepted as different approaches that are able to complement one another and together provide adequate, more appropriate and comprehensive solutions to disease and illness.

Malaria and HIV/AIDS in western Kenya

An essential factor that has been attributed to shaping responses to malaria and HIV/AIDS is a lack of understanding of both diseases in relation to each other as well as to seeking effective methods of help. Malaria and HIV/AIDS have been stated as following two possible treatment courses: indigenous medicine (bush medicine) or modern (biomedical) treatment (Chatora, 2003; Ijumba *et al.*, 2004). Poverty in Kenya restricts the availability of quality health care, particularly in rural areas where care and modern 'knowledge' of disease is limited. Indigenous methods of health care remain predominant in such areas, as well as cultural beliefs and practices that influence both modern and traditional medicines. Currently, such indigenous knowledge is being jeopardized due to modernization of rural communities (Semali, 1999). Malaria as a disease has developed a so called 'fluid' personality due to its endemic nature- which has subsequently influenced the ways in which the local populace understand the severity of the disease (Koenraadt, 2003). This occurrence has impacted the pathways of help seeking behaviour and knowledge of the disease.

Limited effort has been paid towards creating ways in which both models can work in complementarity and not in opposition with each other. In Kenya, education programmes on malaria and HIV/AIDS, though extensive and have not been sustainable, mainly in the rural communities. Attention is slowly being diverted towards health care personnel such as nurses to help further distribute information as well as monitor and evaluate patients suffering from malaria and HIV/AIDS in a variety of rural regions in Kenya. Before such programmes can be noted as 'successful' the roles nurses assume (often which go unnoticed) need to be integrated into their official job description as a means of the profession being treated with more respect in the clinical arena.

Nurses as 'intermediaries'

The term 'intermediaries' has been defined as and associated to people (nurses) who 'distorts, mediates, translates, transforms and modifies the meaning of elements they are supposed to carry' (Wathen *et al.*, 2008: 22) and has only recently made an appearance in health sociology and public health literature. The nuanced *concept* of 'intermediaries' and the spaces in which the process occurs have been neglected within the context disease perception and nurses. Chapman (1982), Walker (1995, 2008) Wathen *et al.*, 2008 and Denny *et al* (2009) are interested in mediation as they realise that health information is rarely, if ever,

intermediated in a simple, straightforward way. Through realising this, all the authors reveal the complexities present within the health care arena and the relation nurses share with their colleagues and patients.

Recent theoretical developments in this field have emphasised that no matter how apparently simple an intermediary and/or the process of intermediation may look, it can become *complex* as is seen with this study and lead in multiple directions which modify all the contradictory accounts attributed to its role (Walker, 1995; Bern *et al.*, 2007; Wathen *et al.*, 2008). Some of the findings in this study affirmed the complexities enmeshed in the literature and also elucidated that nurses meanings attached to malaria and HIV/AIDS are products of a 'negotiated knowledge' that is composed of the biomedical and non-biomedical approach. There lay 'contradictions' between how nurses were 'expected' to practice their profession due to the strict clinical structure they trained and practiced in and what their personal context taught them (see section 'Our knowledge and our beliefs' below).

Research on nurses over the last decade and a half has noted them as having the ability to help doctors expand their doctrine of practice by encouraging them to view diseases as multi-causal and interact with patients and traditional health care professionals on a more personal level. Though difficult to execute authors such as Cook, 1993, Walker, 1995, Ijumba *et al.*, 2004; Wathen *et al.*, 2008 and Denny *et al.*, 2009 in their works have stressed the need for governments to further 'professionalise' the 'invisible' responsibilities assumed by nurses as a stepping stone to create mutual collaborations between the health science and traditional health care approaches. Understanding how this process operates within health care structures is crucial, primarily because such structures are partly informed by the cultural characteristics of its health practitioners. Nurses, as the findings showed, bring to their profession their personal understandings to their professional space, showing that structures for nurses hold symbolic value. Nurses may practise agency when prescribing treatment such that they may encourage patients to engage simultaneously in biomedical and non-biomedical methods of treatment (Luckman, 1999).

Denny *et al* (2009) explore the notion of 'common sense knowledge' and explain that in order to understand (and possibly alter) everyday behaviour, it is crucial for the views of individuals and groups to be studied. This view is helpful in understanding how nurses may enact information and behaviours relating to malaria and HIV/AIDS as well as the relationships they share with doctors and patients when constructing their perceptions of both diseases. Nurses are situated between the information sources and the information seekers. They affect the transfer of health information that can be derived from a variety of sources, through a variety of means to others who are seeking information or who might be expected to seek such information in the future.

The informal sharing of ‘knowledge’ has been derided as a useful tool through which these processes can be understood as it captures elements of discussion, knowledge (re)construction and interaction in its practice (Wathen *et al.*, 2008; Winkleman, 2009). In understanding the commonsense knowledge nurses hold around disease, Walker in her work in 1995 and 2008 shows that they translate information into various sources and in relating it back to others, the knowledge that closely resembles their own understandings and meanings is most clearly expressed. For example, biomedical information relating to malaria and HIV/AIDS in the clinical context in this study was translated into ‘comprehensible’ pieces of information that combine non-biomedical and medical understandings of both diseases.

The above notions shed further light on how Walker (2008) describes the process in which structure and agency in relation to the nurse is practiced. This study showed that though nurses are biomedically trained their approach to handling a patient is carried out through a personal approach affirming Walkers work (2008). Nurses understand the biomedical health care system as having a culture of its own with rituals and a language that is often incomprehensible for patients. Because of this, nurses tend to explore their patient’s cultural background and personal perceptions of disease. Health science practitioners, including nurses, are trained in a community where the attainment of non-biomedical methods of help when treating ailments, are rarely taken into consideration in the diagnostic process due to the knowledge system upon which biomedicine operates.

The duality of knowledge in relation to malaria and HIV/AIDS was crucial for this study, as it has been acknowledged in numerous sources that nurses consistently negotiate between both worlds. Over time they have developed the relevant skills to disseminate information that draws on content from both health care models (Lupton, 1994; Walker, 1995; Bern *et al.*, 2007). Lambert (2000) also explains that disseminating information around disease occurs in contextual and communal ways. In the study, this point surfaced when nurses discussed the causes of malaria and HIV/AIDS and made it obvious that it was difficult for nurses to isolate themselves from their social and cultural environment. This is because the ways in which discourse is shaped and transferred to patients is imbued with social and cultural norms and values (see section explanations on the causes of HIV/AIDS in ‘Nurses perceptions on causality, prevention and treatment of malaria and HIV/AIDS below).

Nursing in Kenya

Kenya has an acute shortage of health care workers and namely nurses and very little literature is available to provide an in-depth understanding of the dynamics and challenges of nursing in the country. In the context of the WHO health worker here implies nurses, midwives and doctors/physicians. This understanding is vital in making efforts to strengthen nursing and midwifery and increase efforts to manage and improve nursing human resources in the country as envisaged in World Health Assembly resolution

(WHA). As identified by the WHO Kenya is one of the 57 medium to low income generating countries with acute manpower shortages in the health care arena. Out of these 57 countries, 36 are in SSA. There are approximately 29,000 nurses in active practice in both public and private health sectors in Kenya which translates to a ratio of 1 nurse per 1,345 populations as compared to the WHO recommendation of a minimum of 2.5 nurses per 1000 population. Since mid 2009, there have been cumulative estimates of 53,500 nurses registered in various registers maintained by the Nursing Council of Kenya (NCK) since 1960, out of which 25,200 are registered and 28,300 enrolled nurses. In Kenya, *The Norms and Standards for Health Service Delivery* defines *staffing needs* as the relationship between annual workload and the standard workload for the staff cadre at the defined level of care (MOH, 2007). *Workload* is defined as volume of work involved in delivering health services that can be accomplished during the course of one year by a competent and motivated health worker working to acceptable professional standards (MOH, 2007)

Kenya's case is unique states Kingma (2007) because over the last decade it has been reported that there are over 7,000 unemployed nurses, despite over 1,300 new nurses graduating annually from local colleges. In 2007, it was estimated that 500 of Kenya's 2,122 dispensaries did not have a single nurse. In addition, averages of 500 nurses have been retiring annually at age 51 and between 300-400 nurses migrate abroad annually (Kingma, 2007: 88). A key factor responsible for the shortage of nurses at service delivery points includes the fast-expanding health care delivery network, which also experiences inadequate recruitment and mal-distribution of staff. Further contributing to the shortage is an aging nursing workforce; lack of proper workforce planning that includes skills analysis and distribution, and lack of up-to-date, accurate and comprehensive data sets to assist in remedying the workforce planning situation (MOH, 2008). When speaking about the everyday challenges nurses faced in their areas of work each to some extent or the other elaborated on the shortage of support from colleagues and government. Menial salaries in relation to output being more than input as well as multi-tasking and assuming multiple personalities within the health care space were also recorded as issues that made challenged the quality of nursing care.

Medical doctors in Kenya (still) play leading roles in heading health care delivery systems at all levels. The Director of Medical Services is the technical head of health care services; the Provincial Medical Officers and the District Medical Officers of Health are the technical and administrative heads at their respective levels; while the medical superintendents are the administrative heads at hospital level (MOH, 2008). They all work through teams such as the Provincial Health Management Teams, the District Health Management Teams, and the Hospital Management Teams. Nursing governance follows the same pattern. The Chief Nursing Officer, based at the Ministry of Medical Services headquarters, is the head of nursing services in the country. There are Provincial Nursing Officers District Public Health Nurses and Nursing Officers in

charge of health facilities. They are all members of the management teams at their respective levels. Efforts to fully implement the position of Divisional Nursing Officers at the Division level, for effective supervision of community-based nursing services, continue to be undermined by shortage of registered nurses in the country.

Enrolled nurses

Nurses at enrolled level are certificate holders trained for two and a half years. They are practical nurses working at operational levels in hospitals, health centres, dispensaries and communities. For many years they have worked in and managed dispensaries. But in recent times registered community health nurses are being posted to take charge of nursing services in health centres and, in some cases, dispensaries (MOH, 2008). Certificate cadre include general enrolled nurses, enrolled midwives, enrolled health visitors, enrolled community health nurse and enrolled mental health nurse.

Changing roles in service delivery and skill mix

Roles played by nurses continue to change over time. Up to the early 1980s, nurses did not establish drips or administer drugs. Today nurses assume more responsibilities in the clinical context. For example, they fix drips as part of their normal routine duties in lower health facilities or in emergency situations. Those with special training such as intensive care (critical care) undertake complex procedures that have previously been the preserve of doctors such as administering drugs, intubation and endo-tracheal suction (Kingma, 2007). In Kenya today nurses even prescribe ARTs in health centres and dispensaries after being trained in comprehensive HIV/AIDS care and treatment services. It is hoped that through studies such as this one, more roles will continue to change and new responsibilities added as nursing education is enhanced which will bring in improved skills, new competencies and opportunities for specialisation. Before such changes occur however crucial changes need to be made in the Nurses Act of Kenya which will prioritise the health care needs at particular settings on the basis of competencies, skills, and experience.

Given the emerging trends in workload, staffing norms have since been revised taking into consideration trends in population rise, increasing poverty, rising disease burden, additional technical and professional responsibilities that have emerged over time at different levels of health care; the need for quality nursing care and the need to balance cost of labour with quality of care. The aim is to increase nurse/patient contact hours to an average of six hours daily for in-patients, and ambulatory nurse-patient contact time ranging between 5 to 45 minutes, depending on client health need (MOH, 2008).

Understanding cultural brokering and its relation to nursing

The concept of cultural brokering is an old one that has evolved into encompassing a range of definitions over the years. It has a long history in anthropology, beginning with the work of Worlf (1956) and Geertz (1960). The concept was developed when anthropologists observed that particular people acted as middle-men, the go-between, mediator or negotiator when disseminating meaning, or controlling the nature of social situations.

The preferred definition of the term for this study is that developed by Jezewski (1990: 497) who defines the term as ‘the the act of bridging, linking, or mediating between groups or persons of different cultural backgrounds, for the purpose of reducing conflict or producing change.’ Cultural brokers in this study refer to a unique group (nurses) who serve as a useful heuristic to link levels of health experiences. This is because the cultural broker has the potential to negotiate meaning between themselves, the patient and others he/she encounters during the course of making sense of a disease.

The process of culture brokering can serve as the bridge between the patient’s personal experience of illness and the broader environmental, community, political and economic constraints. All of these affect the ways in which patients seek and receive care within the biomedical health care system. A type of broker in the health care arena such as nurse may be a person who is a member of the same group as the patient as they are familiar with the health care procedures, norms and values and systems of practice. This person is also someone who is influenced by their socio-historical structure, has his/ her own unique experience with each group and has formulated their own values and systems of belief and practice. Even though such people are often derided as neutral agents, such individuals have a vantage with all the elements that implies, and are in fact not neutral, but active in all aspects of the meaning making process (Wenger, 1995).

It is a well known fact that culture affects the way people approach health services, how they use them, what they expect from them, how and where they look for them and ultimately how they interact with health service providers (Helman, 2001). Providing an equal access and use of services does not mean treating everybody the same but rather offering everybody equal opportunities to attain comparable health outcomes. The fact that services are open to everybody does not mean that they are accessible. In health care provision service providers avail of interpreters when addressing the language barriers of their patients but find themselves at a loss when addressing cultural barriers and managing conflicting or challenging relationships arising from cultural differences. This is exacerbated by the fact that even when conflict happens, service providers find it difficult to distinguish the extent to which the conflict was caused by culture or something else.

The interplay between culture and disease is deeply complex and invites consideration to a number of explanations relating to causes of disease and illness, illness behaviour, methods of treatment, experiences

and perceptions (Cohen, 1999). Even though differences in culture are intriguing and fascinating to analyse, especially in its accordance to disease, it must be understood that culture holds significant weight in dictating the manner in which economic, political and social differences between people, in this case nurses, are formulated (Helman, 2001).

Cultural brokering has been integrated into this study's broader research interest and refers to a process that occurs within the informant group and those they interact with, when meaning on malaria and HIV/ AIDS is constructed and transacted. The preferred definition of the term for this study is that developed by Jezewski (1990: 497) who states that 'cultural brokering is the act of bridging, linking, or mediating between groups or persons of different cultural backgrounds, for the purpose of reducing conflict or producing change'. Cultural brokers in this study refer to a unique group that serves as a useful heuristic to link levels of health experiences as they have the potential to negotiate meaning between themselves, the patient and others he/ she encounters during the course of making sense of a disease.

The process of cultural brokering can serve as the bridge between the patient's personal experience of illness and the broader environmental, community, political and economic constraints that affect the ways in which patients seek and receive care within the biomedical health care system. Clinicians for instance may hold different views of disease to their patients primarily because each individual is influenced by different systems of knowledge which base themselves on different doctrines of practice and symbolic structures. Clinicians are concerned with the diagnosis and prospective treatment options available to their patients (McElroy *et al.*, 2000). Symptom analysis may be understood as having a physiological component to a clinician however have emotional components for a patient. Differences such as these open up space for negotiation where in which a type of broker in the health care arena, such as nurse who can affiliate with the clinician and patient to be called upon when wanting to understand norms and values and systems of practice.

Even though nurses are often describes as neutral agents they are in fact active in all aspects of the meaning making process (Walker, 2008). Cultural brokers such as nurses can conceptualise lay and professional understandings of disease in a similar manner to bridging the gap between people speaking different languages and rituals related to disease perception, a characteristic of theirs that equipped this study with the necessary information to further contribute to public health programmes. Important to understand is that there is much complexity and difficulty associated with evaluating the effectiveness of cultural brokering as the process is often spontaneous in nature and incorporates different sets of knowledge and skill which are demanding and hard to view comprehensively. Also, aspects of the nursing profession such as 'cultural brokering' often tend to be defined as 'invisible labour' in that they are not formally inscribed in a nurse's job description.

Limited studies on the role played by cultural brokering can be associated with the challenges present in measuring its effectiveness. It is very difficult to gain a concrete sense of the levels of cultural brokering that take place within the health space as the process is not necessarily confined to nurses or to the hospital. In fact, recently, the concept of ‘cultural brokering’ has been used in the corporate world, showing that it is not exclusive to the health arena. Various people in the corporate world including sub-managers get trained to translate messages to immigrants who speak different languages. Services in such multicultural environments need to be equipped to offer an equal service to people from different backgrounds.

Cultural mediation and nurses

Denny *et al* (2009) note that when studying the ways in which mediation takes place during the transfer of health information, it is important for interventions to thoroughly address the practitioner at hands knowledge base, attitudes, self-efficacy and skills. Mediation in the health space often takes place between patients and practitioners on an individual and group basis. In the case of this study, mediation of knowledge around malaria and HIV/AIDS extended itself between the nurse, patient and hospital cleaning staff- depicting the layered context within which nurses might enact information and behaviours related to disease perception when hit with misunderstandings or conflict. The cultural mediator’s job is to create a space for dialogue between service provider and client and to formulate explanations in relation to their culture and that of their clients and the effect this background might have on clients/patients when seeking help (Bern *et al.*, 2007; Minervino *et al.*, 2007).

Service providers should view cultural mediation as a resource that can assist them in delivering health care that is culturally competent. Despite its advantage, cultural mediation should not be viewed in isolation as the means to creating cultural awareness and providing the cultural interface for the service provider. The support of mechanisms such as training should also be considered in developing and integrating cultural competence into a service organisation. These also require the cooperation of medical doctors (a big challenge), patients and government institutions. It is in nurturing the abilities and enhancing and making apparent the skills of nurses (many of which go unnoticed) that allow them to educate others- a process that is time consuming and challenging.

Cultural mediation empowers patients by providing them with a means to voice their own needs and concerns and used together with other resources such as counselling, training and capacity building- enable patients to manage their own health and exercise their own choices. Such a process can help patients monitor infectious diseases such as malaria and encourage them to assume an active role in their treatment and diagnostic process. Furthermore, such a process will push the biomedical model to directly engage with the criticisms it has been bulletted with. Due to being able to affiliate with their patients social and cultural

contexts, nurses very well understand the needs of their patients and the obstacles they have to overcome. In addition, engaging such cultural mediators in the health services contributes to making services more inclusive and welcoming to a greater diversity of cultures and peoples (Minervino *et al.*, 2007).

