Perceptions, experiences and practices in relation to lymphatic filariasis in Kwale district, Kenya

By

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DECLARATION

This thesis is my original work; it has not been presented for a degree in any other university or institution.

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Eunice Nyumba Were **Date**

This thesis has been submitted with my approval as the University Supervisor

Dr. Salome A. Bukachi **Date**

DEDICATION

To the loving memory of my Mother Keziah, my sister Rachel and my brother Vincent for their immeasurable faith in me, to my Son Emmanuel thank you for bringing joy to my life albeit for a short while.

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Abbreviations

ADL	Adenolymphagytis
AIDS	Acquired Immune Deficiency Syndrome
ALB	Albendazole
CBS	Central Bureau of Statistics
DEC	Diethylcarbamazine
DVBD	Division of Vector Borne Diseases
FGD	Focus Group Discussions
GPELF	Global Programme to Eliminate Lymphatic Filariasis
ICT	Binax Immunochromatographic card tests
IDI	In-Depth Interview
IVR	Ivermectin
KEMRI	Kenya Medical Research Institute
LF	Lymphatic Filariasis
MDA	Mass Drug Administration
MOH	Ministry of Health
MSG	Monosodium Glutamate
NPELF	Kenya's National Programme for Elimination of Lymphatic Filariasis
SPSS	Statistical Package for Social Sciences
TDR	Programme for Research and Training in Tropical Diseases
TPE	Tropical Pulmonary Eosinophilia
WHO	World Health Organization

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Abstract

Perceptions experiences and practices in relation to lymphatic filariasis were explored in three endemic sub-locations of Vanga in Kwale District in the Kenyan Coast. Both quantitative and qualitative methods of data collection were used in this study. Two hundred and fifty four respondents were interviewed using structured questionnaires. In addition 21 Key Informants Interviews and 5 Focus Group Discussions were held. The findings revealed that people in the endemic areas knew about lymphatic filariasis and could describe the overt clinical signs of the disease and assigned them local terminologies.

The perceived causes of lymphatic filariasis in this area included mosquitoes which was the most common answer amongst respondents. Other causes mentioned included sex, witchcraft, foods like coconuts, weak immune system, dirty water, inheritance, filarial doze and fate. However, most respondents and discussants believed in the duality of causes of this disease arguing that a combination of factors led to this disease. The experiences of people suffering from this disease ranged from disbelief to resignation to their fate. Manifestations of this disease has subjected people with lymphatic filariasis to stigma both self and inflicted, teasing, unsuitability/discrimination in marriage, sexual dysfunction and abandonment sometimes leading to divorce. The practices for management of lymphatic filariasis are varied depending on the stage of the disease. The health seeking behaviour involved popular sector, folk sector and professional sector. The diagnosis of lymphatic filariasis is often delayed and in most cases depends on the overt clinical signs. The treatment can sometimes be harmful to those suffering from the disease Some treatment options used by the patients included piercing of the hydrocele sack to release fluids using bicycle wires or draining using syringes among others. Most of those suffering from lymphatic filariasis are taken care of by their families and maintain a high level of personal hygiene and also massage the affected areas. Due to corrective surgery through hydrocelectomy most of the respondents now believe that hydrocele can be cured.

In conclusion Lymphatic filariasis in Kenya has persisted due to the local perception on the causes and transmission of the disease. The manifestations of the disease and experiences of those suffering from it has perpetuated their suffering and stigmatization.

Special emphasis on the management of the disease in conjunction with better diagnosis, care and treatment methods should be adopted by the government to prevent the overt clinical signs of this disease. In order to eradicate lymphatic filariasis, understanding communities' perceptions of the causes, manifestation and treatment of the disease should be put into consideration while designing local campaigns on awareness and distribution of mass drug therapy.

Chapter One

Background to the Study

1.1 Introduction

Lymphatic filariasis is a tropical mosquito borne infectious disease that affects nearly a billion people (men, women and children of all ages) worldwide. Filariasis is a group of disorders produced by infection with thread like nematodes of super-family *Filariodae.* These worms invade the lymphatic, subcutaneous, and deep tissue of humans producing reactions ranging from acute inflammation to chronic scarring. However the development of the disease itself in humans is still something of an enigma to scientists (WHO.2000). In the initial stages, most people do not know they have the disease. They usually don't feel any symptoms until after the adult worms die. Luckily the disease is not life threatening, although it can permanently damage the lymphatic system and kidneys.

Recent significant advances in understanding of the disease and its control, combined with a realization of its profound contribution to poverty and suffering in affected endemic areas, have within recent years changed the position of lymphatic filariasis from being one of the greatly neglected diseases to one of major concern deserving concerted action. Thus, in 1997 the World Health Assembly called for a strengthening of activities towards its elimination as a public health problem. This was soon followed by initiation of the now very active Global Programme to Eliminate Lymphatic Filariasis (GPELF) (TDR, 2002).