All approaches to cultural mediation are capable of assisting health services to achieve a better understanding of the needs of populations in regions like Kenya and SSA more generally. The primary objective of cultural mediation is not only to resolve conflict between health care providers but to also help prevent and/or manage it as mediators have the capacity to assist and encourage parties to individually create ways to obtain positive outcomes and produce their own solutions. This aspect of the concept is crucial for studies conducted on malaria and HIV/AIDS as both diseases are viewed very differently by biomedical and traditional health practitioners and as has been explored in this study.

Theoretical framework

Making sense of malaria and HIV/AIDS, assessing how clinical professionals and patients formulate knowledge around their causalities and associated symptoms and understanding the complex network of explanations related to treatment are important; especially if public health initiatives, not only in Kenya but in SSA. As reflected by the literature review, this research is located within a broad theoretical framework on nurses as ‘intermediaries’ and how they negotiate between the lay and professional space when understanding malaria and HIV/AIDS. The works of Aggleton (1990), Walker (1995, 2008), Bern *et al.*, (2007), Wathen *et al* (2008) and Denny *et al* (2009) served as a starting point for the study. Factors such as biomedical and non-biomedical conceptions of malaria and HIV/AIDS and how they are understood by nurses according to each health care model, addressing how accessing help is culturally specific, understanding how and whether processes of cultural mediation and levels of knowledge are created in relation to nurses working with both diseases have also been addressed.

Additionally, the study aimed at investigating the position of nurses in the medical hierarchy, their pre-existing logics of malaria and HIV/AIDS and the processes they engage in when negotiating between professional and lay conceptions of malaria, two worlds they can affiliate to. This study also aimed at moving beyond the separation created by biomedicine in sidelining the psycho-socio-environmental characteristics of disease by following the trend which encourages health practitioners to expand their knowledge base by moving beyond the clinical doctrine when understanding what produces and shapes disease, as mentioned earlier. This is implicit in the literature used to inform the study which describes health as an ideal that is unique to each person and culture and states that there are key differences in our seemingly homogenous understanding of health and disease (Ankrah, 1991; Green, 1999; Helman, 2001; Bern *et al.*, 2007).

METHODOLOGY

The research methods used in this study were designed to best access and interrogate the nurse's responses of malaria and HIV/AIDS as well as understand how they function as health professionals, make sense of their everyday experiences, who they interact with and how and these interactions take place- all within the clinical context. An exclusively qualitative approach through the administration of participant observation and semi-structured in-depth interviews, was taken in this research in order for a detailed analysis of who the nurses were, why they chose this particular profession and the constructs they created when practicing their role as 'intermediaries' when dealing with malaria and HIV/AIDS. Specific attention was focused on how knowledge acquired from their biomedical training was internalised and practiced during the transfer of disease information.

Sampling

The sample was drawn from a population of nurses working directly with infectious diseases at GLUK using purposive sampling methods- however participation in the study was voluntary. According to Greenstein *et al* (2003) this sampling method is used to target particular individuals and categories of people for investigation. Twenty female nurses from the ages of 24-45 were interviewed. Nurses in the study were either studying for a post-graduate degree or diploma. Clearly the sample of this research is not representative of the population being studied and does not allow for generalisations to be made on the basis of the study's findings (De Vaus, 2001). While nurse's demographic characteristics did not form the foundation of the project's analysis, such information was requested in order to reflect that the study included a range of nurses from different geographical settings in Kenya and age groups.

Data collection

Data was collected through conducting participant observation and the administration of semi-structured in-depth interviews. Both methods provided detailed 'stories' of the lived experience of nurses when dealing with malaria and HIV/AIDS and encouraged them to discuss their views of both diseases comprehensively. Participant observation afforded the researcher the opportunity to understand and document (via field notes), how subjects interact with each other, their patients, colleagues and context. Observation provided the study with context and helped develop what Lichterman (2002) refers to as '*membership role*.' Interaction with nurses in areas such as their tea room and during their break times was crucial and enabled the researcher to consciously seek out a '*situational identity*' based on '*membership*' rather than observation as it is traditionally understood. A key advantage of conducting participant observation was that it took place in the nurse's professional environment, therefore provided a 'fuller picture' of the methods of negotiation they used when creating meanings around malaria and HIV/AIDS.

Semi-structured interviews were designed to draw in-depth analyses from the subjects' perspectives by asking them to explain how they formulate and translate their perceptions to patients. Questions posed³ were open ended and intended to encourage nurses to provide detailed information about their opinions of malaria and HIV/AIDS. As the interview was semi-structured in nature, flexibility in probing an answer further was used through the inclusion of sub-questions

With the permission of subjects each interview was taped for later transcription. Notes were taken by hand if any non-verbal information was communicated. Interviews were transcribed shortly after they took place.

Difficulties faced in the data collection process

Due to the research being conducted in a medical institution, various protocols had to be followed in order to protect the nurse's identities. No information that enabled the identification of patients was provided by nurses. Nurses were also reassured that the information they provided would be stored safely and that the research was solely being conducted for academic purposes. To further avoid any problems in the research, every effort was made to ensure that the interviews were conducted in an environment in which the subjects felt comfortable to exchange their views openly and honestly. Some nurses for instance preferred to use the tea room while others lecture rooms in the university.

Interviews were scheduled at times that suited the nurses so as to not interrupt their study and work schedules. Additionally, each interview commenced with a series of general questions on the nurses family background and their hobbies in an effort to put them at ease. Another difficulty experienced was the fact that nurses, by the time of the interviews had already interacted with me during the time of participant observation. By being aware of my presence and speaking to me, nurses may have been conditioned to the research topic with the result that their responses when being interviewed may have been formulated by a pre-awareness of the topic. As the interviews took place simultaneously to the observation, any conditioning effect is likely to have been minimal.

Piloting of data collection tool

Once the interview schedule has been devised, a dry run of it was tested on five people to ensure that its content and structure were fit to provide the relevant information. The pilot interviews also ascertained whether the layout of the interview would provide the necessary information. The interview questions and design were refined as indicated by the piloting process.

³ Interview schedule attached in the appendices below (2)

Data analysis

In-depth analysis of the data commenced once the interviews and field notes had been transcribed completely. Initially, the transcripts of the interviews and any notes taken during this process were studied with the aim of creating themes and making correlations with the literature. Following this, the data was coded according to the identified themes. It was hoped that through developing key themes and subsequent codes that prospective data would help answer the initial research question in a detailed and sensitive manner.

Limitations of the methodology

Qualitative research on malaria and HIV/AIDS has paved the way for biomedical health researchers to recognise that disease categories, beliefs attached to “disease”, “illness”, and the framework of social knowledge originate from specific cultural trajectories. Qualitative research usually requires that acquired data be rich, thick and descriptive as opposed to representative in nature (Greenstein *et al.*, 2003). The results of this research were not expected to be generalisable beyond the subjects who participated in the study. Having said this research provided a set of rich and interesting data through the responses detailed across the nurses, all of which gave offered critical insight into their role in Kenya’s medical system.

Ethical considerations

This study operated on the procedure of informed and voluntary consent and was granted unconditional ethics clearance by the Wits University Ethics committee in July 2010. Nurses were clearly informed about the aims of the study and what was required of them. In the case of both participant observation and the interviews, each nurse was requested to read an information sheet⁴ and sign a consent form⁵. GLUK also deemed the research safe to be conducted provided the necessary guidelines were followed⁶. This procedure was used as a protective measure to ensure confidentiality between the researcher and the nurses. The information sheets were sent GLUK a week before their interview and gave nurses the chance decline participating in the study without undue inconvenience to the researcher and nurse. The purpose of the research was further explained to each nurse at the start of each interview. Furthermore, pseudonyms have been used in the study to guarantee the nurses of anonymity.

⁴ Information sheet provided to informants provided in the appendices below (3)

⁵ Consent form signed by the researcher and informants provided in the appendices below (4)

⁶ Letter of consent provided by GLUK provided in the appendices below (5)

ANALYSIS OF FINDINGS

In order to explore and explain how the nurses in this study practiced their role as ‘intermediaries’, the data analysis focuses on four main themes:

- Nurses perceptions on causality, prevention and treatment of malaria and HIV/AIDS
- The world of nurses: Nurse-doctor and nurse-patient relationship
- “Our knowledge and our beliefs”- the nursing experience before and after training
- How the processes of ‘cultural brokering’ and ‘cultural mediation’ instigate nurses to be ‘intermediaries’.

Further, notions of patterns of help seeking behaviour and how nurses view their role as health care practitioners will also be explored. Throughout this analysis, the assumed rigid structure of the biomedical framework and how the nurses navigated their role within through their socio-historical experiences will be documented in the section.

Nurses perceptions on causality, prevention and treatment of malaria and HIV/AIDS

This chapter will discuss the causes of and prevention and treatment options for malaria and HIV/AIDS as discussed by nurses. Though they functioned as biomedical health care providers and were subsequently influenced by the systems methods of practice, elements of non-biomedical views when describing the causes of both diseases were apparent in all the responses.

At the start of each interview, each nurse was asked to enumerate the most common diseases in their areas of practice and current geographic location (western Kenya). Malaria, tuberculosis (TB), sickle cell anaemia, typhoid, meningitis and various types of heart and congenital problems were listed as ‘recurrent’ diseases. HIV/AIDS was acknowledged as a ‘new’ disease in Kenya however was noted as a phenomenon that had become synonymous to western Kenya. The key reason for this was the cultural and ritualistic fabric of the region- a matter that has been discussed in the HIV/AIDS section below.

Causalities of Malaria

Though nurses generally felt that a majority of Kenya’s populace knew malaria was caused by the mosquito, they acknowledged that traditional (non-biomedical) causes of the disease- namely in the rural regions of the country still prevailed. Such causes included malevolent forces (similar to sentiments presented when discussing HIV), the ingestion of raw maize and mangoes, drinking cold water and playing in dirty pools of water. Malaria being caused by malevolent forces affirms Koenraadt’s work (2003) in western Kenya, which notes that despite conscious efforts by the government and public health interventions, a healthy proportion of the rural western Kenyan population attribute malaria as being caused by “*juok*, a Luo expression for evil eye.

Even though many locals in western Kenya, according to nurses sometimes chose not to construct the link between the female *Anopheles* mosquito and malaria, their social knowledge allowed them to realise the need to keep away from stagnant pools of water, fetid marshes and swamps. This point reemphasises that local populaces or lay people who have no biomedical training develop their own conceptions of disease and its aetiology, all which are informed by their cultural contexts (Aggleton, 1980; Helman, 2001; Trostle, 2005). Such locally derived causal explanations were explained as patients not fully recognising the value of vector control activities, or the benefits of sleeping under medicated mosquito nets. Non-biomedical understandings of malaria were discussed in relation to past experiences, particularly when the nurses were in their youth. Most of the nurses who participated in this study either grew up in rural parts of Kenya, or visited their families from time to time which added to the variation in the responses around the causality of malaria and HIV/AIDS.

The term ‘malaria’ was described as being used quite fluidly by patients such that they used the word to describe a range of ailments from pneumonia to stomach piles, due to the diseases ‘ordinary’ and ‘everyday’ symptoms which include headaches, joint pains and fevers. Malaria’s common symptoms made it very difficult for patients to pin point the actual cause of the disease.

Sister Kuria highlighted this point by saying:

“Malaria is believed to be everywhere in this part of Kenya and it has been here for a long time. Some people say it is in them so the symptoms of the disease are played down. People have heard a lot about malaria eradication and the lifecycle of the mosquito but they are not worried. Malaria is not seen a big problem as everyone has suffered from it at one point or the other.”

Sister Alice⁷ grew up in Eldoret, a town in western Kenya and was a trained ICU nurse and was studying towards a diploma in Tropical Medicine at GLUK when interviewed. She reflected on her childhood when speaking about the causes of malaria and drew upon her family’s conceptions of the disease extensively and said:

“When I was young I used to get told not to play in the rain by my grandmother. I was told that if it rained on me I would get malaria. There are even people who think that if you eat raw mangoes you will get malaria. There was this one lady who told me that her son got malaria while climbing on a mango tree. Mosquitoes hide in the leaves which increase the chances of someone interacting with mosquitoes and therefore exposing the parasite to the person.”

Interesting to note was that even though nurses such as Sister Alice knew malaria the biological cause of malaria was the external agent and parasite *Plasmodium falciparum*; this explanation was used in tandem with a series of socio-environmental and past personal experiences.

Though causes such as ‘eating mangoes and drinking cold water’ are what would be referred to as ‘medical myths’, nurses appeared to draw some meaning from them. Certain symptoms of malaria such as abdominal pains and vomiting were derided as ‘common’ and detracted patients from taking them seriously. This was apparent in Sister Alice’s quote above when she justified why people contract malaria from mango trees. Sister Alice maintained that the bite of a female *Anopheles* mosquito was the ‘actual’ cause of malaria when carrying out her role as a nurse in the hospital. Though her impression of the disease had changed due the professional training she had received, she was unable to distance herself from the belief structure she grew up under as a young girl. Sister Alice used her affiliations to the non-biomedical explanations of malaria interrelate with her current views of the disease. The fact that she was and still remains part of a system that sees truth in the non-biomedical causes of the disease, she was able to distance herself from these when discussing treatment options with her patients. When not working in the

⁷ Pseudonyms have been used to ensure the subjects of anonymity and to maintain confidentiality

hospital she referred to herself as ‘being in the patient’s shoes’ as she retreated back to a system where biomedicine was not the predominant field of practice, nor was it a system that people referred to as a primary source of help.

Sister Mary in her interview also spoke about her experiences around the causality of malaria as a young girl growing up. Even though Sister Mary emphasised that ‘things were changing’ it was obvious that familial and village hierarchy still dominated the ways in which causes of malaria were understood and how help was sought after in her village. Strong reference to understanding her patient’s social, religious and cultural ‘ways of doing things’ was made when she discussed the causes of malaria.

“When I was a young girl I was told that various seasons that brought malaria- like when the maize was ready to be picked even when there was no rain. These explanations were what we grew up with. People would get sick when they ate the green maize. They would get some stomach pains and vomit. As abdominal pains and vomiting are sometimes associated with malaria, people have grouped these common symptoms to the disease.”

Nurses decoded a range of Kiswahili words used by patients when describing causes of and/or symptoms associated to malaria. The study found that the term ‘malaria’ was widely used in Kiswahili discourse to describe illnesses in which fever were experienced. Some participants went one step further and described how fever was interpreted by patients.

The Kiswahili term *homa*⁸, *homa kali*⁹ and *homa joto*¹⁰ stated nurses were the most commonly used descriptions interchangeably used when patients described malarial symptoms. Moreover, the term *homa* often has other implications in the wider taxonomy of disease, particularly when explaining illnesses believed to be caused by malevolent forces, such as mental illnesses. However in this particular case, *homa* and *homa kali* always carried a primary association with *mwili joto*¹¹. Both terms, malaria and *homa*, were reported to be current and carry the same meaning in the vernacular Luo as well as local Kiswahili discourses. Another term used to describe malaria was *homa ya maleria*.

Different names were ascribed to malaria as further explained by Sister Mary:

“I do not know the contents of the green maize but they would associate it with malaria. They knew of this ailment as malaria. They used to call it cheptikon¹².”

⁸ Kiswahili term for “fever”

⁹ Kiswahili term for “harsh/ fierce fever”

¹⁰ Kiswahili term for “hot fever”

¹¹ Kiswahili description for “hot body” (also: *mwili kuchemka*, “boiling body”)

¹² Term used for ‘East coast fever’ by the Nandi peoples of Kenya. The Nandi live in the Nandi Hills and Rift Valley Province

When asked whether she believed in the above mentioned causes of malaria and whether she still does, Sister Mary said:

“Occasionally, I used to believe in these causes before- but not now. Because now even when I was being brought up they used to give me some herbs. I used to take them because I was a child, even up to now I have a sister in law who gives her children these herbs as she believes they have the ability to protect her children from several ailments including malaria.”

It is evident that malaria in the eyes of nurses had a justified biological explanation; however they did not dismiss the non-biomedical views that they previously held/still draw upon when discussing the causes of the disease according to their patients. Also explicit in the interviews was the notion that nurses were strongly influenced by their socio-historical context as most suggested that attention must be paid to local realities (including cultural practices) a factor derided as being a major influence in shaping patients’ ideas around disease perception. Professional knowledge on malaria was described as being disseminated with ease within the clinical setting, as opposed to in the home or local environment. Although nurses mainly recognised and appreciated their pre non-biomedical conceptions of malaria, some nurses such as Sister Kivu and Sister Jane completely disassociated themselves from this belief structure. When asked about whether she or her family knew of any alternative causes of malaria and where treatment was received Sister Kivu stated:

“May I use the word civilised? My parents are educated, as am I. Malaria is caused by one thing- the female Anopheles mosquito and my parents know this. If they got/ get sick they (would) do the right thing and go straight to the clinic or hospital. I have never heard of a herbalist in my home area or known that my parents have been to one.”

Understanding the cause of malaria from a professional/ biomedical perspective was the only way of dealing with the disease. Though she termed herself as ‘civilised’ and dismissed the idea of knowing a herbalist, Sister Kivu spoke extensively of her great grandmother- a ‘very wise woman’- who knew many things about ‘malaria and those types of diseases.’ When requested to elaborate about her grandmother’s role in her village in relation to understanding the causes of malaria, Sister Kivu said:

“My shosho¹³ believed that the cold season brought malaria. Many people used to get sick of pneumonia when I was growing up, so I guess they associated the cold with malaria as well. Utapata hio njogo¹⁴ they used to say. I didn’t really believe in these explanations as I used to go to school and could see that my books were saying different things. So I can’t say that I believed or believe in these so called causes of malaria. At the same time though- I couldn’t say my shosho was wrong as I respected her.”

Responses such as Sister Kivu’s boldly express the multiplicity of beliefs attached to malaria. Sister Kivu was aware of the so called ‘alternative’ causes of malaria even though she didn’t believe in them. Further probing about her grandmother’s viewpoints made it apparent that even though she didn’t agree with her

¹³ Kiswahili word for grandmother

¹⁴ Translated in English as “You will get that disease”

explanations of malaria she could not overtly discharge these attitudes. Nurses accounts were not simply rooted in the biomedical model as each elaborated on the socio-environmental and historical components of malaria.

Malaria- prevention and treatment

Nurses vocalised the need for effective preventive malaria measures to be followed by patients. Sister Alice noted:

“Simple measures such as closing your windows after sun set, wearing long sleeved clothing and clearing bushes in the garden can help control malaria incidence. These don’t affect your culture but we can’t just change people’s behaviour with a click of our finger. We can keep talking but if patients don’t listen there is not much we can do.”

Though nurses felt patients knew well the biological causes of malaria, they still decided to follow their own instinct with regards to seeking treatment for the disease. In this case, patterns of human behaviour stand as the fundamental factor underlying the leading cause of disease and ill health.

Malaria treatment as unpacked by Koenraadt (2003) in western Kenya follows two possible courses: indigenous medicine (bush medicine) or modern treatment. Poverty in many developing nations like Kenya and which have been ravaged by the disease has restricted the availability of health care, particularly in rural areas. Care and modern knowledge in rural areas of the disease is limited. Indigenous methods of health care remain predominant in such areas, as well as cultural beliefs and practices that influence both modern and traditional medicines. Malaria has been understood and managed through a traditional or folk approach in Kenya for decades and has not been received positively by health science practitioners. In line with the literature, biomedicine and traditional health care have been studied in isolation (Bury, 2000; Gilbert *et al.*, 2010) and though difficult to engineer, consistent effort is being made by public health practitioners to ascertain effective ways in which both systems can complement each other and not oppose each other in malaria prevention and treatment.

The decision to use seek help from multiple sources was partially influenced by how malaria symptoms were recognised by patients, perceptions of the severity of disease, cost, distance, religious beliefs and the quality of health care ascertained nurses. Patients were described by prescribing to self-treatment by purchasing malarial medication from chemists, consulting local public health care facilities and/or the local healer- who in the case of malarial treatment was always an herbalist. In many cases patients opted to let the ailment run its course and ‘just lived with the disease’. Seeking help from more than one source was asserted as a fear some locals have towards biomedical institutions and medical experts due to their incomprehensible diagnoses and treatment regimes.

Sister Pamela asserted that patients from different cultural groupings followed their own pathways when seeking treatment:

“People believe in their own things and hop around to find answers instead of coming to us. We can’t change that. Only when they finally come to us do we have to see what we can do. At the end of the day patients make it more difficult to treat malaria or for us to help them. We do not know what they have done before coming to us and because they are so sick we can’t even conduct a detailed medical history as they are so fragile and you don’t want to distress them even more.”

Biomedical institutions were used as an ultimate source of help by patients stated Sister Anne:

“Sometimes it is too late when patients come to the hospital 80% dead. We do not know what the herbalist has done and how much medication he has given the patient. We have to do some serious intervening because the patient has come to us with their final hopes.”

Implicit in most of the interviews was the nurses’ puzzlement over the focus of malaria. Nurses explained that patients living in poverty face a range of serious problems such as employment and familial insecurity, hunger and lack of opportunity. Such societal phenomena explained by nurses had made ‘poor’ Kenyans wonder why outsiders pay immense attention and resources on what they viewed as a minor concern within the range of problems they faced every day. This finding is accentuated in Koenraadt’s work (2003: 26) which notes malaria, due to its hyper endemic status and long disease history in Kenya as a disease whose symptoms have been diluted by patients over the years. Malaria didn’t appear to be weighted as seriously as HIV/AIDS, despite the fact that it has the potential to kill people at a faster rate. Nurses stated that people did not connect uncomplicated malaria with complicated malaria, believing that witchcraft or social unrest gives rise to convulsions.

“We have been hearing this word malaria for a long time. We know it. As a child I always remember someone being down with malaria. My elders never really paid attention as they knew it would pass. We also know how to treat it. Medicines are everywhere as the government has subsidised them. If you feel sick all you do is go to your local chemist. People don’t do this with HIV. People think HIV is a death sentence. It is a matter of understanding. HIV is recent-not malaria.”

Nurses stated that in theory, biomedical treatment for malaria was widely available to all patients due to the easy availability of malarial drugs such as Coartem tablets in Kenya. Sister Bernadette openly acknowledged that patients were able to access malarial drugs without even stepping into the hospital. However, in practice, the only option for patients who contracted severe malaria was immediate hospitalisation. Intravenous Quinine was the key intervention that could help a very sick patient suffering from severe malaria. Since according to nurses patients did not necessarily opt to use biomedical interventions as an initial source of treatment nurses asserted this phenomenon was changing.

The administration of dual/multiple methods of treatment were explained as being detrimental for a patient's health. When talking about the best ways to seek treatment for malaria Sister Grace said:

“One is never really sure how the body reacts when biomedical and traditional interventions are used in tandem with each other. It makes it difficult for us to know how to treat patients when they have received treatment from healers and administered it on their own.”

The interaction of both interventions due to a difference in dosage and type of medication used was described as often leading to patients experiencing more side effects and possibly even death. It didn't matter whether a patient went to a clinic, hospital or dispensary, according to the nurses, as long as they subscribed to using biomedical interventions to treat malaria as herbal remedies according to them were not adequate for controlling malaria.

Causalities of HIV/AIDS

Nurses understood that HIV causes AIDS and some even explained the virological characteristics of HIV and onset of AIDS in great detail. Sister Grace's explanation expressed the association between HIV and AIDS clearly.

“HIV and AIDS are two different conditions and people don't know this. HIV causes AIDS. As soon as they hear they have HIV, they think they have AIDS and panic! This doesn't really happen with malaria. People start wanting to sell their homes and possessions because they think they will die soon.”

Later on in the interview she detailed the biological features of HIV by saying:

“HIV is a lentivirus- which means a slow killer, and like all viruses like this it attacks the immune system. HIV causes AIDS by killing the CD4 and T cells directly or indirectly after a long incubation period (about 10 years). When the number of these cells reach very low levels- a patient's immune system diminishes. It is only at this stage that what we call the opportunistic infections kick in. When they do the patient has contracted AIDS.”

Despite their biomedical insight of the disease, nurses spoke broadly of various cultural, behavioural and social causalities of HIV/AIDS and summarised it as a 'disease of lifestyle' and was closely associated as being a product of malevolence and jealousy. Nurses used this explanation extensively when discussing patient's perceptions of the causes of HIV/AIDS and made obvious the need for biomedical theorists and practitioners need to understand "disease" from a 'macroscopic' and not a 'microscopic' perspective (Bury, 2000; Gilbert *et al.*, 2010). This is because so called 'commonsense' views, or lay beliefs, as much as biomedical beliefs, constitute themselves upon understandings within expert paradigms- as was depicted by the nurse's explanations.

When illuminating her views on the causes of HIV/AIDS and its multidimensional nature, Sister Bernadette noted:

“Many patients still think HIV/ AIDS is caused by an evil eye- you know when someone looks at you badly- these causes are still widespread in these parts of Kenya. We can’t chase patients away when they don’t listen. There are many factors to consider with HIV. Occupation, money, culture and education. All these things cause the disease to increase or decrease”

Malaria and HIV/AIDS were referred to as multifaceted diseases. Malaria however, was noted as a ‘one time event’ and HIV/AIDS ‘a phased condition that was hidden and slow killing’ distinguishing it from other epidemics. Such is a characteristic that has played a fundamental role in defining the way the epidemic has developed as well as how various African contexts have grown to understand the phenomenon (Chatora, 2003). Blood transfusions, the exchange of bodily fluids and infected needles were also noted as key causes of the disease. References to biological theory in relation to causality were more frequently discussed with malaria as opposed to HIV/AIDS.

Sister Jane, a Luo nurse grew up in Kisumu. Her responses when discussing the cause of HIV included ‘infidelity and particular lifestyle choices.’ In her interview she stated:

“In some communities there are some people who are not sure of the causes. Patients don’t understand that HIV is something that is sexually transmitted when your partner spends time with someone else who is infected. We choose to behave in certain ways. These are the key causes of the disease.”

Simultaneous to talking about particular polygamy, malevolence and jealousy were also discussed as key causes of HIV/AIDS when nurses spoke of their patients perceptions. Western Kenya was classified as a unique space in that local practices intrinsic to the Luo peoples¹⁵, such as bride inheritance and polygamy were widely practiced customs in the region.

More than other ethnic groupings in Kenya, the Luo were regarded as strict followers of the above mentioned practices. Luo culture, according to Sister Jane demands that widows should display an identifying symbol and be sexually cleansed. This western Kenyan ritual as explained by Ayikukwei (2007) encourages widows to wear the clothes of their late husband briefly as a symbol of fidelity; shave their heads as an act of honour and respect; and/or tie a rope woven out of banana fibres around their waistline to symbolize their unclean status and bondage to the deceased. As part of the sexual cleansing rite, Luo widows are required to have sexual intercourse with one of the male in-laws, most usually the brothers or cousins of the husband, as a ritual to get rid of the husband’s spirit or ghost. Intricate sexual practices such as those researched by Ayikukwei (2007) in this high-burden population were denominated

¹⁵ The Luo are Kenya’s second largest ethnic group and are found in the western part of Kenya in the well known Nyanza province

as a virulent cause for HIV/AIDS by nurses. Sexual intercourse according to nurses was deeply entrenched in the cultural framework of the Luo community.

An evil spirit causing HIV/AIDS was known as “*chira*”- a common concept used by patients. “*Chira*” was noted as being as a curse which befalls on people who have gone against society’s pre-conditioned customs and traditions, an occurrence Ayikukwei (2007) discusses extensively. Persons affected with “*chira*”- develop similar signs and symptoms of full blown AIDS- hence the close association. Conflict appeared to exist between “*chira*” and AIDS amongst the Luo as per the interviews. Nurses declared that according to Luo traditions and customs HIV and AIDS do not exist. It is “*chira*” that exists. Additionally, “*chira*” was not thought to be transmitted through heterosexual intercourse but by going against social and cultural customs and practices. Ayikukwei’s work resonated in Sister Jane’s response when she imputed that many of her patients still believed that there was a difference between HIV/AIDS and “*chira*”. Sister Jane expanded on this concept by conveying:

“Patients talk of thing called chira. It is a term that suggests that someone has done something wrong or has wronged you. A person with Chira has to be cleansed. For many people HIV/AIDS is viewed as being a curse. People panic when they find out they are HIV positive, but not so much when they have malaria even though malaria kills faster than HIV/AIDS.”

Further reading on “*chira*” interrogates how ideas about sexuality are both informed by ‘traditional’ beliefs and practices, and how these beliefs are reconstructed within the context of HIV/AIDS in Kenya, and more specifically within the Luo community. The interviews made evident that nurses thought “*chira*” depicts the impact of ‘modernity’ on Luo traditional ways of understanding illnesses and diseases. This finding was also associated to how elements of Christianity and emerging modern medical discourses have affected traditional ways of explaining and understanding illness. In the process, such discourses have been adopted, transformed, and modelled in terms of the pre-existing traditional cultural, religious, and medical structures among the Luo people. As a result “*chira*” focuses on the way the Luo reinterpret AIDS and associate it with a traditional disease, using pre-existing explanatory systems to give meaning to the new epidemic of HIV/AIDS (Chatora, 2003; Ayikukwei, 2007).

Patients were described as either not knowing the causes of the disease due to fear and/or denialism. Though exploring the concept of stigma was not a key aim of this study, nurses recurrently made reference to the concept and assigned the phenomenon as a reason HIV/AIDS had become a ‘problem’ in Kenya and more so in western Kenya. In understanding the causes of HIV/AIDS stigma, particularly in relation to HIV/AIDS, discussions have taken an entry point of Goffman’s (1963:13) definition of stigma as “an attribute that is deeply discrediting” resulting in a ‘spoiled identity’ which leads to social devaluation and discrimination. Herek (2002) defines HIV/AIDS stigma as an enduring attribute of an individual infected with HIV that is negatively valued by society and thus disadvantages people living with HIV/AIDS

(PLHA). Herek's (2002) definition alongside broader traditional psychological approaches to stigma imply that it is partly or wholly a problem of individual dysfunction or ignorance (Deacon *et al.*, 2005).

Sister Evelyn when talking about stigma with regards to understanding the causes of HIV/ AIDS said:

“With HIV we are dealing with moral issues and people do not want to be judged. Things like sex and multiple partners are very private and people don't want you to know their secrets. If they have the disease, they won't tell you as it will show people they are dirty or going to die soon. Those who die soon from a disease are seen as being weak. Malaria has no stigma attached to it as a mosquito causes it. The cause is different.”

She further went on to say:

“People talk a lot. If they suspect someone to be HIV positive because all of sudden they have a rash or start moving in and out of a hospital- they start talking and when I say talking, I mean they say a lot of things. Things such as –“Like- that man- I knew it, I saw him come back late to his wife the other night and I knew something was wrong!” I even know of some families who have disowned people from their own family network. Today they are your friend but when you have HIV, you can die alone.”

Sister Evelyn also spoke of various behavioural traits such as a number of individuals, though in the minority, sharing the belief that HIV could be transmitted through sharing certain public spaces such as restroom and hospital rooms. Such opinions alludes Aggleton (1990) have been formulated by the knowledge and beliefs various individuals have been exposed to. Such beliefs emphasise that till today, select individuals strongly believe HIV patients as 'risky' to associate with, at any level, as they are guaranteed to influence HIV negative patients. The complex sexual network system in western Kenya is considered as one of many influential tools in contributing towards the high prevalence rate of HIV in the region. A change in sexual practices, for instance encouraging monogamy between couples and the use of contraceptives according to nurses was a difficult task to administer. This is because perceptions and beliefs related to health and disease are strongly dictated by the social, cultural, historical and biographical context (Nettleton, 1995).

Nurses advocated that effectively addressing HIV/AIDS-related stigma is essential for the fight against HIV/AIDS. Unmitigated HIV/AIDS-related stigmatisation and discrimination fuels new HIV infections as it can prevent people from getting tested and discourages those who are HIV-positive from openly discussing their HIV status (Parker *et al.*, 2003; Simbayi *et al.*, 2007). The persistent and powerful stigma attached to AIDS compounds the fear and mysteriousness surrounding the epidemic by inhibiting opportunities for open public discussion on the epidemic, resulting in persistent denialism and 'silence' regarding HIV/AIDS (Posel *et al.*, 2007). Individuals, who suffered from what biomedical practitioners referred to as full blown AIDS, which is contracted via the exchange of body fluids, did not necessarily

meet with patients' views of AIDS. HIV/AIDS was regarded as being understood differently by different social and professional and cultural groupings affirming Helman's view point (2001).

Effectively addressing the causes of HIV/AIDS-related stigma was deemed crucial by nurses for the fight against HIV/AIDS. Unmitigated HIV/AIDS-related stigmatisation and discrimination was thought to fuel new HIV infections by nurses, as it can prevent people from getting tested and discourages those who are HIV-positive from openly discussing their HIV status (Parker et al, 2003; Simbayi *et al.*, 2007).

Malaria and HIV/AIDS

Interestingly, malaria noted some of the nurses were used as a 'cover up' for HIV/AIDS for those patients who didn't want to disclose their status, a fascinating finding. This was highlighted when Sister Anne this occurrence by saying:

"They would rather have malaria or another sickness but not HIV. They think HIV will take them in a few days and don't understand that if put on the right treatment, they can pretty much be normal."

As elaborated by eight nurses, patients claimed they were malaria positive due to the 'common' symptoms they recurrently suffered from. Symptoms such as diarrhoea, joint pains, general fatigue, fevers, oral thrushes and varying skin conditions were treated as 'malaria' by many patients. Some of the above mentioned symptoms outlined nurses were direct signs of HIV.

When talking about malaria being used as a 'cover up' for HIV/AIDS Sister Nyongesa illustrated that:

"HIV/AIDS is all over Kenya, but is very high here in Nyanza. The problem here is that people do not like knowing. Sometimes when people have HIV in these parts they say they have small malaria' niko na malaria kidogo (small malaria). They have fever and chills and think it is malaria. So when they come to the hospital, you treat them for malaria though their blood sample confirms they are HIV positive. They don't want to hear the words HIV/AIDS. Patients come back in two weeks and say their malaria is not gone."

Sister Nyongesa spoke about this phenomenon at length. HIV according to her was becoming more and more common in Kenya but mainly in western Kenya. She had been practicing as a nurse for 16 years and had interacted with a range of patients both male and female from different age groups and cultural groupings over the years.

Prevention and treatment for HIV/AIDS

Nurses openly acknowledged that HIV/AIDS has challenged biomedicine and medical research particularly as biomedicine has always prided itself on eradicating disease through the administration of a cure. They also saw the positive changes in patients who abided to antiretroviral therapy (ART) treatment properly. Though ART's were thought of as being helpful to patients the issue of culturally relevant interventions

such as the administration of family planning classes in local dialects in the rural areas which require time and expertise was noted as being important for the battle against HIV/AIDS. As explained by Sister Bernadette:

“You just can’t expect someone to start taking all these pills when they don’t understand what they do. It is a commitment and you are on them for life if you have HIV. With malaria you take them for a while and then when the malaria has passed, you stop. Not with HIV/AIDS.”

Treatment was only possible if cultural sensitivity was maintained. This included accessibility, appropriate language or idiomatic formats and other cultural practices such as bride inheritance which have a direct impact on interpersonal relations, disclosure and ultimately treatment. The dissemination of culturally sensitive community based prevention strategies were noted as a key way for the reduction and treatment of HIV/ AIDS.

Behaviour was also listed as contributing towards increasing the incidence of HIV/ AIDS and was a characteristic that nurses derided as taking years to change before a decline in HIV rates could be documented.

“Behaviour is the key element. One has to take medication at regular intervals. I mean are you going to hide these from your wife/ husband forever? What about TB? You can easily transmit it to your partner/ family as it is airborne. And when the person is bed ridden...how are you to hide the disease?”

Seeking traditional treatment for HIV/AIDS was not encouraged by nurses as a primary method of help as nurses felt it stopped patients from understanding the full potential of biomedical interventions such as ART’s. Though nurses said it was difficult to distance patients from their cultural customs they believed that through the administration of effective community health programmes that behaviour and perceptions could be changed.

“Those of us working in the rural areas have to help where we can. It is hard but we have to try. If we monitor a few patients we can try bring down the levels of the disease.”