The global strategy for control of the disease has, therefore, been redefined, and is now principally based on annual, single-dose treatment with either *Diethylcarbamazine* (DEC) or *Ivermectin* (IVR) with *Albendazole* (ALB), for all eligible members of endemic communities (Wamae *et al.,* 2006). This strategy is based on the evidence that single annual doses of antifilarial drugs (DEC with or without ALB or IVR) can suppress *Microfilaraemia* for prolonged periods, and the cumulative effect is expected to lead towards the elimination of lymphatic filariasis (Wynd *et al,* 2007). Furthermore a breakthrough has been made in the testing of lymphatic filariasis antigen using *Binax immunochromatographic* card tests (ICTs) which can be used during the day to detect microfilariae and give results in 10 minutes.

Lymphatic filariasis in Kenya has been reported since 1910 and the disease remains endemic in the six districts of coastal Kenya, namely, Kwale, Mombasa, Malindi, Kilifi, Tana River and Lamu where about 2.5 million people are at risk of infection (Wamae *et a/.,* 2006). The disease is mainly confined to the coast province of Kenya whose indigenous population is the Mijikenda, the Swahili and the Arabs. Kenya's National Programme for Elimination of Lymphatic Filariasis (NPELF) was formed to fight the spread of lymphatic filariasis using vector control, morbidity control and mass chemotherapy and also to liaise with other organizations and countries which are fighting the same disease. The study was conducted in Vanga location in Msambweni district (newly created from Kwale district).

1.2 Problem Statement

Lymphatic filariasis is a major public health problem which afflicts a considerable social and economic burden on many tropical and sub-tropical countries (Ramaiah *et a/.,* 1996). Although the disease is not fatal, the chronic symptoms usually afflict individuals at their most productive stage in life (Gyapong *et al.,* 1996). Globally, the disease has received little attention (Bandyopadhyay, 1996) although it puts at risk more than a billion people in"hiore than 80 countries (WHO 2000). It has affected over 120 million people, over 40 million of whom are seriously incapacitated and disfigured. One-third of the people infected with the disease live in India, one third are in Africa, and most of the remainder are in South Asia, the Pacific, and the Americas (WHO, 1992). In sub -Saharan Africa, it is estimated that about 512 million people are at risk of infection and about 28 million are already infected (Michael and Bundy 1997).

In Kenya the disease is endemic in Kwale, Kilifi, Lamu, Malinda and Tana River, it is also found in some pockets of Mombasa. Everyone who resides in these endemic areas has an equal chance of being infected with the lymphatic filariasis. It is a debilitating disease which is responsible for significant numbers of disfigurements in the form of elephantiasis and hydrocele. In endemic countries low priority is given to lymphatic filariasis as, it does not kill like Malaria and AIDS and other fatal diseases, though it is responsible for a lot of psychosocial suffering amongst those affected. Despite medical advances, people's awareness of the causes and transmission of lymphatic filariasis is poor and their ideas on prevention in most cases have no basis. Misconceptions about the disease are deep-rooted and based on observation (Ramaiah *et al.,* 1996) and local understandings of the disease are confined to outward gross manifestations of elephantiasis and hydrocele. This is due to lack of overt clinical signs in childhood and symptoms similar to other tropical diseases like malaria. People's understanding of the causes of the disease continues to be linked to cultural and traditional beliefs which emphasize spiritual and supernatural concepts, these perceptions affect every aspect of their health-care seeking behaviour (Gyangpong *et al.,* 1996).

Vector-borne disease control programmes mostly rely on controlling the parasite and/or vector and have often overlooked the importance of the target population's knowledge, beliefs and behaviour in the transmission and control of disease (Ruebush *et al.,* 1992). Although the disease has been eradicated in some parts of the world like Japan, it still persists in Kenya. This is because control of this disease in developing countries is often unsuccessful and unsustainable, because strategies employed are inappropriate for the endemic areas and most often do not take into account the folk perception of its causes, treatment, prevention, and control (Gyangpong *et al.,* 1996). Ignorance and incorrect beliefs can lead to negligence in control measures and in accepting inappropriate treatment (Ramaiah *etal,* 1996).

This study sought to explore perceptions, experiences and practices in relation to lymphatic filariasis in Kwale district, Kenya.

It sought to answer the following questions:

1. What are the community perceptions on the causes of lymphatic filariasis in Kwale?

2. What are the experiences of people suffering from lymphatic filariasis in Kwale?
3. What are the practices of people in Kwale district in relation to lymphatic filariasis?

1.3 Study Objectives

1.3.1 Broad Objective

The broad objective of the study was to explore the perceptions, experiences and practices of people affected with Lymphatic Filariasis in Kwale district in Kenya.

1.3.2 Specific Objectives

1. To investigate the community perception on the causes of lymphatic filariasis in Kwale district.
2. To establish the experiences of people with lymphatic filariasis in Kwale district.
3. To identify the practices of people in Kwale district in relation to lymphatic filariasis in Kwale district.

1.4 Justification of the Study

Lymphatic filariasis though not fatal, is a debilitating disease which causes tremendous suffering to its victims. Control programmes for vector-borne disease mostly rely on controlling the parasite or the vector and overlook the importance of people's perceptions, beliefs, and practices (Ruebush *et al.*, 1992). This disease has been documented in Kenya since 1910 (Wamae *et al.,* 2006) but as one of endemic countries it is a low priority disease though it is responsible for significant numbers of disability.