Though nurses were well aware of the biomedical causes of malaria and HIV/AIDS, they maintained that non-biomedical causes still prevailed and were difficult to ignore. Nurses understood that malaria was caused by the human parasite *Plasmodium falciparum*, though acknowledged the importance of environmental changes, human behaviour and the economic status of their patients. Many nurses spoke of their past experiences when discussing malaria and mentioned family members understanding the disease to be caused by the a) ingestion of raw maize and mangoes b) playing in dirty pools of water and c) “juok” a Luo association to evil eye. When asked how HIV/AIDS was caused, not one nurse directly referred the biomedical explanation of the HIV virus being responsible for causing AIDS.

Causes of HIV/AIDS were situated in the social explanation in that practices such as infidelity, polygamy and bride inheritance were premised as being the cause of the disease. “*Chira*” a Luo formulation for a curse was a phenomenon nurses understood as HIV/AIDS, though community members viewed them differently. “*Chira*” has psychological usefulness as it helps people who are affected to place the burden of HIV/AIDS within a comprehensible cultural environment. Therefore, the concept of “*chira*” stated nurses, helped people in the Luo community and by extension Kenyans, to contextualise HIV/AIDS within a recognisable cultural milieu and as a consequence provides an entry point to dealing with the HIV/AIDS phenomenon. Malaria was not stigmatised to the same level as HIV/AIDS and was often used as a ‘cover up’ for HIV/AIDS. Nurses preferred patients to seek biomedical treatment for both diseases immediately. Treatment options for malaria and HIV/AIDS were assessed as being available to all seekers although in practice were not necessarily asserted as being utilised. This was due to several reasons such as a) combined treatment options b) use of biomedicine as the ultimate source of help c) the cost of accessing particular health care facilities and d) the deep seated belief in traditional and/ or local interventions.

The world of nurses

In this chapter, the ways in which nurses explained their role as ‘providers of help’ are discussed with the aim to clarify why they were ‘inspired’ to take up this particular occupation. Specific attention is paid to what nurses thought were the most important aspects of their profession; how they interact with patients and doctors and what aspects of their formal and non-formal training guide them (and why) when dealing patients with malaria and/or HIV/AIDS. Key questions such as why nurses ‘go out of their way’ in some cases to speak to their patients in either a local dialect or Kiswahili, encourage family members to play a part in their patients’ treatment procedure, while at the same time maintaining their role as ‘biomedical’ health care personnel are also documented and discussed.

Understanding how nurses view themselves is a product of how a myriad of knowledge roots are closely tied to their current professional context (Luckman, 1999). When analysing their role as health care professionals within the range of their various responsibilities, their responses expressed modes of balancing between clinical, social, cultural and psychological factors-all which were shaped by past experiences, knowledge and view of people they had interacted with before, during and after their training.

The multiple roles of the nurse

Nurses hold more than one status position and share multiple relationships with different people within the health care environment. These so called *multiple roles* are a distinct characteristic of the nursing profession in that each role has many facets and modes of interaction. Many individuals and groups help define a role. The individual will first make note of a group to which he/she either belongs or to which he/she aspires. There have been many sociological studies which have revealed a wide range of tasks covered by a nurse on a normal day. Some of these include giving a patient the physical care they need, talking to the patient, keeping records, accompanying medical doctors on ward rounds, feeding patients, interacting with patients’ families and so on. All these may have a direct or indirect impact on patient care but what is enlightening is the relative importance of these tasks in the eyes of the nurse and in the eyes of the patient.

Nurses are socialised into the clinical environment, however the multiplicity of roles they assume can lead to changed behaviour which each nurse develops on his/her own. The model on the next page (41) is an adaptation of Chapman’s (1982) and graphically expresses the multiple interactions nurses in the study held with people within and outside of the medical context. All these interactions impacted on their perceptions of malaria and HIV/AIDS and subsequently on how they went about discussing aspects of malaria and HIV/AIDS to patients.

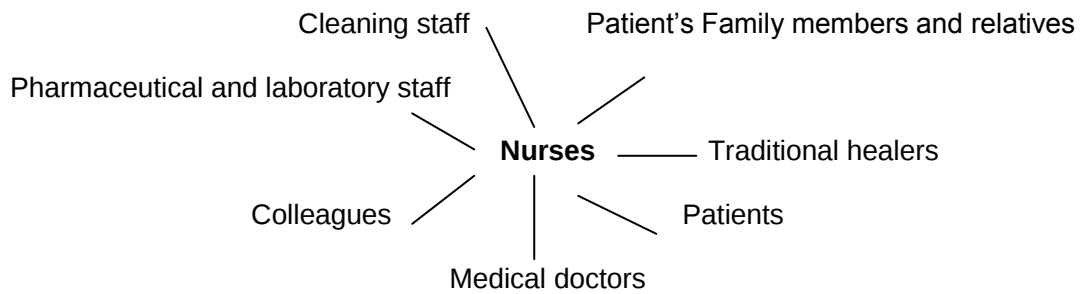


Fig 1- Multiple relations nurses hold in the biomedical and non-biomedical contexts

Crucial to note is that conflict often arose in these relationships. For instance, though nurses in this study understood the non-biomedical causes of malaria and HIV/AIDS were still required to practice some level of authority with their patients when in the biomedical context. Most nurses with the exception of some affirmed their role as being that of a care giver and mediator of sorts between the doctor and patient and assuming different responsibilities when in their work space. The cultural mediator's job as illustrated by Minervino *et al* (2007) is to create a space for dialogue between service provider and the client with a different cultural background. This is evident in the following quote by Sister Alice when elaborating on her role as a nurse:

"We do many things in the hospital. We know everyone from the cleaners to the doctors. It is hard for hospitals to run without its nurses. Sometimes when the cleaners are late or are not at work, we clean. When the doctor needs more help, we help. We are the support system in every way."

Sister Alice realised it was hard to run hospitals without nurses as they were in many ways the backbone of the clinical environment. By noting it was 'hard to run hospitals' without nurses elucidated that nurses assume roles 'above' their ranks as well as 'below' and in a way they take responsibility for the whole 'entity'. Their role was to 'support' and make sure that everything runs smoothly, a characteristic of their role that has been documented in a range of literature (Luckman, 1999; Walker, 2008). The multiple roles nurses assumed influenced their role which to some extent they noted as 'affecting their job' for the wrong reasons, especially when it came to interacting with other nurses.

Sister Grace made this explicit when she vocalised she preferred to take care of her own patients and not interfere with her colleagues.

"I don't think nurses have a relationship with each other. I am head of my unit and have learned a lot in theory but find it hard to fulfil what I my books taught me. Not all of us follow what we learn when we train. There is competition and Nurses are worried about money. With HIV-one has to do so much, nurses are not bothered."

When linking her situation to HIV/AIDS she declared that nurses do the bare minimum as the disease expects nurse to multi-task even more than they do including overcoming differential perceptions, helping with counselling and advocating for biomedical methods of treatment.

“That healthy relationship with my fellow nurses is not really there which impacts on the way we deal with our patients.”

Responses such as Sister Amanda’s, who was born and raised in Nairobi, asserted that nurses preferred not to interact with each other when it came to taking care of their patients. Fascinating to hear was what nurses were expected to do as a part of their training- especially with the rise of diseases like HIV/AIDS. According to Sister Amanda, nurses didn’t necessarily practice what they were taught in practice as they were frustrated and under paid and thus preferred not to assume multiple, but particular roles within the hospital.

The issue of HIV/AIDS and its link to nurses as described by nurses had increased (their) workloads in hospitals and changed the kind of skill sets nurses needed to care for increasing numbers of terminally ill patients. New tasks included more in-depth counselling and providing antiretroviral treatment. Nurses stated they didn’t have adequate support from their colleagues and medical doctors- hence had to make do with what they have. The epidemic in countries like Kenya further reinforced all the negative influences impacting the nursing workforce in Africa which as revealed in this study, seriously undermines their morale and motivation (Munjanja *et al.*, 2005). This is linked to the previous point about the general ‘professional status’ of the nurse and how HIV/AIDS has challenged their role as health care providers. Sister Bernadette also drew examples on how nurses viewed their role through what they learn when training and what is expected of them as practicing biomedical professionals. She found it difficult to cope with the high numbers of patients and sometimes felt unable to provide adequate care as prescribed by her training and text books. The work space was different and one ‘learned new things on the job.’ Aspects of nursing such as lack of technological equipment, minimal staff support and pay and recognition from medical doctors made it tough for nurses to practice their profession in the way they aspired to.

When speaking about the complexities nurses faced Sister Bernadette asserted:

“As a nurse, you know your work in theory. There is a long list of what nurses should be, how they should behave and how they should talk to their patient. I do not think these qualities come out as well as they can in the work space. I will be surprised to hear of a nurse who actually does what she was taught when in college or university. It is too hard. What is practiced doesn’t come out as learned. We learn new things when we are on the job. We have to make a living- and with all these patients, even we are starting to become like the doctors.”

Sister Bernadette insinuated that high numbers of patients and lack of support stopped her from meeting her patients half way. Doctors according to her didn’t ‘bother’ going the extra mile- a characteristic of theirs that rubbed off on nurses. Practicing nursing after some years in the case of Sister Bernadette had

become a process 'she was just a part of' but 'didn't live.' She was not happy with her situation and stated that many nurses she knew felt the same way. Nurses as she noted 'just to the bare minimum now'. There seemed to be some conflict with what nurses were expected to do and what they did due to pressure from medical doctors.

"If doctors can do what they want, so can we. We just can't cope anymore."

As described by Sister Bernadette, nurses didn't necessarily practice what they were taught on the job. Self motivation influenced how they viewed themselves- a factor nurses didn't always have due to being over worked and not being appreciated. Sister Amanda for instance wanted to spend more time with her patients however couldn't as there was a lot to attend to in her work environment. She felt as if she was compromising on her abilities and self expectations. Due to the increasing pressures within the clinical environment as well as the fear of losing her job forced her to diagnose patients quickly which according to her was what the doctors favoured. This is also an attempt to fit in with the clinical environment dominated by doctors. Nurses often favour following doctors demands rather than their moral responsibilities with patients. Sister Amanda and Sister Bernadette's responses showed that there exists a lot of conflict between with the need for nurses to care for their patients and motivate themselves at the same time- a very difficult task.

Inspiration behind becoming a nurse

On the whole, nurses described their attraction towards the nursing profession because of its 'caring' personality- with a few even drawing on Florence Nightingale's work and implementations as a key source of inspiration. This quality is echoed in McFarlane's (1970) work cited in Chapman (1982: 103) who noted that "the unique function of the nurse is to give nursing care. To this function both nursing management and nursing education are in a service relationship. Their excellence can only be judged by the excellence of nursing care which they enable." The ideals McFarlane endorsed in his work almost three and a half decades ago resonated in most of the nurses responses emphasising the value of the profession in the medical fraternity.

Most literature on nurses (Melia, 1987; Trostle, 2005; Bern *et al.*, 2007; Minervino *et al.*, 2007; Wathen *et al.*, 2008) argue that when a nurse is asked why he/she commenced nursing as a career the first answer usually given is interest in people and the desire to care for them. This type of answer is often considered to reiterate the idea of nursing as a vocation, indicating if not a call from God, at least an overwhelming urge to give oneself to the care of others. My interviews brought to life that motivation of this type does not emphasise return to health for the patient but concentrates on what is normally an intermediate goal for the patient, that of care.

When asked to describe the ‘push factors’ that made nurses choose their career, most related to either their parents or family friends who they had seen become ill as a prime reason. Nurses elucidated that they had been in direct contact with nurses and witnessed the intense care and concern they showed their families and friends. Interestingly, some attributed the associations they held with the hospital context in the form of one’s father being a clinical officer or cousin being a nurse, as being responsible for them opting to study nursing. Three nurses said the opportunity to study nursing “just came by chance” in that they were actually wanting to train to become teachers- however as those chances didn’t come through- nursing was viewed as the next best option.

When required to explain why she made the conscious decision to become a nurse, Sister Kuria expressed that:

“The most important thing in me is to get the qualities that Florence Nightingale had and be able to attend to any type of patient, regardless of their illness or background. Yes...I am always very joyful when I see a patient who comes in on a stretcher and leaves walking (very happy). That intense and committed caring of the patient, what we call bed side nursing, I just love that part of my job. It is who I have become.”

Sister Kuria’s explanation elucidates the important association between the nursing profession and the concept of care. All the nurses attached a lot of importance to caring for their patients in whatever way possible. I felt that each consciously acknowledged their patients cultural context, which explicated why immense attention was paid to disseminating care. Nurses hoped that if patients were cared for well and felt at home when in the hospital or clinic, they would use such institutions as a primary source of help and not delay seeking effective medical attention. A few nurses admitted that they were initially interested in studying medicine however opted against it as the science was ‘too technical’ in nature. This is not to say that nurses were not interested in providing excellent physical care. They were interested in contributing towards further bettering medical care yet at the same time were interested in working with issues surrounding gender and fulfilling societal expectations.

“I set out wanting to become a doctor- but then when I was applying to university, I realised I wouldn’t have the time to do what I wanted you know? I wouldn’t have time to have tea with my patients, make sure they are happy. Medical doctors are always competing- they are always on the go. So are nurses, but in a different way.”

(Sister Grace)

“I remember taking my father to hospital when I was young. The nurses took such good care of him- they made sure he had eaten, bathed, taken his medicines. They made the horrible environment feel like home. It was this aspect of the profession that inspired me. I remember seeing the doctors come and go so quickly, but it was the nurses who were around. I also loved what the nurses wore. It is for these reasons I became a nurse.”

(Sister Bernadette)

“I didn’t want to become a nurse because I had never thought about it. I wanted to become a teacher. I wrote my exams to enter teaching school but never got my results. In the mean while I thought I would just do a nursing diploma to just kill time, but then in the process saw that as a nurse, I am a teacher. I don’t regret my decision. I provide knowledge on disease that people don’t have.”

(Sister Alice)

The above responses explain why nurses opted to assume this particular line of work. Similar to when explaining the causes of malaria and HIV/AIDS, nurses drew on their past experiences when explaining their motivations behind becoming a nurse. Reverting to their past was also noted when nurses explained the causes of malaria and HIV/AIDS. Nursing according to Sister Alice though a medical profession also had elements of teaching. She had to incorporate aspects of teaching into all aspects of her practice-whether it was helping new nurses adapt into the hospital system or educate patients on the biomedical features of malaria and HIV/AIDS. Teaching was also described as having mediating qualities such that nurses had to ‘mix and match’ different views and then inform their patients about the best way forward.

Sister Amanda said she continually taught her patients and took an active role in their learning and shared ideas for new educational opportunities such as mobile clinics in the rural areas. This finding ties in neatly with the literature on cultural competence as a form of teaching (Winkleman, 2009) which states that at a personal and individual level, it can be argued that every encounter with another human being is a cross-cultural encounter. Cultural competence is a crucial aspect of teaching and helps nurses to deal appropriately with a variety of individual diversities and how they relate to their specific cultural and social contexts.

Nurse-patient relationship

In one way or another nurses realised that there was a difference between the concepts of “disease” and “illness”. Nurses described health as an ideal that is unique to each person and their cultural background. Amusingly, nurses in their own ways noted that patients hold distinctions in the way they view health and disease. Patients as described by nurses were individuals who didn’t necessarily conform closely to rules and standards. This meant that nursing was understood as a profession that was guided by basic principles that took into account individual variation (Minervino *et al.*, 2007). With reference to malaria and HIV/AIDS, nurses elaborated that the key aim of patients when diagnosed with either one or both diseases was to return to full physical health post treatment. Patients according to nurses decided when they were “healthy” or “ill” according to their own cultural context.

Much debate within the social medical sciences has been centred on understanding the journey of a patient from when he/she is termed ‘healthy’ or ‘ill’. Parson in his work notes that once the patient is ‘sick’ or ‘ill’ he/she has a societal obligation to want to get better, or seek competent help in the form of the biomedical

model. Parson's model concentrates on the physician's role in legitimising illness and pays limited attention to the role of the patient in their healing procedure and relation with other health care providers, such as nurses, local healers, and family members. In addition, the model is asymmetrical in fashion in that it assumes that the individual a) voluntarily accepts the sick role, b) may not comply with expectations of the sick role, may not give up social obligations, may resist dependency, may avoid public sick role if their illness is stigmatised and c) may not accept 'passive patient' role.

The key realisation at this point of the study was the fact that nurses were open to appreciating the different patient understandings of health and illness. Dependencies on non-biomedical or non-professional care were noted as justified practices and methods of help seeking behaviour in cultures all over the world. This was apparent in my study when nurses spoke of community members (patients) prescribing to use different methods of help when seeking treatment strategies for malaria and HIV/AIDS. Community members interacted with their family, community, traditional healers, nurses as well as medical doctors. This finding of mine is evident in Colson (1971) and Helman's pivotal assertions (2001) which both state that it is wrong to assume that an ill person only has a relation with his/ her clinician when they have been diagnosed with a disease.

Nurses drew on HIV/AIDS more often than malaria when talking about "health" and "wellness". The reason for this was linked back to stigma and denial towards the disease. Assessing one's health with reference to HIV/AIDS was noted as a form of compromised well-being, and had links to aspects of disability as well as mental, physiological and emotional problems (Murray *et al.*, 1996). Furthermore, the relation shared between the patient and the health care practitioner in this case the nurse were influenced by their geographic, behavioural, ethnic, cultural, economic and social structures. All these aspects contributed to how the patient described their illness to the nurse, when and where he/ she may attain medical and/ or traditional health care, and how he/ she changes their everyday practices in order to live 'healthily' or live with a particular illness/ illnesses (White, 2002; Young, 2004).

"There is no manual we follow at my hospital. I know what I have to do, but the patient comes with his/ her own idea too. I am not going to compromise what I know, but have to be open to hearing what the patient thinks. They also have their reasons for believing in other forms of treatment. These may not work at times. This is where I come in."

Sister Anne's last sentence is very important as it speaks directly to mediating and/ or brokering between both the biomedical and lay space. Evident in her response was her 'open mindedness' in that she realised patients came to the hospital with their own conceptions of disease. Though certain of her role as a biomedical practitioner, Sister Anne asserted the importance of the views that her patients held by incorporating them into hers. Her method of practice highlighted that nurses themselves negotiate meanings around disease between themselves, their patients and others he/ she interact with.

The interviews revealed that nurses were well aware of the multiple meanings patients ascribed to malaria and HIV/AIDS and was made apparent when the causes of both diseases were discussed (discussed in detail the section, 'Nurses perceptions on causality, prevention and treatment of malaria and HIV/AIDS' above). The social, natural and cultural forces that influenced patients' views influenced the ways in which nurses understood their role as disseminators of information. Though they saw their prime role as providers of biomedical knowledge, they emphasised that it was impossible to ignore the meanings their patients attached to risk perception, behaviour and cultural constructs.

Sister Pauline referred to HIV/AIDS when talking about when describing what she thought of her role as a nurse. She realised that patients become distressed when notified of their condition due to the stigma attached to the disease. She said:

"There is a lot of denial around HIV/AIDS, even though health education is rampant. How we help patients deal with their stress when they are told they are HIV positive is very important to me. I know what it feels like to have an illness you don't want as my own sister has the virus. We have to guide them and let them know there are ways they can protect themselves."

Exciting for me in this account was that Sister Pauline saw herself as a 'guide' and was similar to Sister Anne's who saw it as part of her role as being a teacher. By acting as their patients guide, nurses came across as caring and non-forceful in their diagnostic approach. This differed to the methodology taken by doctors who often preferred a 'top-down' style when interacting with patients.

Sister Pauline's interview in particular made it obvious that denial with regards to HIV/AIDS was a phenomenon that occurred when technical help was either not sought after or rejected. A range of emotions were displayed when a patient was told he/she was HIV positive. The ways in which nurses reacted to different reactions either affirmed or deformed their patient's trust in them as health care professionals. The possibility of over-reacting, exaggerated pity and sometimes over-optimism may be displayed and are emotions nurses have to interact with on a daily basis. The response patients receive from nurses when notified of their status informs their perception of medical and nursing care and makes them peculiarly vulnerable to exploitation by those who care for them.

In her interview Sister Pauline elaborated on her approach- one that she described as being time consuming but necessary. She felt as if spending limited amounts of time with patients and affirming them during their treatment process was essential despite her intensive work load.

"I have had patients who start selling their land and possessions when they hear they are HIV positive. These patients are mainly from the rural areas. When they come to the hospital shouting and weeping, you can't just tell them to take the medicines. You have to calm them down and then talk through their options with them. If I come and say I don't have time, they will never come back. Sometimes I get tired as it doesn't seem as if the work we do is making a difference. But then when you see one patient who is doing well, you are encouraged."

The extent of the nurse's self-role and their reactions to their patients appeared to be challenged on a regular basis, especially when dealing with HIV/AIDS. Nurses' past experiences were constantly challenged by their medical knowledge and patients views. Cultural socialisation influenced both the nurse and patient to respond to each other in different ways and to assign special meaning and patterns of action to the experience of pain and disability. This cultural variation may produce interpersonal problems when a patient and nurse come from different cultural backgrounds and can give rise to 'uncooperative patients' or 'unfeeling of nurses'. Sister Bernadette spoke about this phenomenon in some detail in her interview by saying:

"I am Kikuyu, so when I first came to Kisumu, I didn't really know that some people don't agree about coming to the hospital because of their religion. I think it is some sort of Adventist group. When the patient was forced to come and referred to me, I asked them why they didn't come earlier and they got very angry and may be a bit scared for being questioned in that way and they left. It took me some time to get used to a new space and different people."

The theory of 'social exchange' (Chapman, 1982) is useful in explaining some of the ways in which individuals behave with each other. This theory was kept in mind during my interviews when the subject of nurse salaries was brought up. Patients according to nurses felt as if their level of care was poor due to their salaries which according to nurses were not very decent, compared to the work they do around the hospital. Some patients however, felt as if nurses went over and above their duties to make them feel comfortable and at ease. This made it evident that there may be a unique relationship where the nurse may be seen as a giver, that of her care and the patient the receiver without having to return the nurse with a gift.

Nurse-doctor relationship

The nurse-doctor relationship is a complex one affected by the fact that doctors are more frequently male and nurses female. Nurses' elaborating on their relationship with medical doctors was a finding I didn't foresee. Male dominance in the medical field and female subjugation tended to cloud the issue and brought about the issue of 'clinical imperialism' headed by medical doctors and specialists. Such findings emphasised that medicine as a field of study and profession is well established while nursing in many respects is still developing and still doesn't have clear cut professional characteristics. Furthermore, while society openly acknowledges the work that nurses do, it frequently gives more appreciation and monetary rewards to medical practitioners. Another attitude held by some doctors noted by nurses who came across in some of my interviews was the occurrence of paternalism. Even though doctors practiced this through expressing gratitude for the services nurses undertake either to the patient on their behalf or to themselves there is always a degree of surprise that the nurse was capable of such a high standard of care.

"At the end of the day, the most important thing about being a nurse is filling in, naturally...you know, helping people who are in need. Doctors also do that, but they do not have the time. Ok, they come in to the ward, see their patients, make sure that everything is

running smoothly, but they don't go the extra mile. They don't have time to sit down and have an in-depth conversation with their patients. So at the end of the day, it is the nurse who is there to take care of the patient and make sure that everything runs properly."

Evident in most of my interviews was the tension between nurses and doctors especially when nurses talked about the ways in which doctors diagnosed their patients. In most cases, nurses didn't feel as if doctors fully credited them for their efforts and support- often leaving nurses feeling frustrated and tired. This finding supported the literature provided by the MOH (2008) in Kenya- which described this conflict as creating further antagonisms in the country's health care system. Medical doctors according to nurses preferred as many patients as possible to go through the system and simultaneously follow their treatment recommendations.

Not a lot of attention was paid towards the relationship between a patient's cultural context and health. Such was an issue nurses opposed, but found themselves unable to fully challenge the doctors they worked with as they were referred to as ultimately making the 'final decisions'. Such findings emulate the sometimes antagonistic nature of practice between nurses and doctors- both of whom sometimes follow their own methods of diagnoses and treatment procedures. An occurrence such as this one often leaves the patient feeling more isolated as nurses and doctors practice medicine in their own way- according to what each feel is best. The communication that takes place between a nurse and patient is complex and unique and very different compared to how the doctor and patient interact. Some nurses vocalised this boldly in their interviews. Sister Margret when explaining this occurrence said:

"Doctors have their own way of doing things I guess- they are the bosses and us the workers. I understand they have a lot to do as there is a shortage of them and a lot to do, but if we keep using this as an excuse, doctors will never learn."

It appeared as if the medical doctors who worked with the nurses in this interview resented the fact that nurses tended to control their affairs, especially with the rise of HIV/AIDS. Patients were described as 'feeling more comfortable' with nurses. Medical doctors were ascribed as having no time to 'find out more about their patients' and were also encouraged to start changing their ways especially when dealing with HIV/ AIDS as it is a very fragile disease compared to malaria which can be treated. Such responses reiterate Florence Nightingale's view of the role of nurse in that she pushed her students to not to allow the doctor to make himself 'head the nurse!' (Florence Nightingale quoted in Chapman, 1982).

Even though the dominant pattern of answers described the relationship between doctors and nurses as having their differences, some nurses didn't feel this way. In her interview, Sister Oluoch was surprised when I asked her about her relationship with the doctors in the hospital she worked in as an ICU nurse.

"I have worked as a nurse for about 14 years. I have not had a bad experience with a doctor and I respect what they do. Some of them value us and some don't. This does not mean we just

stop what we are doing. We know about how nurses get treated before deciding to become a nurse- so we have to get on.”

Nurses who felt subordinated by doctors were more likely to carry out their tasks as dictated to them. This didn't however excuse them from practicing their profession in a way that suited them. Nurses who had 'no problems' with medical doctors and their methods of practice was also conscientious in obeying orders however contrary to what some of the literature suggests, were able to stand their ground and challenge their fellow colleagues. Sister Amanda for instance saw herself as a colleague with the right to express and share her views with the doctors she worked with. Opting to be this way was not an easy process she explained especially as fellow nurses didn't support her position.

In her response Sister Amanda said:

“I guess because they (doctors) have so many patients, they just ask about what symptoms one has been having. You know so they can quickly find out what the patient is suffering from so they can send them for a test. This one time, the doctor I work under said I should send this patient for a HIV test. I did so, but wanted to find out about the patients family. When I asked how many wives the man had, he said three. I realised this meant he was not the only one who could have been HIV positive.”

The importance of doctors treating the nurse as a compatible colleague respecting her views was implicit in Sister Amanda's interview. Medical doctors as noted by her had to meet the nurse half way and let them do their job and take into cognisance the nature of their practice. Nurses were proposed as being more likely to provide a clearer insight into the patient's condition than the medical doctors more transitory medical examination. Proof of this can be seen in Sister Amanda's example above (page 50).

Understanding the structure of the medical system in which biomedical practitioners function is crucial. This is primarily because part of the structure is partly informed by the cultural characteristics of its health practitioners. Nurses bring their own traditional understandings into the hospital, showing that structures for nurses hold symbolic value. The presence in the nursing profession of an increasing number of males and the voice given to nurses is changing the stature they hold in the biomedical area, an occurrence in my view which is well over due. The last three decades have seen various courses and degrees in other disciplines associated with nursing such as sociology and human biology have been integrated into the education system. Though nurse graduates of such programmes have been met with opposition from many members of the medical profession, such an innovative step has proven to be very beneficial in developing countries such as Kenya where medical doctors in the rural areas are a rare commodity (Ijumba *et al.*, 2004).

Nurses in the study shared similar opinions to the medical doctor regarding the causes of malaria and HIV/AIDS, due to their biomedical training. Having said this however they were explicit in highlighting

that some healing methods used by traditional healers in the treatment of ‘other diseases’ such as stomach piles and the common cold were regarded as beneficial treatment interventions that could be adopted by patients. In addition to this, nurses, more than the medical doctors in the study, extensively discussed their patients help seeking journeys, and took into cognisance the multiple forms of treatment used.

“Patients go here and there. Take me for instance, when I am sick in my stomach, I would rather take some natural relievers instead of taking a pill for everything. Home remedies like this work, but when you say herbs can CURE HIV (shaking head) that is not right. Doctors have no time to hear these stories- they get angry. I can accept some things about the traditional model, but some of the things make no sense, they are uncivilised ways of thinking.”

Nurses such as Sister Grace derided indigenous knowledge systems as dismissing science as a justifiable tradition of knowledge in relation to making sense of illness, health and disease (Semali *et al.*, 1999). The dismissal of scientific logic by the traditional care model, has been supported strongly because of its incapability of acknowledging and explaining the super natural component associated to illness and disease. Additionally, the presence of nature as something more than a scientifically observable construct is also a component ignored by biomedicine when analysing the cause of illness and disease.

Infectious diseases such as malaria and HIV/AIDS as can be seen from this chapter have boldly challenged the manner in which the concepts of health, illness, illness behaviour, and disease are understood not only by lay believers but by clinicians, nurses and public health researchers. The multiple roles assumed by nurses and their relationships with medical doctors and patients dually influence the ways in which they negotiate between and extrapolate meaning from both their biomedical and professional context and from their non-biomedical background. This proved their ability to mediate between both spaces, highlighting it as a crucial part of their profession. In turn these interactions affected the perception of the nurse of herself and her perception of her interaction with her patient and her fellow colleagues. Nurses occupied a unique position as health care providers, as they appeared to negotiate whilst simultaneously understanding the knowledge systems of the biomedical, traditional and popular health systems. I have therefore denoted their perceptions of malaria and HIV/AIDS as being ‘multiple’ due to the diversity enmeshed in their knowledge framework, and their openness to discussing the multitude of perceptions attached to the disease.

Moreover this chapter has posited that a nurse’s practice of medicine appreciates the socio-cultural and biological aspects of disease. It has highlighted that even though nurses may be trained and practice in structured clinical settings; their interaction with patients, unlike doctors has embedded within it, some level of agency and mediation. The practise of agency is evident, especially in terms of the patient explaining his/her symptoms to the nurse. Both patient and nurse can discuss disease from a traditional and biomedical sense and discuss the advantages and disadvantages of the particular method of healing. This quality, contributes significantly towards drawing a parallel between the biomedical and traditional analysis of disease (Lupton, 1995). Without patient communication, the patient wouldn’t receive safe and effective

care and the nurse wouldn't be able to do his or her job efficiently. Also show cased in this chapter is the notion that doctors are often hurried and unable to adequately listen to their patients concerns in their entirety. It is the job of the nurse to relay the vital information to the doctor in charge to make sure their patients are taken care of. Among the many other duties a nurse performs in the hospital, listening to what their patients have to say about how they are feeling and what they need is one of the most important aspects of being a 'good nurse.'

“Our knowledge and our beliefs”- the nursing experience before and after training

Exposed in the in-depth interviews were the extensive links between how views of malaria and HIV/AIDS changed after undergoing biomedical training, existing views of pre-conceptions of the disease and the role nurses play in this conversation. In the face of continued incidence of malaria and HIV infection in western Kenya, nurses have been noted as potential creators of a mutual space that merges existing and new knowledge and challenges nurses pre-existing understandings of disease. Denny *et al* (2009) draw on Davis’ work (1975: 116) by stating that over the course of training, students are socialised into nursing- a process “by which the student passes from identification with a ‘lay’ to a ‘professional’ culture. Assuming the role of a fully fledged nurse practitioner in this study appeared to be a layered process that enabled each professional to pass from ‘lay innocence’- when his/ her imagery of nursing was that shaped by past experiences, to ‘stable internalisation’- where the self-image of the student is that of a professional nurse.

The findings in this study emphasise that the internalisation of nursing values is not just a result of increasing knowledge but also a social and cultural process that creates an environment for prospective nurses to dually make sense of their ‘lay’ and ‘professional’ knowledge pre and post training. Biomedical training made the nurses aware of their ‘medical perceptions’ and pushed them to question their pre-held views of disease and in most cases placed them in an awkward position of ‘knowing more’ than their elders- a situation that was received with mixed views. When explaining how her ‘non-biomedical’ background influences her ‘biomedical’ context Sister Nyongesa highlighted some of the challenges she faced. ‘Culture’ according to her was an aspect of her practice she couldn’t distance herself from as it was part of who she was as a professional. In her professional space however, she found it difficult to empathise with patients showing that the clinical structure informed the types of decisions she made. She was noted as saying:

“Yes, to an extent, I am influenced by my cultural background and it is a tough thing especially after we have trained and gained experience and perspective. Sometime we don’t have time to listen anymore! It is hard to take a patient out of this context. They build walls around these explanations. You have to break those cultural beliefs.”

The prime intention of this chapter is to draw attention to the process of training, the contributions it makes towards the professionalization of nursing and how patients respond to nurses after they have been trained. Nurse’s views of the concepts of “illness” and “disease” pre and post training were documented through an integrated analysis of the biomedical (allopathic/ professional) and the psycho-socio-environmental (social) models. The disease-illness distinction is important conceptually in such a study as the biomedical approach has often been derided as outmoded and unhelpful in that it acts ‘strait-jacket’ for thinking about nursing care (Denny *et al.*, 2009). Disease, defined clinically as deviation from medical norms, is

considered to be a western biomedical category and not universal. Illness, in contrast, is the experience of impairment or distress, as culturally defined and constructed. Cause of the illness may also be located in social, personal and spiritual realms, meaning that aetiology may include sorcery, soul loss, and spirit intrusion (Kleinman, 1980; Trostle, 2005; Winkleman, 2009).

This chapter argues that even though biomedical training is an essential procedure that formalises knowledge in relation to disease perception, lay forms of knowledge are not completely disregarded once nurses have been trained. Such pre-existing knowledge which many professionals refer to as, ‘medical myths’ were in some cases (in this study) used as a point of reference for nurses when making sense of their patient’s views of malaria and HIV/AIDS. Moreover, nurses tended to understand that when patients felt ill, it wasn’t certain that the biomedical institution would be used as an initial source of help. The socio-environmental structures in which patients were born in and lived within shaped their views of malaria and HIV/AIDS. Often nurses shared similar backgrounds to their patients which called for further understanding and patience between practitioner and patient. A new developed model will be presented to explain the central role played by training in the nursing profession when creating meaning around malaria and HIV/AIDS.

The function of biomedical training in the professional development of Nurses

Nurses described biomedical training as playing a crucial role in their professional development.

“I thought otherwise before college and was shocked when I learned all this new information. When I realised that the views I had before were wrong in a way, I started to reflect back on both views to see how the two were connected. The biomedical and non-biomedical views link and should not be treated like they don’t.”

Discussing the role training played in nurses’ professional development highlights the need to understand the structure of the medical system in which nurse’s function- one that also assumes its own culture. Despite undergoing bio-clinical training it is apparent that nurses brought to their professional context their own traditional understandings to their work space showing that structures for nurses hold symbolic value. Having said this however, nurses viewed themselves as biomedical practitioners who understood their patient’s context but preferred not to encourage the use of herbal or alternative methods of seeking treatment for malaria and/or HIV/AIDS.

Melia (1987) when studying the transition from student to nurse argues that student nurses’ experiences of education and training found that a division exists between the way nursing was presented when in college and the way it was practiced in the hospital. This is often referred to as the ‘theory-practice gap’. Nursing

has always been viewed as a 'hands-on' profession, both in terms of social status and financial reward. Many arguments in sociological literature (Melia, 1987; Hancock, 1991; Cook, 1993; Castledine, 1998; Wathen *et al.*, 2009) have emphasised that nurses should not become technical substitutes of clinicians. With inclining patient numbers, a shortage of qualified nurses, under-resourced health institutions and the fact that nurses are expected to take on more and more tasks carried out by doctors have brought about various changes in the 'core' tasks nurses assume. Such a phenomenon in countries like Kenya is challenging the norms and values of the nursing profession and the role nurses play in combining traditional and professional boundaries with the aim of preserving the best interests of future nursing practice and ultimately the care of patients.