Lymphatic filariasis still persists in Kwale despite the efforts of National Programme for Elimination of Lymphatic Filariasis (NPELF) to control the disease, this is because of their indigenous concepts of the causation of illness which still exerts much influence on their response to available health services. It is important to study the perceptions, experiences and practices of people in this area with regards to lymphatic filariasis. This is because the causes of illnesses in Kwale ranges from natural causations for simple ailments to breach of taboos, evil spirits, magic, theft, and ancestral spirits which are disillusioned by their kinsmen for many illnesses thought to be beyond the natural realm Lymphatic filariasis in Kwale is believed to be caused by evil spirits, (Wamae *et al.,* 2006) witchcraft, sexual intercourse, breaking of taboos and consumption of burnt foods (Amayunzu, 1997). These beliefs affects how people responds to this disease either by seeing a traditional healer, performing a ritual or a ritual dance to chase away the evil spirits or appease the ancestors or just go to the hospital.

Most of the studies (Wamae *et al.,* 2006, Wijers and Kaleli 2006, Estambale,e/ *al,.* 1994, Mukoko *et al.,* 2004) that have been undertaken in this area focus on the scientific dynamics of the disease and very few studies (Amayunzu, 1997) have been undertaken on social cultural dynamics of the disease. The social context in which the disease occurs and how individual, family members and the community perceive and experience lymphatic filariasis affects their choice of treatment. It is the sufferer's interpretation of his or her own experience and the meanings and notions of causality provided by the society to explain the illness or misfortune as it might be called, that affects the action that, he or she will take in combating this disease. Also the mode of treatment or action that one takes will depend on how threatening or susceptible a person is to the disease and also the benefits, the cost, and accessibility of treatment itself. In order to tackle this problem there should be a clear understanding of the social context in which this disease is occurring, the societal notion of causality and the sufferers own experiences of the disease. This will give a better understanding into the health sector that is chosen by the person which in turn can offer insights into why the disease has persisted despite the global efforts to eradicate it.

Since this study was exploring perceptions, experiences and practices of people affected with lymphatic filariasis it answered questions related to Medical Anthropology. It included how different populations perceived a mosquito borne infectious disease in this case lymphatic filariasis. It also tackled how disease was socially constructed, and the experiences that individuals went through from the diagnosis to the manifestation of the disease. It also explained how one treated the disease in effective and culturally appropriate ways. The findings should be aimed at stimulating debate on theories related to the socio-cultural context and implications of disease and illness in a society. And also the complex relationship between health-seeking behaviours, self-care practices and the cultural context of these behaviours among people who live with chronic manifestations of lymphatic filariasis. It should also be aimed generating more literature to aid in the study of lymphatic filariasis in Kenya and Medical Anthropology in general.

This study therefore aimed at generating information on the cultural and behavioural aspects of people in Kwale that have hindered the control of the lymphatic filariasis. It also established the perceived causes of lymphatic filariasis and how the people interpreted and experienced the disease. The study also established the practices that people undertake to combat this disease and this included their health seeking behaviour and care practices. This information will be useful in unearthing some of the underlying factors that have led to the persistence of the disease and provide information for policy makers, implementers and health workers as to why their attempts to combat the disease has borne little fruit. The findings can also be used in the intervention campaigns and educational programmes that take into consideration people's culture and traditional practices. It would also benefit the academic community by providing more insights and literature into the social cultural understanding of lymphatic filariasis in Kenya.

1.5 Scope and Limitations

The study was carried out in Vanga location of Lunga Lunga division in the newly created Msambweni district. The sample included those infected with Lymphatic Filariasis, those who live with them and other members of the affected community. It also targeted stakeholders in the control and eradication of this disease; these included the health practitioners and local authority. The study concentrated on the people's knowledge of the disease, their beliefs and practices associated with it and finally how these factors interplay in their choice of treatment. Other factors such as economic impacts of the disease to the household, poverty, accessibility, and availability of the health facility which both determines and influences the choice of treatment and the health care seeking behaviour of the people were beyond the scope of this study and were therefore not tackled.

The study was limited in that its findings cannot be generalised to all endemic areas at the Kenyan coast as different programmes are being undertaken by various stakeholders to eliminate the disease. At the same time, the structured questionnaire method employed in data collection may in itself have been biased because of the family relationship that existed amongst some respondents who settled in a certain area. But this was countered by other methods of data collection such as FGDs and KIIs to elicit more responses from the discussants.

1.6 Definition of key terms

Perceptions: this is an image or feelings that people have according to the way they understand or see certain or see certain things.

Experiences: this was first-hand knowledge of situations and emotions that people suffering from lymphatic filariasis live through on a daily basis.

Practices: this includes the action that was taken by a person who was suffering from lymphatic filariasis to treat and manage his/her illness. In this case it was measured as a combination of health seeking behaviour, treatment and care practices.

Lymphatic filariasis: was defined as a mosquito borne infectious disease caused by nematode parasites *Wucheria bancrofti* living in the lymphatic system of the human body.

Supernatural forces: these are events, forces or powers that cannot be explained by the laws of science and that seem to involve god or magic.

Stigmatised: this is the token of shame or disgrace that characterises a person having lymphatic filariasis, it can either be self or inflicted.

Definition of disease: this is the way a community label, or classify a disease

Chapter Two

Literature Review

2.1 Introduction

This chapter reviews the literature that is relevant to this study; this covered Lymphatic Filariasis, its magnitude, symptoms, management, treatment, and control. It also contains people's perceptions regarding this disease and the practices that arise due to these perceptions. It also discusses the theoretical framework of this study.