It is important to question why nurses despite the promotion of holistic care in nurse education for decades persist in attaching more importance to those characteristics of care underpinned by biomedicine than to those influenced by social, cultural, spiritual and psychological paradigms of knowledge. As much as nurses in this study saw themselves as negotiating between both the lay and professional space and at the centre of providing care to patients, all the nurses viewed themselves as medical practitioners first. Most nurses noted that they wanted to spend more time with patients, however due to their circumstances and the poor system placed them in a difficult position. Sister Joyce in her interview spoke about how training breeds a culture of 'elitism' amongst nurses especially as there is a lot of competition to get into college.

"In colleges we are taught about how to effectively communicate with patients and doctors. Yes, ok, you are meant to take into account the social, emotional and cultural factors, but these days you hardly see that. We don't practice what we are meant to but compete with each other. Nurses at different grades think they are better than others and do anything to get a promotion to director of nursing or something like that."

Nurses have a reputation of being undermined by medical doctors and specialists and have been noted as often conducting the 'dirty work'. Denny *et al.*, (2009) however speaks about vertical elitism when discussing nurses and their role post training. Nurses, who progressed within an organisation, as explained by Sister Joyce, gain more prestige and often move away from their clinical obligations and assume a more managerial role. Even though nurses were aware of their secondary position to doctors in the health care arena, the training they received enabled them to challenge medical decisions made by doctors.

Biomedical training provided nurses with the grounding to contribute to decision making. In addition to this, conserving with patients on a more personal level in a manner that made them comfortable facilitated the creation of a 'safe space' in which patients could discuss concern specific issues. Such moments in the study reiterated some of the trends highlighted by the literature on nurses and further encourage developing a pool of debates around issues of perception brokering in the health science environment (Walker, 1995; Helman, 2001; Munjanja *et al.*, 2005; Bern *et al.*, 2007). Nurses had the authority to identify and solve (or

attempt to) their patients problems and instituted a formally sanctioned decision making processes that were independent from the system they worked in. This point has been raised on page 29 and 35 when nurses spoke of encouraging patients to elaborate on their views of malaria and/ or HIV/AIDS and discuss how they wanted to be treated.

Biomedical training, according to this study, encouraged nurses to deconstruct their own beliefs of malaria and HIV/AIDS as a means of formalising their knowledge as advocated by the biomedical model. As discussed earlier, this model attributes the cause/s of diseases as having a specific aetiology (microscopic). The social model on the other hand, holds a macroscopic view of disease in that suggests that diseases are multi-causal and provides solutions that are dependent on the patient's social, environmental, geo-political and cultural context (Glibert *et al.*, 2010). The biomedical approach, according to the social approach, is disappointing in that it doesn't pay close attention to various social inequalities that may affect one's health status. Issues such as minimal/restricted access to and of basic needs, lack of education and exposure to harsh environmental conditions are considered peripheral by the biomedical approach. Such are aspects that nurses were cautioned about when in training. When talking about her perceptions of malaria pre and post training and the role her training played in her professional development, Sister Jane said:

“My training tells us that one of our key tasks is to tell patients the actual causes of malaria and HIV. It isn't about disowning your culture, but creating a new one. We have to make medical knowledge more accessible to our patients. This is why I am happy I know the patients context- if I didn't it would be hard.”

Sister Jane's father was a clinical officer, hence was exposed to the biomedical environment from a young age. She grew up in the city and had not heard her family relating the causes of malaria and/ or HIV/AIDS to malevolent or superstitious forces. She was however aware of people in the villages regarding malaria and more so HIV/AIDS occurring because the 'God's had been angered.'

“They would then slaughter a chicken of a certain colour to appease the God's. So these rituals are alive in our society. When I trained I remember most of my colleagues talking about these beliefs- they are everywhere. In my view, such views bar people from accessing proper medical help.”

Going through training enabled nurses like Sister Jane to be exposed to different views around the causalities and treatment of malaria and HIV/AIDS- even though she was already aware of the biological causes.

Training provided nurses with the platform to debate about whether traditional medicine as component of ‘culture’ had the capacity to help reduce the prevalence rates of malaria and HIV/AIDS.

“Training helps us to tackle different types of patients and hear about new cases. There are those patients who say that going to a hospital is like getting a curse- they say it is their culture. I mean you can’t say you can’t go to the hospital because it is part of your culture you know? Sometimes we use the word culture out of fear. That is not right.”

The process of discussing different methods of understanding and help seeking strategies was in itself a characteristic of cultural brokering. Though most nurses did not advocate for traditional methods of treatment, their training made them come to terms with the different circumstances their patients are faced with. This brought to mind the fact that a series of complex relations were developed between nurses, their patients and family members. Such relations still applied to the nurses’ professional and non-professional contexts and applied themselves in a range of ways according to specific circumstances in the clinical arena and were more apparent within informal decision making processes than in formal ones.

Patients and community response to training

When reminiscing about how her mother and family members received her ‘new knowledge’ of malaria, Sister Amanda said:

“I was amused when I started training as a nurse. In fact the first time I went home for the holidays from training college, after having learned about malaria, my mother said I have to take some herbs to protect me from getting the disease. Because I realised taking herbs would not protect me- I started to tell her that there are other ways patients can protect themselves from the condition. It took me a long time to convince her that her way was not the best way.”

Going through biomedical training illuminated the importance of preventive interventions (clear bushes, wear long sleeved clothing and sleeping under sprayed mosquito nets) for Sister Amanda. Her training emphasised the need for community members in Kenya to practice ‘simple’ steps to reduce malaria rates. Her mother on the other hand resorted to taking herbs. Both strategies aimed to reduce malaria. Even though Sister Amanda understood the procedure her mother engaged in when aiming to ‘protect her from contracting malaria’ she supported the knowledge she attained at college.

When further elaborating on her mother’s experience Sister Amanda noted her mother’s initial disapproval of her training and ‘new’ way of making sense of malaria- a tough territory for the nurse in training to manoeuvre. Sister Amanda attributed her training as changing her views of malaria and HIV/AIDS but at the same time didn’t make her forget the views she and her family held before she decided to train as a nurse. Even by Sister Amanda training and sharing her ‘new knowledge’ with her family and community, she realised that people still preferred to hold on to what they knew best- even though her mother’s case was different. When talking to Sister Amanda during one of her ward rounds, she alerted me with an example from her own family by describing a time when her mother got sick.

“She didn’t used to like it but of late and with time she has accepted it. There was a time she got very sick and I took her for a blood test and she saw that she had malaria so she came to believe that the cause of malaria is not just what she used to think before. But many people still believe in non-biomedical causes of malaria and HIV/ AIDS. Such views are part of the challenge- we can’t pretend they are not there.”

Further on in her interview she went on to say:

“You know, we can’t just forget what our ancestors used to think. Even though I may disagree now, I used to believe it, I still do. It is psychological, I think. I remember being beaten once when I back answered by grandmother when she refused to take anti-malarial medication. I knew I had to keep quiet but I couldn’t keep seeing her suffer anymore. People do not know why they should go to the hospital- that is the thing. I learned this in my training. I as the nurse have to let them know there is nothing to worry about.”

Responses such as the one presented above, depict the complexity and multiplicity of beliefs associated to disease in general, and not just malaria and HIV/AIDS by nurses in the study. Noted in my interviews was that nurses when exchanging views of malaria and HIV/AIDS deriving the cause of malaria practiced a constant negotiation between non-professional and professional simulations of knowledge.

“I come from the same places as some of my patients and I know why they think in the ways that they do. I have lived with my parents but I am not bound by those cultural values. You do not have to hold on to something even if it is killing you. You can relax and look at the options you have been given. That does not take you away from your cultural roots. Take what is adding value to you.”

Throughout their narratives, nurses drew extensively on the concept of culture and how they incorporated them into their understandings of their profession and subsequently views of malaria and HIV/AIDS. Furthermore, family members sent explicit messages as Sister Amanda’s grandmother did of socially acceptable ways of constructing and enacting knowledge around disease. Such messages often conflicted and reinforced the challenges present between formal and informal modes of understanding disease and overall, were drawn upon in their constructions. Like Sister Amanda’s grandmother, many rural dwellers expressed adamant disagreement with biomedical information around malaria and HIV/AIDS.

Contrary to Sister Amanda’s experience with her family, Sister Nyongesa succinctly tells different story:

“Wow, people really appreciate me. They say I am learned. Even when I go home they come to my mother’s house. They come with all sorts of questions, especially questions on family planning. I answer the questions as they come. Someone may ask me something about family planning and say that if someone is on the programme they may get cancer. There are a lot of beliefs around family planning which patients hold close to them. You can’t just tell them they are wrong!”

Going further Sister Nyongesa talked about ‘explaining the truth’ (referring to biomedical knowledge) to her patients and community members. Biomedical knowledge was understood as providing patients with sufficient explanations around the causes of malaria and HIV/AIDS and safe preventive methods that have

been tested through trials. Sister Nyongesa admitted that patients often experience dissatisfaction when they visit traditional healers in the hope of ‘curing’ HIV/AIDS however seldom confessed this to nurses. In her aim to provide ‘comprehensible’ clinical information, Sister Nyongesa aimed to translate cultural concepts into clinical language for practical application- which she noted made those in her community be less reluctant to speak to her. Translating biomedical information to patients was done via using local examples and speaking in either a local dialect or in Kiswahili- bringing to the platform nuances of negotiation and mediation. This process of exchange was described by Sister Nyongesa when she was talked about family planning as a preventive measure for HIV/AIDS.

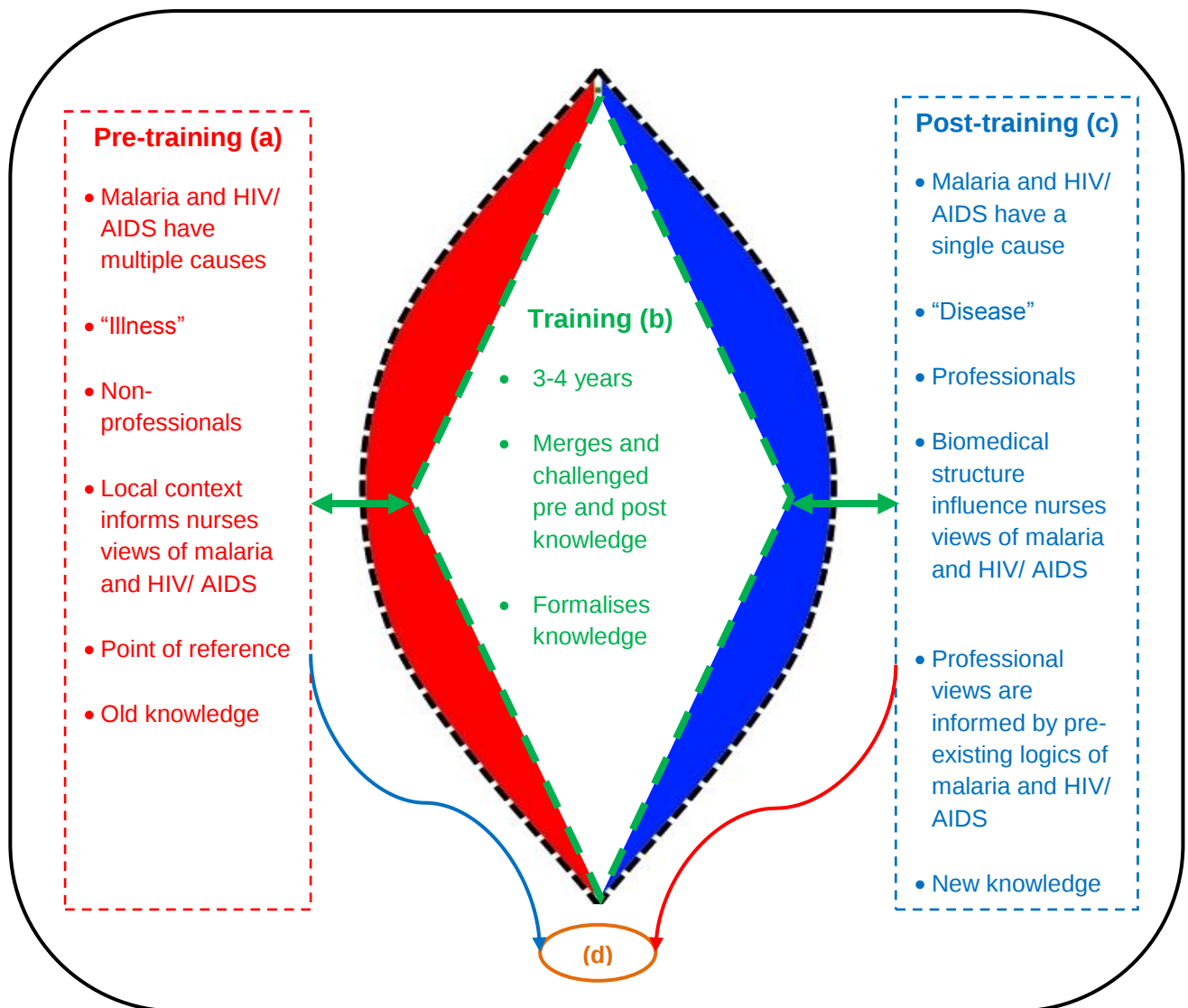
“In relation to HIV and family planning, patients may say, we understand that if we use family planning methods at one time you may even conceive by using them. I am learned so I must explain the truth in a way that makes sense to them and say that if they (females) take the pill they can’t become pregnant. There is always a small chance though. So if you are part of that 1% you can become pregnant They feel happy when you know thir mother tongue!”

Interesting to note is that even though nurses knew of their patients cultural and knowledge background, they aimed to formulate their own views of malaria and HIV/AIDS, something they learned on the job- as a means of making the information more accessible. Though some reference was made to ‘medical myths’ nurses appeared to draw some meaning from them when formulating health messages.

Also, the manner in which nurses dressed themselves stood as a key inspiration for nurses such as Sister Bernadette. The ‘white dress’ was a mark of professional credibility and symbolised the biomedical knowledge nurses acquired through their training. Surprising to hear was nurse’s talk about how various family members and friends perceived their professional attire. The white dress when work outside the biomedical environment was often seen as a marker of medicalisation and/or modernisation of healing practices. The symbolic meanings attached with white (outside the clinical space) affect perceptions of the image of nurses and reinforce their role in society (Winkleman, 2009). Sister Bernadette and Sister Amanda affirmed that even though they were proud of themselves as nurses when wearing their uniform, they realised their mode of dress depicted a ‘different type of knowledge system and social status’ something they had to be very careful of.

Biomedical training made nurses realise the need to look presentable for their patients. In order to explain the role played by training and how nurse’s perceptions of malaria and HIV/AIDS were informed by this process, please refer to the model on the next page (60).

Model depicting the ‘shift’ in nurses perceptions of malaria and HIV/ AIDS pre and post training



Nurses social and professional backgrounds which are their cultural contexts pre and post training

1. Field notes and interviews revealed that time had played an important role in further enhancing most of the nurses opinions of the traditional model. This was reflected in over ten nurses referring to childhood experiences, when explaining their illness experience. Most nurses attributed their **clinical training as responsible for altering their childhood perception of malaria and HIV/AIDS** and their prospective treatment methodologies. Malaria and HIV/ AIDS were understood to be illnesses (subjective experience) as opposed to diseases (objective experiences)
2. The model shows that training (b) merges both non-biomedical views (a) and biomedical views of malaria and HIV/AIDS (c). Their final perceptions (d) appeared as being a conglomeration of both a and b, even though they advocated for biomedical methods of prevention and treatment

3. Despite the fact that each nurse was aware of the traditional explanations related to malaria and HIV/AIDS their exposure to biomedical aspects of the diseases influenced the way in which their current perceptions were formulated
4. Nurses constantly negotiated between a and b, a complex process- in the hope of distributing clinical information that patients could make sense of
5. Though biomedical training 'changed' nurses views they were unable to distance themselves from the belief structure they grew up in when younger. When not in the clinic practicing nurses, they too assumed the role of community member/ patient. Such was a space that consistently pushed them to traverse between creating meanings around both diseases
6. Receiving biomedical training allowed nurses to reflect on and critically assess non-biomedical/ traditional views of malaria and HIV/AIDS more holistically. Perceptions before training played an instrumental role to their current space and role as health care providers
7. The training process didn't disregard nurses from completely reformulating their views of malaria and HIV/AIDS but rather enhanced their perceptions which resulted in a more holistic and socially conscious way of understanding ill health and help seeking behaviour
8. Nurses simultaneously combined their non-biomedical and biomedical knowledge when carrying out their role as biomedical experts. I have therefore denoted their perceptions of malaria and HIV/AIDS as being '**multiple**' due to the diversity enmeshed in their knowledge framework, and their openness to discussing the multitude of perceptions attached to both diseases
9. Regardless of whether they accepted or disagreed with the alternative conceptions of malaria and HIV/AIDS, nurse subjects in this study saw the need to **understand their patient's cultural background**. All nurses saw themselves as having to be aware of their own sub-culture, as well as the values and associated behaviours of other sub-cultures, in order to be effective in holistic patient care delivery and patient advocacy
10. Nurses in this study occupied a **unique position as health care providers (d)** as they appeared to negotiate between the professional and lay space when disseminating information on malaria and HIV/AIDS to their patients. Though d has been placed directly in between a and b in the model, nurses didn't always occupy a middle position. In some instances as can be seen from the interviews, they were more rooted in a than in b and vice versa. The position of d has been placed where it is for clarity purposes. Even though nurses were professionally trained biomedical practitioners, their responses made it evident that their familial and village hierarchy still influenced how they interacted with their patients

Perceptions of malaria and HIV/AIDS before undergoing structured biomedical/ professional training were formulated according to popular and folk explanations, though some nurse's social and cultural contexts were aware of the biomedical explanations of both diseases. Undergoing biomedical/ professional training somewhat altered nurse's perceptions of malaria and HIV/AIDS in that various myths surrounding both diseases and their causalities were no longer interpreted as the key explanation of the diseases cause. Though perceptions of both diseases had been modified, non-biomedical causes of malaria and HIV/AIDS were not dismissed as invalid.

Nurses acknowledged their historical and cultural context when making sense of their patient's perceptions of malaria and HIV/AIDS and when disseminating information on the prevention and treatment of both diseases. Biomedical training expanded nurse's perspectives of malaria and HIV/AIDS and was a space that challenged their pre-existing logics of disease. The fact that some nurses commented on either using or growing up with family members who frequently resorted to traditional methods of treatment when feeling ill, made me realise the extensive knowledge they had of the traditional/non-biomedical framework. Even though nurses showed awareness of non-biomedical perceptions of malaria and HIV/AIDS, they didn't regard themselves as advocates for traditional medicine especially with regards to the diseases' treatment. Biomedical training as nurses described it 'changed' their views of thinking about diseases and their treatment however didn't excuse them from taking into cognisance the non-biomedical aspects as their patients, family and community members (mainly from the rural areas) still attached truth to these explanations.

Key to understand as has been highlighted in this chapter is that:

- Experiences before, during and after training were not isolated but worked in relation to each other
- Training enhanced perceptions of malaria and HIV/AIDS, which made their overall views of the disease more **holistic** and **socially conscious** way of understanding ill health and help seeking behaviour
- Biomedical training brought together pre-existing and new forms of knowledge, challenged nurses perspectives of malaria and HIV/AIDS and created new pathways for creating more nuanced ways of understanding both diseases and distributing health information
- Though professionally trained responses showed that **familial** and **village hierarchy** strongly influenced how nurses interacted with and were received by patients and community members
- Undergoing biomedical training pushed nurses to increase their role as health care practitioners and negotiate between both spaces by carrying out what I like to refer to as invisible labour by engaging in processes such as '**cultural brokering**' and '**cultural mediation**'. Training emphasised important aspects of the nursing profession such as speaking in a local dialect/ Kiswahili, taking down detailed notes, administering effective follow up programmes and making the hospital/ clinic environment as comfortable as possible for patients

Despite the fact that nurses were trained to assume a particular role within the health care arena through their training, this process didn't necessarily mean nurses practiced what they were taught. Due to certain constraints such as under-resourcing, clinical imperialism and lack of social and government support as indicated in some of the responses, nurses 'stepped down' and fulfilled the bare minimum- which resulted in the malfunctioning of the public health system at large.

How ‘cultural brokering’ and ‘cultural mediation’ instigate nurses to be ‘intermediaries’

“Sometimes I am here and sometimes I am there. The doctor makes sense sometimes and the patient at other times. This puts me in a tough situation as I have a relation with both.”

(Sister Pauline)

There is a need for health professionals to effectively deal with cultural differences relating to awareness, sensitivity and competence. Nurses in this study tended to express qualities of *cultural awareness* and *cultural sensitivity*; a process that goes beyond awareness to provide an appropriate response to cultural differences (Winkleman, 2009). The interviews and participant observation eluded that nurses were *culturally competent* in that they had fine tuned various methods of their profession to effectively deal with differences of perceptions of malaria and HIV/AIDS effectively. Methods included reflecting on their views on both diseases before and after training, consulting with doctors about particular cases and pushing for a triadic dialogue between doctors, themselves and patients, encouraging community members to aid in the treatment process of both diseases and speaking to patients in either Kiswahili and/ or a local dialect to make them more comfortable in the clinical context.

The ways in which nurses responded to different perceptions and methods of treatment around malaria and HIV/AIDS has been conceptualised as the ability to respond to patients care needs in a way that was congruent with the patient’s cultural expectations. Though noted as difficult to practice and administer in the rural areas by nurses in the study, biomedical training as they noted, and sufficient experience in the clinical context pushed for the transfer ‘cultural knowledge’ and skills to others such as dispensary staff and primary health care workers with the aim of disseminating comprehensible clinical information. Cultural mediation and cultural brokering in this study also refers to nurses personal, interpersonal and organisational skills, including behaviours, attitudes and policies that enable people to work effectively with various cultural groupings they serve. Nurses themselves came from different geographical and cultural contexts in Kenya including western and Nyanza Province, the central highlands, the north-west and coast. Training in itself was culturally specific in relation to malaria and HIV/AIDS as different groups attached different meanings to both diseases.

This chapter discusses how nurses described themselves as ‘cultural brokers’ and ‘cultural mediators’. This was gauged by assessing key processes they engaged in when creating meaning around malaria and HIV/AIDS. Both ‘cultural brokering’ and ‘cultural mediation’ are two processes this study has attributed as pushing nurses to fulfil their role as ‘intermediaries’. The ability to deal with cultural issues in the clinical context involves a series of negotiations between health professional and patient. The biomedical approach and interactional style has a history of being authoritarian, dictatorial and largely unskilled in counselling and communication methods and is intended to control the interaction with patient (Cohen, 1999). Nursing

however, though situated within the biomedical framework has the ability to create ways in which biomedicine can be complimented with a more holistic personality. The formation of professional attitudes necessary for cross-cultural clinical relations, the acknowledgement of the effects of culture on one's self and clinical practice and gaining knowledge of how to adapt to these influences all have to be considered when aiming to understand how cultural brokering and cultural mediation takes place (Winkleman, 2009). Through speaking a similar language, spending quality time with patients, assuming the role of patient in some cases and consistently negotiating with medical doctors and family members, nurses in this study were able to respond to feelings of discrimination that client may harbour, clinical imperialism and enabling the negotiation of an acceptable treatment plan that includes both clients and providers perspectives. 'Translations' in the form of the above methods were the most apparent qualities of cultural brokering used by nurses in the study.

The interviews described the nursing profession as providing a therapeutic service to patients. Nurses practiced their interviewing skills with patients, managed relations between physicians and patients and helped patients and their families cope with the effects of disease as well as other problems that affect social life. Being an 'intermediary' involved nurses being concerned with patients views of their conditions and their social and personal needs. Observing nurses work in the university clinic enabled me to see how they interacted with their colleagues and patients. Most of the nurses used both disease and illness models and mediated between client perceptions and biomedical orientations in creating a 'safe and comfortable' space for patients.

As the literature suggests (Wenger, 1995; Walker, 2008) a cultural broker has the potential to negotiate meaning between themselves, the patient and others he/she encounters during the course of making sense of an illness, characteristics that were evident in my interviews and observations. The process of culture brokering in this study served as the bridge between the patient's personal experience of illness and the broader environmental, community, political and economic constraints. Nurses therefore, didn't just provide medical help, but offered moral and psychological support to patients. When discussing whether the nurse takes into account her patients (non-biomedical views) and her knowledge of malaria and HIV/AIDS Sister Amanda articulated that:

"You can place the nurse somewhere between the patient and the doctor. The nurse is with the patient 24 hours and the doctor only sees the patient for about 10 minutes. Nurses monitor everything about the patient. We just don't monitor, we do everything. Sometimes we even have to change the doctor's opinion. When a patient has been in the hospital for long- you know them and must intervene."

The above response by Sister Amanda proved that some level of mediation between the doctor, patient and nurse took place. When assessing how (and if) nurses negotiate between the biomedical and lay space to

affirm whether they are in fact ‘intermediaries’, linkages were made towards their relationships with medical doctors and their role as health care professionals who are challenged to create their own identities.

This study found that nurses through creating a functional space between the medical doctor and patient, developed unique ways of understanding malaria and HIV/AIDS- an identity that incorporated their professional and non-professional environments. This did not mean that nurses didn’t advocate for biomedical methods of treatment, rather pointed to the fact that nurses challenged the biomedical system and its practitioners, namely medical doctors, for the ways in which it/ they explained causes and treatment strategies to patients. As clearly evident in sister’s Pauline statement that:

“Doctors just say malaria is caused by the female Anopheles and AIDS by HIV. You think a patient understands this? No they don’t. A mosquito is a mosquito to the man on the street. If doctors don’t have time, neither do we, but we still try make them understand otherwise people will just suffer.”

This finding reflects on the critique found in the literature of the bio-medical model as being reductionist in nature and too removed from people’s lives and realities.

When trying to analyse how Sister Pauline enacted some of the characteristics of a cultural broker I found myself referring back to the ongoing battle between doctors and nurses and the roles both undertake within the health care context. Such was a relation that involved a lot of negotiation which often sidelined the multiple roles nurses carried out. This relation shared between nurses and doctors has been discussed in detail in the section above: ‘The world of nurses’ (page 40) and sheds further insights into their role in the context of this study.

Traditional aspects of nursing culture in the aim of providing direct care to patients served as the basis for extending the role of the nurse within the biomedical space. Part of what nurses do according to sister Pauline is to interpret health information that is not known to patients and make it easy for them to understand. In order to do this, nurses have to be aware of both contexts. In her analysis, it was crucial for health care providers to determine how clients, their families and communities perceive malaria and HIV/AIDS. In some instances, she found that patients knew the causes of both disease and the biomedical methods of treatment- however still opted not to use it as an initial source of help. Gaining perspective was important as it provided the basis for negotiating an appropriate treatment plan that incorporates their concerns and values. Active listening was therefore a key tool nurses in this study tried to implement when interacting with patients, especially those from different cultural groupings.

Sister Pauline followed her comment by discussing the relevance of speaking in the same language as her patients as a means of making sure she understood their perceptions of malaria and HIV/AIDS and then

compared them to hers. When trying to explain the methods she undertook when communicating with her patients she pronounced the importance of conversing with patients in a language they understood.

“I talk to patients in a language they understand because there may be some misunderstanding of some words. I may speak in Kiswahili or English and the patient may not understand what I am saying. You should always ask the patient which language they are comfortable in talking to you with.”

Intriguing was Sister Pauline’s further comment:

“If need be, you must ask someone else to come and help translate. It is difficult and challenging. In such a situation, you have to make patients understand that it is important for someone who understands their language to be present in translating the knowledge and information we have as this will help patients more and help them open up to you more.”

Sister Pauline’s interview made me realise that it was misleading to think of ‘cultural brokering’ and ‘cultural mediation’ as processes that were confined to the clinical space or intrinsic to the nurse. Nurses such as Sister Pauline encouraged community and family members to aid in helping patients understand their condition and often took such subjects in confidence. Replies such as Sister Pauline’s emphasise the need for countries with high malaria and HIV/AIDS rates to further involve nurses into their primary health care programmes as a means of overcoming cultural barriers to adaptation of modern health practices to local conditions.

Though nurses didn’t necessarily use the terms ‘cultural broker’ and/ or ‘cultural mediator’ when discussing how they viewed themselves as health care workers, they lay key hints in their explanations. These were often hidden and impacted on the ways in which nurses understood their role and positionality. Even though nurses appeared to carry out more of a brokering role when analysing malaria and HIV/AIDS, other staff members, other patients, family and community members (inside and outside the clinical context) also to some extent, played the role of ‘cultural broker’. This further extended the nurses role outside the health context as it established somewhat of a ‘network of cultural brokering.’

“I come from Nairobi. I am working in Kisumu because my husband got a job here. I didn’t grow up with Luo people. So when I first heard of Chira I had no idea what patients were referring to. Then the cleaner one day told me, people usually say they have Chira as a means of saying they think they have HIV/AIDS.”

Sister Jane continued to say:

“Because I never had to deal with those issues of superstition which I now realise disease such as HIV/ AIDS cannot be freed from, I realised that witchcraft was linked to causing HIV/ AIDS. I had to put myself in my patient’s shoes. The cleaner told me that people who say they have HIV (Chira) are sick on and off and by the time they come to you they have probably seen the witch doctor and undergone a range of rituals.”

Despite being aware of her personal and professional context, Sister Jane had to be guided by another source (in this case the cleaner) before fully understanding how to make sense of HIV/AIDS in western

Kenya. Though she knew part of her role was to create ‘new’ ways for patients to identify with biomedical notions of HIV/AIDS by hearing her patients views, she was unaware of what her patients meant when describing their HIV like symptoms as *Chira*. The cleaner in this particular case acted as the ‘go-between’ the patient and the nurse. For the medical doctor, making a patient understand the biological causes of malaria and HIV/AIDS is a method of cultural brokering as he/ she is translating information to the patient. For the nurse, cultural brokering is creating an explanation that extends the doctor’s. This was done by assimilating both the biomedical and non-biomedical explanation, speaking the same language and making sure the patient has someone to relate to within their community. The process meant different things to each health care practitioner and was essential to health care providers as each formulated a particular view that was specific of their context of practice. Additionally, each practitioner occupied a position in which they could help their patients in a way that made sense to them, exemplifying their role as negotiators of disease.

Hospitals were derided as not usually funding translators and often relied on bilingual employees such as cleaners, ambulance drivers and nurses. Serious challenges were described by nurses for patients who could not speak the same language as their clinician and/ or nurse. Challenges didn’t just include mis-diagnosis but an uncomfortable relationship between the health care provider and client- an experience that often discouraged patients from returning to medical institutions. Patients were regarded as ‘getting confused’ by providers’ professional terms which allow them to communicate within their profession but not with their clients. The biomedical focus on information relevant for diagnoses, a ‘doctor-centred’ rather than a ‘patient-centred’ approach, contributes to patients dissatisfaction. It appeared as if nurses were responsible for ‘instigating’ dialogue between doctors, patients, family and community members and cleaning staff and enabled them to straddle between the clinical and non-clinical setting.

Sister Kuria in her interview said:

“Although some patients from the rural areas say they must come to the hospital they will still seek treatment elsewhere especially if they don’t like what you have told them- they still believe in what the herbalist has to say. Occasionally, they just come to the hospital to please you. It is hard to change what you believe.”

She later went on to say:

“As trained health scientists we have to do our part and make patients want to come to the hospital for help when sick with malaria and/ or HIV/AIDS. We don’t want them to be scared or fear coming here because they don’t understand us. We all say we will try make them comfortable by doing a, b and c but when there are so many of them it gets tough.”

Malaria, throughout the interviews was described as a ‘minor malady’ and proved to be a disease nurses found quite hard to advise patients about. The term ‘malaria’ seemed to be inscribed in the social fabric of western Kenya and was not viewed as a threat for most patients. Trying to explain the severity of malaria

was a complex process that entailed a lot of dialogue between the nurse and patient. Even patients who knew the biomedical causes and the possible treatment options opted to ‘self treat’ highlighted Sister Kuria:

“What do you do when a patient knows the biomedical explanation and treatment choices but decide to do their own thing? We have to involve family members and follow up with such patients. In such cases I do not involve the doctors or threaten patients like some nurses do. I prefer to involve family members.”

Medical concepts as explained by Sister Kuria had to be made intelligible for patients. Some patients were also described as not having the language to express their experiences within the medical purview- which nurses stated should push health care providers to acquire patient’s health models and vocabularies to communicate effectively. Nurses encouraging familial and community interventions were forms of negotiation and mediation. Nurses realised that when wanting to effectively treat patients suffering from any disease, not just malaria and HIV/AIDS, they had to do ‘things a bit differently.’ By this they meant keeping cognisance of the social, interpersonal and situational factors of their colleagues and patients. In order to be ‘intermediaries’ they had to be informed about what ‘both sides of the coin’ look like.

“I used to work in west Pokot and didn’t know the language at all. This created a barrier between me and my patients. Sometimes I didn’t know what was wrong with them as they don’t really express themselves when they are sick. They didn’t feel comfortable. They also didn’t like me discussing their illness with other nurses, so I had to learn the local dialect which was hard. You don’t get taught about these things when you are school- things like importance of language and learning about culture and all those things.”

Sister Alice’s case emphasises the importance of language and the role it plays when assessing conditions and caring for patients.

“I realise that learning a language that is not mine, brings about a lot of good things. I learn more about cultures. There is nothing wrong in having your beliefs rooted in culture, as long as they are not retrogressive and damaging to your health. The Pokot are very nice people. When I was in Pokot I used to speak in Pokot and can still speak the language.”

Although Sister Alice understood the significant role played by language when transmuting information around malaria and HIV/ AIDS she preferred not to use it as a mechanism to create a ‘comfortable environment’ for her patients all the time. When practicing as a nurse in her home environment she opted to speak in Kiswahili and not in her local dialect.

“Now in my own district I prefer not to use my own language as the patients tend to prefer me to the other nurses. This is not good as they (nurses) can feel demoralised as I look like I know everything. But sometimes I talk to them if the case is special. I prefer if they speak to me in Kiswahili, so they know how to express themselves when I am not on duty. By speaking in Kiswahili, you are also empowering them and teaching them another life skill. It also gives them a sense of pride. They learn how to express themselves.”

Evident in Sister Alice’s statement is the indirect competition between nurses and how she maintained her rapport amongst her colleagues. Not all her work mates spoke her local dialect (Nandi) and so to maintain a

line of stability in the work space, she found it advantageous and fair to speak in Kiswahili- a language everyone (including the patients) understood. Making such decisions also requires some level of personal negotiation and mediation.

How nurses viewed themselves as health care providers who were aware of their own as well as their patients cultural frameworks tied in with some of the jobs they carried out. Asserted earlier in the section ‘The world of a nurse’ was the notion that nurses assume multiple roles within the clinical context. This finding fits in with how nurses described some of their tasks that are not officially part of their job description (often referred to as ‘invisible labour’).

“I see myself as a cultural negotiator. I do a lot! If the cleaner doesn’t come, we have to clean- we have to make our patients feel at home. We work with everyone. My role is to effectively communicate with doctors and patients. Patients have to be given messages they understand. Patients have to trust you.”

Sister Pauline’s denotation of herself as a ‘cultural negotiator’ alluded to the fact that she moved between the clinical and non clinical space. She like all the nurses in the study didn’t use the exact words of ‘cultural broker’ and/ or ‘cultural mediator’ however references such as ‘negotiator’ linked to both definitions as posed by the literature; emphasising the multi-dimensional personality and skill of the nurse.

These aspects were outlined when I spent some time with Sister Kivu in the lab when she stated:

“I can’t bar a patient from drawing on their cultural explanations, but I can try and make them understand the biomedical explanation and may be talk them out of it so that you see the sense without devaluing your culture. One should be able to synthesise and filter what makes the most sense. Leave what doesn’t make sense and pick up what does.”

Sister Kivu saw herself as ‘moving all over the place’ when trying to help some patients. When speaking of her during her tea break she recalled:

“The doctor may come and want to prescribe a drug that you know the patient doesn’t need. Some doctors take it well and some don’t. In fact, those who deny your intervention often come back later and say we are right. I have to translate knowledge from the doctor and myself and then to the patient, so I can help them understand themselves better.”