2.2 Clinical Aspects of Lymphatic Filariasis

Lymphatic filariasis is a mosquito borne infectious disease caused by nematode parasites *Wucheria bancrofti, Brugia Malay*, and *Brngia timori,* living in the lymphatic system of the human body. It is a widespread and debilitating disease affecting millions of people in tropical developing countries (Simonsen *et al*., 2004). It is transmitted by ingestion of infected blood by female *Culex aedes* and *Culex anopheles* mosquitoes. The development of *microfilariae* into the infective stage inside the mosquito usually takes 7-21 days. The parasites mature within the human host between 3 to 15 months migrating into the lymph nodes where it pairs up with the adult of the opposite sex and produces *microfilariae.* As a result of this parasitic infection, the lymphatic system gets damaged and blocked preventing the proper flow of lymphatic fluids. The accumulation of lymph fluids leads to chronic manifestation of lymphatic filariasis in the extremities of the body, causing elephantiasis of the upper and lower limbs (Plate 2.1) and hydrocele which affects the genitalia of men (Plate 2.2). In the absence of re-infection humans harbour microfilariae for 5 to 10 years although some reports indicate that some worms can live up to 20 years (WHO, 1996).

Lymphatic filariasis is rarely fatal, but it can cause recurring infections, fevers, severe inflammation of the lymph system, and a lung condition called Tropical Pulmonary Eosinophilia (TPE). In its most obvious manifestation, lymphatic filariasis causes the enlargement of the entire leg or arm, the genitals, vulva and breast (WHO, 1998). In about 5% of infected persons, a condition called elephantiasis causes the legs to become grossly swollen. This can lead to severe disfigurement, decreased mobility, and long-term disability. Testicular hydrocele is a disfiguring enlargement of the scrotum (Plate 2 2) As many filariasis patients are physically incapacitated, it is also a disease that prevents patients from having a normal working life.

Plate 2.1: Elephantiasis of the Leg

Plate 2.2: Hydrocele of both scrotums

Elephantiasis puts at risk more than a billion people. In tropical and subtropical areas where lymphatic filariasis is well-established, the prevalence of infection is continuing to increase. A primary cause of this increase is the rapid and unplanned growth of cities, which creates numerous' breeding sites for the mosquitoes that transmit the disease. Lymphatic filariasis is usually acquired in childhood while its visible manifestations occur in adults leading to temporal or permanent disability. The prevalence of this disease increases with age and is usually prevalent in males than in females (Estambale *et al*, 1994). It is prevalent in remote rural areas and in disfavoured periurban and urban areas. In a sense making it a disease for the poor, since it is a physically incapacitating disease, it prevents patients from having a normal working life.

Self care activities are severely affected because patients depend on their families for self care (Krishna *et al.,* 2005). Approximately two thirds of the people in endemic areas show no overt evidence of the disease but when tested demonstrate some degree of parasites associated immunosupression and may show evidence of renal dysfunction. The development of the disease itself in humans is still something of an enigma to scientists, though the infection is generally acquired early in childhood, the disease may take years to manifest itself (WHO, 2000)

Little knowledge has been formally collected into how communities incorporate lymphatic filariasis, its origin and impact into the local knowledge (Shona *et ai,* 2007). The role of mosquitoes in transmitting the parasite agents of lymphatic filariasis is poorly appreciated by people in many endemic communities and thus there is little awareness in these areas in the importance of minimizing mosquito contact for prevention of infection (Shona *et ai,* 2007). Numerous studies have been carried out on causality and transmission of the disease. Although most people understand that mosquitoes spread malaria, few understand that mosquitoes could also spread filariasis, this is despite intensive community education campaign organized in various countries. In a study carried out in India only 9.3% of the affected and 20% of the unaffected individuals knew that filariasis is caused through mosquito bites (Ramaiah *et a/.,* 1996). In a study in Malaysia only 9 out of 108 respondents associated filariasis with mosquitoes (Haliza and Mohd, 1986).

2.2.1 Perceptions Related to Lymphatic Filariasis

In most endemic communities the causes of Lymphatic Filariasis can be categorised into two broad groups, personalistic beliefs (the belief that a disease is either caused by active aggression of some agent which might be human, non-human or supernatural forces) and naturalistic beliefs (this is where nature and its agents are believed to be the cause of the disease). Many people in endemic areas share a common belief that the disease is caused by supernatural forces. This is because illness is considered to be either of the natural or supernatural nature. In Haiti, lymphatic filariasis is considered a mystical illness caused by placement of magical powders *{pile poud)* along the foot path. If stepped on by a wrong person it causes *gwo pye* (elephantiasis) which can only be treated by voodoo healers (Addiss *et al.,* 1998). In Ghana, elephantiasis is believed to be caused by stepping on spiritual medicines thrown on the ground by juju men during war dances performed at funerals, stepping on herbs pricks of thorn on dwarf habited areas and removing of the thorn(s) by oneself could also lead to elephantiasis. Husbands are also said to use charms or smear herbs on their wives' legs while they are asleep to inflict on them elephantiasis so as to make them undesirable. On the arm, elephantiasis can be caused by picking a juju mans tail (of horses, donkeys or cows) by mistake (Gyapong *et al.*, 1996). In India it is believed that building houses near the graveyards causes the disease due to influence of the evil spirits (Ramaiah *et al.,* 1996) while in Kenya, elephantiasis is associated with evil spirits (Wamae *et al.,* 2006) and witchcraft (Amayunzu, 1997).

Naturalistic causes associated with lymphatic filariasis include sexual intercourse, burnt foods consumption as noted in Kenya (Amayunzu, 1997), poor blood circulation, carrying heavy loads, prolonged standing, bathing in or drinking swamp water, and personal contact with infected individuals (Shona *et al.,* 2007). Other causes include excessive coldness of the body, injury to the foot, water, bad blood in the body, poor nutrition, retention of bad fluids, occupation, fate /destiny, and fever. In India, people in endemic areas believe that the disease can be caused by weaving due to excessive movement of the body parts. Pond and well water have also been cited as the cause due to absence of the disease on children less than five years who have only been drinking piped water (Ramaiah *et al.,* 1996).

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In Ghana, irrigation dams in the endemic areas have also been blamed for the disease. In addition the use of *monosodium glutamate* (MSG) artificial spices in cooking is believed to contribute to hydrocele. Eating very sweet things like mangoes and sweet potatoes brings fever which also leads to *paa machale* (elephantiasis) (Gyapong *et al.,* 2006). In many endemic communities it is also believed that the prevalence of the disease on some parents and children in the family is due to heredity. This is because of the belief that when hydrocele runs in the family it must have been transferred from father to son through semen at the time of his conception. The other common belief is that accumulation of bad fluids and neglect of treatment of an injured foot often leads to elephantiasis and hydrocele. In addition the swelling of the lower limbs due to pregnancy leads to retention of bad fluids which causes elephantiasis.

In all endemic societies ethnomedical terms used to describe lymphatic filariasis depends on the size of lymphoedema or hydrocele or the severity of the pain. In South India, people with lymphoedema of the lower limbs are called *yanaikkal* (elephant's leg), hydrocele *veraveekkam or veravadam* (swelling of the scrotum) and filarial fevers are *nerikatti juram,* a classic symptom of acute *adenolymphangitis* (ADL) episodes (Ramaiah *et al.,* 1996). In Ghana, the most recognized terms are *Natintim* or *Napimpim* (large or heavy leg). Similarly elephantiasis of the arm is *Jitintim* or *Jipimpim* while acute ADL is *nasaana.* Hydrocele is *machale* or *lani* and acute ADL is *paa machale* (Gyapong *et al.,* 1996). In Kenya and Tanzania, the local terminologies for the disease are *mcitende* and *mshipa wa kutserera* for elephantiasis and hydrocele, respectively, while *adenolymphangitis* (ADL) is *homa kali.* In cases of lymphatic filariasis the name given to this disease corresponds to the physical appearance of the disease or the symptoms of the disease.

2.2.2 Practices Related to Lymphatic Filariasis

Traditional intervention or treatment of lymphatic filariasis varies from one region to another due to its perceived mode of causation. People with filariasis almost never use hospitals because of the supernatural belief in the cause of the disease and lack of awareness. Hydrocele can be treated by surgery which is usually beyond the reach of many rural populations. However the belief that someone might die during surgery reinforces the fear (Gyapong *et al.,* 1996). In Africa, however, few have examined the complex relationship between health-seeking behaviours, self-care practices and the cultural context of these behaviours among people who live with chronic manifestations of the disease.

In Haiti, traditional treatments for elephantiasis consist of applying leeches (*sansi*) or bloodletting *(vantouz)* to release the 'bad blood' believed to cause the swelling. Bleeding is sometimes preceded by cupping the area with a heated glass or small gourd vessel *(ti* kwi) to draw the blood to the surface. A razor is used to cut the skin, in a cross pattern at the site of oedema. Both the application of leeches and bloodletting are sometimes done by family members, older people adept at the technique and by traditional healers usually herbalists *(medsen fey)* (Gyapong *et a/,.* 1998). Other home remedies for *gwo pye* include herbal preparations and soaking of the feet in salt water. Among the herbal remedies are manioc leaf, custard, apple and oak. Salt water soaks included the use of spirits of ammonia, table salt, and sea water. The leaves are applied as poultices. Other folk treatments include wrapping the foot in cooked cornmeal or plantain, applying castor oil, animal faeces, cooking ashes, or commercial salves. In rare occasions plantain mixtures are combined with human urine, or lime juice.

In Ghana, studies have revealed that most filariasis sufferers have become very resigned to their chronic disease. As a result, people no longer spend their meagre resources in attempts to fight the disease that has been with people for several decades because they are unsatisfied with the treatment options available. This is because either their conditions gets worse after seeing soothsayers or herbalist or have spent a lot of money and fouls in meeting the demands of the healers. They say "We will leave God to decide on what will happen to us because we do not know what to do any more" (Gyapong *et al.,* 1996)

In Ghana the first source of care is usually the soothsayer who tells sufferers whether the disease is of natural^or supernatural cause and advises them on what to do. They perform some rites, if it is deemed to be spiritually related, or told to consult herbalists if the condition is naturally caused. If the soothsayer is also a herbalist, both treatments are administered. The herbalist typically gives people with elephantiasis of the leg or arm herbs to smear on the affected part of the body. He also cuts open the affected part and holds it over steam. Some people smear fresh cow dung on the affected leg, as it is believed to squeeze and drain fluid out of the leg as it dries up. They believe that cows eat a combination of herbs, some of which are medicinal; their excrement is, therefore, rich in "good medicine". The few people who had elephantiasis of the breast usually smeared herbal preparation or grounded millet on the affected area. This is believed to act in a similar way as the cow dung, which is never put on the breast because women practise prolonged breast feeding (sometimes up to 4 years) and cow dung could be **harmful** to children (Gyapong *etal*., 1998).