By aiming to understand how nurses like Sister Kuria conversed with patients, how conversations occurred and what was discussed within them made alluded to the structured and interactional nature of conveying disease information. This refers to the interplay between who the nurse is as a social being and how they apply this characteristic to their professional environment. Furthermore, their personal context informed their approach with a broad understanding of religious or social norms, values, beliefs and attitudes. This enhanced their conversations and relationships with patients and medical doctors. On the surface it looked as if the nurses were the prime practitioners of cultural brokering and cultural mediation. This subsequently

derided them as ‘intermediaries’ due to their constant negotiation between the biomedical and traditional perceptions of malaria and HIV/AIDS.

As a more integrated study of the data was conducted however, it was made evident that aspects of the concept at a broad level, expressed themselves in different ways throughout the study. For instance, how patients acquired the agency to follow or reject treatment and where to seek it from, was a method of cultural brokering and mediation. Investigating how cultural brokering and cultural mediation presented themselves in this study showed that symptoms, signs, classification of illness and beliefs within communities about illness transmission and treatment differ from biomedical models. This finding affirmed the broader trends in the literature (Fitzpatrick, 1968; Aggleton, 1990; Gilbert *et al.*, 2010). The finding also asserted that communication between specialists and local people is often fraught with misinterpretations. Determining the manner in which malaria and HIV/AIDS were understood in the Luo linguistic world and the perceptions of the word reflected the broad cultural, lexical range attached to both diseases. In my view, this calls for an interesting way to further research concerning the traditional conceptions of malaria and HIV/AIDS. Such a study would bring to the surface more examples of the ways in which cultural brokering and cultural mediation as expresses itself amongst community members and health care practitioners- as sedimented in the semantic range of key lexical terms related to malaria and HIV/AIDS.

This chapter has tried to explain the mechanisms nurses adopted when interacting with patients suffering from malaria and/ or HIV/AIDS in order to explain whether or not some element of cultural brokering and mediation is in fact practiced. Negotiating between both the biomedical and non-biomedical space was not an easy process. Nurses were often helped in their ‘mediation’ process by other members of staff namely cleaners, who often shared a close proximity to them and patients. It seemed as if due to their ‘middle’ position between the biomedical and traditional health care models that nurses had to engage in a more consistent method of negotiation as opposed to medical doctors who were rigidly adherent to the biomedical perspective.

The fact that nurses said they “tried to put themselves in their patient’s shoes” highlighted they were able to assess their patients’ methods of understanding and compare these to their own professional views. Phrases such as ‘negotiator’, ‘in-between’ and ‘try making them understand’ all allude to the fact that some level of movement and translation between nurses, their patients and colleagues. The purpose of this study was to explore how cultural brokering and cultural mediation manifest themselves amongst nurses dealing with malaria and HIV/AIDS. Both processes seemed to express themselves in instances that were not expected- including between nurses and non-biomedical staff and between patients themselves as a result of interventions from nurses. There was a difficulty associated with evaluating the effectiveness of cultural brokering as the process was often spontaneous in nature and incorporated different sets of knowledge and skill. These were demanding and hard to view comprehensively. Nurses were often unaware of the

procedures they involved themselves in as these had 'become part of their job description' though were not officially pronounced.

As Wathen *et al* (2008) and Denny *et al* (2009) suggest all approaches linked to formalising nurses as 'intermediaries' have the potential of assisting health services to achieve a better understanding of the needs of populations in developing and developed parts of the world. The primary objective of understanding what happens in the space nurses have created is not only to resolve conflict between health care providers but also help to prevent conflict. As can be seen in this chapter, nurses can assist when conflict arises through speaking the same language/ or not, challenging the medical doctor and involving family and community members to assist in finding ways to obtain positive outcomes when understanding and treating malaria and HIV/AIDS. This aspect of the concept is crucial for studies conducted on malaria and HIV/AIDS as both diseases are viewed very differently by biomedical and traditional health practitioners and as has been explored in this study.

GENERAL DISCUSSION AND CONCLUSIONS

Kenya's minister of public health and sanitation Beth Mugo (MOH, 2008) stated that "health systems strengthening the development of effective medicines, human resources capacity building and more will be necessary to achieve reducing malaria and HIV/AIDS." Though certain in her statement, Kenya in the last 30 years has been unable to fully cope with the complexities attached to malaria and HIV/AIDS. The powerful presences of both epidemics and the limited attention paid to the enhancement of nursing care in the country have affected the methods in which information on both diseases is conveyed to patients. Answers to the initial research questions posed in the study were obtained by providing nurses with the adequate space to openly discuss their views before and after becoming biomedical professionals. Furthermore, their responses were testament to the complexity of this issue and also confirmed that malaria and HIV/AIDS cannot be understood purely from a biological perspective alone. Both diseases are influenced by an individual's socio-cultural, historical and geographic context- affirming that "illness and disease" are multifaceted phenomena (Burry, 2000; Blaxter, 2004; Gilbert *et al.*, 2010).

This research project aimed to explore how nurses negotiate meanings around malaria and HIV/AIDS, how and whether they moved between their professional and non-professional context when making sense of both diseases, the types of knowledge they use as practicing biomedical experts and the ways in which they translate comprehensible information to patients. As portrayed in the analysis and findings, nurses assumed multiple personalities in the clinical context be it from negotiating between biomedical and non-biomedical causalities of malaria and HIV/AIDS, calling upon non-clinical staff for help and conversing in different languages with patients to make them more comfortable. Such aspects of their profession decoded them as knowledge and cultural brokers within the clinical context. Due to time limitations this study was unable to look at the roles nurses play outside the biomedical context so as to get a sense of whether their 'brokering' (in relation to malaria and HIV/AIDS) characteristic extends itself beyond their professional space. In addition, how nurses are received by family and community members when not wearing their white dress/nursing uniform- though still conveyors of disease information, can also serve as an area of future interest for this research as a means of assessing how space and professional attire stand either as markers of professional credibility and/or medicalization and/ or modernisation.

Conducting semi-structured in-depth interviews and participant observation exposed the situated ways in which malaria and HIV/AIDS were embedded and subsequently explained in a certain locality by nurses. Both research tools proved to be effective in achieving the study's main objective, which was to understand how nurses process and create meaning when dealing with malaria and HIV/AIDS- two diseases they interacted with on a daily basis. In spite of the small sample size (twenty nurses) which could be viewed as

a key limitation of the study, detailed information obtained through the interviews helped in gaining an understanding on how nurses carried out their role and the processes they undertook when mediating between both worlds. Mediation within the hospital space didn't only occur between nurses and patients but amongst nurses and medical doctors, cleaning staff, family and community members as well as amongst nurses themselves. This depicted that in being 'intermediaries' nurses occupied a strong position in the clinical context, despite not being fully appreciated. Their sphere of influence was felt everywhere due to their extensive network within their area of work- an aspect of their role that expanded outside the hospital/clinic when they involved family and community members in diagnostic and treatment procedures.

The qualitative methodology used in this research was able to capture the everyday experiences nurses underwent in their professional environment by taking into account the different characteristics of the nursing profession and make sense of their professional, socio-historical and cultural contexts. Adding to the complexity of malaria and HIV/AIDS was the fact that each is expressed in different languages, images and metaphors that are 'experience near' and that enable everyday experiences of populations to be acknowledged (Ulin *et al.*, 2005). Gaining 'experience near' views was achieved by giving nurses the platform to personally express their opinions of malaria and HIV/AIDS, document how their views of the diseases have changed/not after undergoing biomedical training, learn about their relationships with medical doctors and patients and the actions undertaken when they dealt with conflicting views of the biomedical and non-biomedical space.

Despite working in a structured clinical environment, nurses- when discussing the causalities of malaria and HIV/AIDS with patients and doctors constantly drew on biomedical and lay knowledge. Nurses' responses made it clear that they understood "disease" as a product of a specific aetiology, however also married the feelings experienced by patients when ill against a broader social, cultural, psychological and historical framework. Malaria and HIV/AIDS according to patients noted nurses had two distinct aetiologies which existed in tandem with each other. This pushed nurses to extrapolate meanings from both views and create their own 'unique knowledge pool' as a means of ensuring effective ways in which disease information was conveyed to patients.

The biomedical approach explained nurses, attributed malaria to a mosquito born parasite (*Plasmodium*) and HIV as the virus that causes AIDS. *Juok*- a Luo expression for evil eye was decoded as the prime cause of malaria amongst locals and symbolised malevolent intentions of individuals. *Chira* a common concept used to describe a curse which befalls on people opposing society's pre-conditioned customs was described as the non-biomedical cause of HIV/AIDS. Even though many locals in western Kenya according to nurses were aware of the biomedical construct between the female *Anopheles* mosquito and malaria and HIV and AIDS, they preferred to hold on to their own knowledge. This allowed them to negotiate between the biomedical and non-biomedical health care models when seeking treatment and reiterated that local

populaces or lay people develop their own conceptions of disease and its aetiology, all which are informed by their cultural contexts (Helman, 2001; Chatora, 2003).

The study exposed that nurses did not necessarily occupy a firm position in either the biomedical or non-biomedical space as they appeared to constantly engage in some form of mediation process with themselves, medical doctors and patients. Additionally, the findings illuminated that the personality of the nurse, her method of diagnosis, professional experience and cultural background allowed her to interact with patients and medical doctors and exchange and question views on both diseases at varying levels. Fascinating to hear were nurses descriptions on malaria being used as a disguise for HIV/AIDS. This was generally because malaria in western Kenya was considered a minor malady and not stigmatised to the same level as HIV/AIDS. Nurses preferred patients to seek biomedical treatment for both diseases immediately. Treatment options for malaria and HIV/AIDS were assessed as being available to all seekers although in practice were not necessarily asserted as being utilised. This was due to several reasons such as a) combined treatment options b) use of biomedicine as the ultimate source of help c) the cost of accessing particular health care facilities and d) the deep seated belief in traditional and/ or local interventions.

Nurses often referred to their background as a means of expressing their perceptions, experiences and approaches related to malaria and HIV/AIDS and how these had changed after receiving biomedical training. The multiple piecing together of knowledge from the biomedical and non-biomedical context made implicit their role as 'intermediaries' in the study. The findings in this study are an example of how an understanding of multiple interpretations of disease can serve to better adapt health messages to the local context and indicates the importance of health workers' knowledge- in this case nurses, to be taken into account as they represent local realities.

Understanding how nurses made sense of malaria and HIV/AIDS through documenting their relationships with colleagues, medical doctors, patients and family alluded to how further research on how nurses can be used to develop culturally sensitive ways in which meanings related to disease can be attained and integrated into every day clinical encounters.

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APPENDICES

1. Map of Kenya- obtained from Google Maps (2010)



2. Interview schedule

Theme 1- Choice of profession

- 1) Tell me a bit about your career as a nurse, what inspired you?
- 2) Where did you train? What do you find attractive about the profession? Being a nurse can be quite challenging, how do you cope with multiple demands in your place of work?
- 3) What do you see as the most important aspect of your role as a nurse?

Theme 2- Malaria as the disease of focus for this study

- 4) Please may you comment on the types of diseases that patients in this part of Kenya suffer from the most?
- 5) I am really interested in malaria and HIV/ AIDS as a diseases and in particular the role you play in the management of malaria and HIV/ AIDS. Please may you explain to me:
 - a) What you think is/are the causes of malaria and HIV/ AIDS?
 - b) How you diagnose malaria and HIV/ AIDS?
 - c) How do patients explain their symptoms to you?
- 6) Can you remember what your family believed about the causes and treatment of malaria and HIV/ AIDS when you were growing up?
 - a) What do you think of these views today?
 - b) Did you agree with them then/ now?
 - c) Did everyone in your family and/ or community agree with these views then/ now?
- 7) If possible, please may you elaborate on how your perceptions on malaria and HIV/ AIDS changed when you were:
 - a) Training as a nurse
 - b) Practising as a nurse
 - c) What else do you think influenced these changes? Please may you explain these reasons to me?
- 8) **In the case of non-biomedical explanations of malaria being discussed (me)**
 - a) Why do you think patients hold such views?
 - b) How do they explain them to you?
 - c) What is usually your reaction/ response?

Theme 3- Malaria in comparison to HIV/ AIDS

- 9) What (if anything) is different about views linked to malaria compared to HIV/ AIDS?
 - a) In what ways do patients describe their feelings of ill health to you?
 - For example are there any words patients use when talking about 'malaria' or 'HIV/ AIDS'?
 - Do patients often feel comfortable speaking to you in the native and/or traditional language?
 - What language do patients use when they talk about malaria and/ or HIV/ AIDS?
 - Are there any differences? If so- why?
 - How do patients react when they are notified that they are malaria positive?
 - Is there a difference in reaction when they get told they are HIV positive?

- b) What types of treatment for malaria and HIV/ AIDS do you recommend and why?
- c) Are such treatment accepted by patients?
If so, why and if not, please explain and give examples if you are able to

Theme 4- Role as health care personnel

11) What are the main problems with patients' understandings of malaria and HIV/ AIDS?

- a) What do you think of their views?
 - b) What factors do you think influence your patients' views?
 - c) In the case of some patients not believing the cause of malaria or HIV/ AIDS to be biomedical, what do you do?
 - d) As a nurse, how do you help patients understand the bio-medical explanations of the disease?
 - e) In your view, is it important for patients who have non-biomedical beliefs about malaria and HIV/ AIDS to change their views? Why?
 - f) How do you or other health practitioner's deal with these problems?
 - g) What, according to you, is your role in treating a patient that has malaria or HIV/ AIDS?
- What factors do you keep in mind when informing a patient of their condition?
 - What is most important for you as a professional nurse in this case?

12) Do people with malaria or HIV/ AIDS come to the hospital in their initial phase of malaria?

- a) If not, why do you think this is so and what do you think of this occurrence?
- b) Do you think there are any differences between malaria and HIV/AIDS in this sense?

13) Is there an alternative place patients may opt to go to in order to seek treatment for malaria and/ or HIV/ AIDS?

- c) If treatment fails in these places, at what point might they come to this facility?
- Do you think there are differences in relation to causality between malaria and HIV/AIDS?
 - What do you think of these views?

(In the case of answers stating that patients do not use a biomedical institution as an initial source of help)

Why do you think patients do not come to this health facility first, what do you think stops them from coming?

(Remember socio-economic status, transport cost, distance to health care institution, socio-cultural background etc)

- d) Do you think individuals make a personal decision about coming to this clinic when they feel sick?
 - Who do you think makes the decision? How is this decision made?

(Probe further by asking why and ask to give examples)

- e) What forms and levels of education have most of the patients that visit this institution received?
 - Do you feel this affects their understanding of the disease?
 - Does it make a difference to your role as a nurse in the treatment process of malaria and HIV/ AIDS?
- d) Tell me about the patient-nurse relationship and explain what is happening in the process
 - Is there a specific method of approach that you use?
 - What are the principles that guide you? What is most important in this relationship?

3. Information sheet distributed to informants



Department of Sociology- University of the Witwatersrand (Wits)

Information Sheet

My name is Aalyia Sadruddin. I am a Kenyan student currently studying a Masters degree in Health Sociology at Wits University, in Johannesburg, South Africa. I am particularly interested in understanding nurse's perceptions of malaria and HIV/ AIDS in Kisumu and the ways in which they carry out their role as 'intermediaries' in helping bridge the gap between biomedical knowledge and lay conceptions of malaria and HIV/ AIDS.

This is a research study that is **strictly being carried out for academic purposes**.

It must be understood that you are under no pressure to participate in this study. If you do decide to participate in this study, I will start by asking you to introduce yourself by saying your name, your region of origin and the duration of time you have been working at this clinic.

- 1) If you feel that you are unable to participate in this study at any stage, after having agreed to do so, you are welcome to withdraw
- 2) Any information that you do not feel comfortable will not be included in the research study
- 3) If you decide to participate, I plan to interview you for about forty minutes to an hour
- 4) The interview will comprise of a series of questions of which you have no compulsion to answer
- 5) You are free to choose the time frame according to your schedule in which are to meet
- 6) Any information that you do not feel comfortable being published will not be included in the research study
- 7) Under no circumstances will your name appear in my research report. This is a strictly confidential research report. Pseudonyms will be used in order to protect each participant
- 8) Whatever information you choose to supply will be kept completely confidential

Please feel free to contact me or my supervisor if you have any further queries regarding my research.

Aalyia Sadruddin- E-Mail- aalyia.sadruddin@gmail.com Mobile Number +27 72 465 1886 (Johannesburg, South Africa)

Professor. Leah Gilbert- E-Mail- leah.gilbert@wits.ac.za Office Number +27 (0) 11 717 442

4. Copy of consent form signed by researcher and informant



Department of Sociology- University of the Witwatersrand

Consent Form

In order for me to gain a precise understanding of our conversation, I will record each interview, provided I have your individual permission. The recordings will be transcribed and sent to you in the post for your comments.

Please sign below, if you agree to participate in this study. Thank you for your participation.

Participant's Signature: _____

Interviewer's Signature: _____

Date: _____

5. Letter of consent from GLUK



GREAT LAKE UNIVERSITY OF KISUMU (GLUK)

Tropical Institute of Community Health and
Development (TICH)

AALYIA SADRUDDIN
UNIVERSITY OF THE WITWATERSRAND
JOHANNESBURG

Dear Madam,

**RE: LETTER FOR CONSENT FOR CONDUCTING RESEARCH AT GREAT
LAKES UNIVERSITY OF KISUMU.**

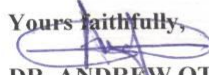
This is in reference to your letter seeking to be permitted to conduct research entitled **Understanding nurses perceptions of malaria and HIV/AIDS and the role nurses play as intermediaries in bridging the gap between professional and lay knowledge in Kisumu, Kenya.** We are happy to inform you that the university has no problems with you conducting the research but your proposal will have to be reviewed by the ethical review board of the university before you start the research.

The nurses we have in the university are student nurses and therefore it is important that your research does not have serious ethical issues and that it will not interfere with their learning process. Through this letter therefore we request you to send a copy of the proposal to the university as soon as possible so that you are not delayed in starting your study.

Great Lakes University has several research oriented programs and I think it will offer a conducive environment in which to carry out your study and I do believe that once the nurses consent to participate in your study you will get enough participants. Once you arrive in the country you will be attached to Mr. Odero of the faculty of health Sciences to assist you until you complete your research.

Do not hesitate to contact me in case of any queries.

Yours faithfully,


DR. ANDREW OTIENO
Head of Academics (TICH)

c.c. Prof. Stephen Okeyo
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