In Ghana as in Haiti self- medication is the most common treatment of lymphatic filariasis. Although most people know the benefits of hospital treatment, the hospitals are always very far and sometimes lack medications and so people opt to buy analgesics and antibiotics from drug peddlers in the market place, apply 'Chinese Robb', a kind of mentholated balm, to the leg and hydrocele, or use herbal preparations recommended by friends and family members. Some people also use pharmaceutical products such as *Flanax, Tetrazan, Saridon,* and *penicillin* as treatments of filariasis.

In Kenya however, only few individuals associated elephantiasis to mosquitoes (Wamae *et al,* 2006). Many people have no knowledge about this association and attribute the disease to heredity, fate/destiny, evil spirits, collection of "bad fluid" in the body, fever, and various diets (Wamae *et al,* 2006). In Kwale the community attributes elephantiasis to causes other than mosquitoes including witchcraft, sexual intercourse, and consumption of burnt food (Amayunzu 1997). There exist well-defined terminologies for elephantiasis and hydrocele, that is, *"matende"* and, "*mshipa xva kutserera* respectively. In Kenya traditional healers use an assortment of herbs to treat or control the symptoms of lymphatic filariasis (Plate 2.3). Many people also acknowledge that the disease could be treated er prevented by modern medicine.

In Kwale most diseases are not treated in hospital because they are believed to be caused by supernatural forces. These include marasmus, which is believed to be caused by a breach of taboos by the parents or relatives of a child. The treatment is directed towards the person who broke the taboo but not at the child suffering from marasmus. People whose illnesses are believed to be caused by spirits in Kwale are forced to avoid some foods like eggs, milk, meat and fish. Malaria is believed to be caused by mosquitoes but when the disease changes to cerebral malaria it is believed to be caused by supernatural forces.

Plate 2.3: Some herbs used by traditional healers in Vanga

The clinical aspects of lymphatic filariasis have been well documented including the causes, modes of transmission and manifestation of the disease. Also the perception of the disease is well documented all over the world with causation categorized either as supernatural or natural forces. Although lymphatic filariasis is debilitating disease there is very minimal literature on self care practices as opposed to traditional forms of treatment which are well documented. There are also very few literatures highlighting awareness campaigns, methods of control or eradication undertaken by governments or development partners in endemic areas in most countries especially in Africa. This proves how neglected topical diseases are relegated to the periphery while their eradication campaigns can be tied to other killer diseases like malaria.

2.3 Theoretical Framework

2.3.1 Health Sector Model

The study was guided by the health sector model. The health sector model, as developed by Arthur Kleinman, is based on the premise that looking at any complex society, one can identify three overlapping and interconnected sectors of health care that is, the popular sector, the folk sector and the professional sector. Each and every sector has its own way of explaining and treating ill health. The model also defines the interaction between the healer and the patient in a therapeutic encounter (Helman, 1990).

The popular sector is the lay non professional sector where the disease or ill health is first recognised and health care activities are initiated. In this sector all the therapeutic options that people utilise without consulting any professional are involved. They include self medication, advice or treatment given by other people, healing and mutual care activities, consultation with a person who has experienced the same illness. Here the main area of the healthcare is the family and most of the care givers are women who diagnose most common ailments and treat them with the remedies at hand. In this sector people follow a series of guidelines specific to each cultural group and it takes place on people who are tied together through kinship, friendship, religion, and other social groups. It is made up of a series of informal and unpaid healing relationships.

The folk sector is made up of certain individuals who specialize in some form of healings that are either sacred or secular. These healers occupy an intermediate position between the popular and the professional sector. There are a variety of folk healers found in a society; they include bone setters, tooth extractors, midwives, herbalists and spiritual healers. Most folk healers share the basic cultural values and world view of the communities in which they live, including beliefs about the origin, significance and treatment of ill health. In societies where ill health and other forms of misfortunes are of social causes (witchcraft, sorcery and evil eye) or of supernatural causes (gods, spirits, ancestral ghost, or fate) sacred folk healers are particularly common. Their approach on dealing with illnesses are usually holistic, that is, they deal with all aspects of a patients' life, including the relationship with other people, natural environment and supernatural forces as well as any physical and emotional symptoms. In many non- western societies all these aspects of life are part of the definition of health which is seen as a balance between people and their social, natural and supernatural environments. A disturbance in any of these can result in physical symptoms or emotional stress (Helman, 1990).

The professional sector is the biomedical sector which comprises the organised, legally sanctioned healing professionals. It includes physicians, paramedics, nurses, midwives occupational therapists and physiotherapists. This form of scientific medical practitioners formed the only group of healers that were recognised by the law but this has changed in several countries where other forms of practitioners are now recognised such as herbalists, or spiritual healers like *Sangomas* in South Africa (Helman, 1990). The professional sector is also not complete without a health facility which sometimes has an inpatient or bed capacity where a patient diet, behaviour, sleeping patterns and medication are tightly controlled or managed. However, all these health systems cannot exist without the other and cannot exist in isolation from other aspects of the society.

Other studies that have been guided by Arthur Kleinman's health sector model as part of their theoretical framework includes Margaret Gyapong's socio-cultural aspects of lymphatic filariasis and the role of communities in its control in Ghana (Gyapong *et al.,* 1998). Others include, lay people's knowledge, perceptions and practices regarding the transmission and management of human and porcine cysticercosis in Mbeya rural district of Tanzania (Kalage, 2009) and community perceptions and practices regarding transmission and management of human and porcine cysticercosis in Angonia rural district, Mozambique (Cuinhane, 2010)

2.4 Relevance of the Model to the Study

The perceptions of the people, that is, their beliefs, attitudes and knowledge of lymphatic filariasis affects how people view, interpret, and experience the disease according to their social context. Their perception of the disease, their culture and the environment in which they live affects their definition of the disease and how they categorise it. The way in which people classify diseases is influenced by their own observations and understanding of the disease process. The meanings and notions of causality as provided by the culture will determine the role which a person takes with regard to the illness. A person can decide to be ill without a corresponding disease and decide not to take up the sick role in the society.

The health sector model was used to explain the care practices that people with lymphatic filariasis undertake. This was determined by the sector of health care that one chose, whether the popular, the folk or the professional sector or whether they used two or all of the sectors for their self care practices. This was conditioned by the perceived causes of the disease and the seriousness or severity of the disease. It was also determined by the perceived knowledge held by both the health specialist and non specialist about the sickness and health. Each health care sector has its own way of **explaining** and treating ill health, defining who the healer and the patient is and specifying how the healer and the patient should interact in their therapeutic encounter (Kleinman, 1990). Each and every patient will choose the sector or sectors that they see fit for their condition or category of illness. Therefore, in order to understand the health seeking behaviour of an individual, we have to understand the social relationships that they have and the cultural context in which the disease is being treated.

2.5 Assumption

The assumptions of this study were:

1. The community in Kwale believe that lymphatic filariasis is caused by supernatural forces
2. The experiences of people suffering from lymphatic filariasis causes stigma.
3. The practices of the people with lymphatic filariasis are influenced by community definition of the disease.

Chapter Three

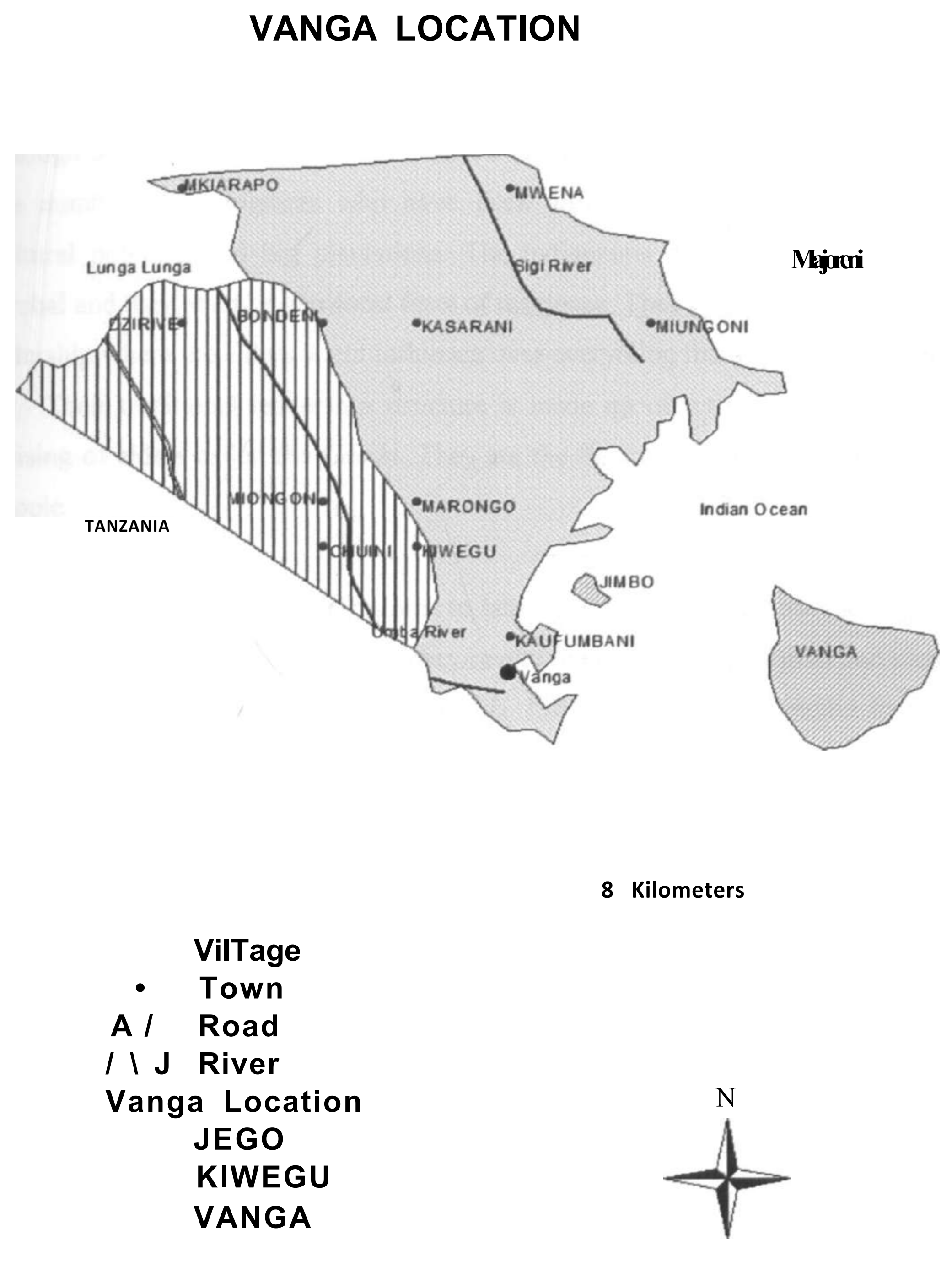
Methodology

3.1 Introduction

This chapter describes the study area, the study design, study population, and sample population. It also describes the sampling procedures that helped in the selection of the units of analysis. Methods of data collection, data processing, analysis, and presentation are also discussed. Lastly, the chapter describes the ethical procedures that were taken into consideration by the researcher to maintain respondent confidentiality and privacy.

3.2 Research Site

Kwale district is situated in the southernmost tip of Kenya and is bordered by Taita Taveta district to the west, Indian Ocean to the east Kilifi district to the north and Tanzania to the south. Kwale District is an administrative unit in the Coast Province. The district has a population of 496133 with a total area of 8295km^2 (CBS, 2006). It is divided into five divisions Kinango 72,027, Kubo 48,769, Matuga 73,377, Msambweni 211,814, Samburu 91,011, and Shimba Hills 135 (CBS 2006) (Now administratively divided into three districts Kwale, Kinango and Msambweni districts). Settlements are concentrated along major road networks, the slopes of plateau and river valleys. The study was conducted in Vanga location (Map 3.1) of Msambweni district with a total population of 15765 inhabitants (CBS, 2006). Msambweni district is made up of three divisions namely Diani, "Msambweni, and Lunga Lunga. All these divisions border the Indian Ocean to the east.



Map 3.1: Map of the study area

3.2.1 The People

The indigenous inhabitants of Kwale district are the Mijikenda (Digo and Duruma) who occupy the eastern northern and western regions of the district, and the Segeju who occupy the southern coastal area as far as the boarder with Tanzania. The Swahili (Shirazi and Vuma) occupy various pockets in the district were the first to penetrate the area though they did not have an impact on the indigenous inhabitants. There are also a sizable number of immigrants who have been attracted to the district due to its agricultural potential and big plantations. The indigenous populations of Kwale are patriarchal and they practice patrilocal form of residence They have a gerontology form of leadership where the elders wield influence over everything that is taking place in the society. Their traditional leadership structure is made up of a traditional government comprising of elders called the *Gambi.* They are the final authority and are revered by the people.

Religion in Kwale ranges from traditional to Islam and Christianity. Both the Digo and Duruma love their traditional cultures. They revere their traditional religion and blend it with either Islam or Christianity (Were *et al.,* 1987). It is not uncommon to find a Muslim or a Christian who also adheres to and practices some aspects of traditional religion. Belief in the supernatural plays a very important role amongst the two communities (Were *et al.,* 1987). They also believe in offering sacrifices to help remove and overt misfortunes and also to cure diseases. Education plays a very important role *m* in these communities, it is undertaken by the elders and emphasis is put on good virtue and respect for elders. Mothers imparted knowledge at an early age but after initiation the role is taken over by the elders. Animal characters are used to depict good virtue in story telling.

3.2.2 Topography and Climate

Topography of Kwale can be divided into two, the hinterland and the coastal plains. The coastal plains are low-lying with an altitude of 50 ft to 100 ft above the sea level. Along the ocean shores can be found a few estuarine systems which are surrounded by mangrove swamps. Other than that the area has poor sandy soils with low thorn bushes and shrub vegetation this turns into fine sands which provide fine beaches to the tourist. The hinterland rises up steadily to an altitude of 800ft and 1400ft respectively and is characterised by rolling hills and deep valleys. The soils here are fertile particularly in the areas that receive heavy rains. The district is drained by a number of permanent streams and springs important ones being Sigi, Umba, Ramisi, and Mwachi. Some of these rivers are important source of irrigation water.

There are two seasons of rainfall in a year, the long rains *(Mwaka)* begins in March and ends in June while the short rains (*Vuri*) begins in September and ends in November. The mean annual rainfall in most parts of the district is 42.5 inches while in Shimba hills it can go as high as 50 inches. The lowland region is very wet and humid especially during the rainy season; it is very swampy and bushy, with no proper drainage system because the area is filled with several swamps and ponds and estuaries'. It is also very prone to flooding during rainy seasons and this always leads to destruction of crops and human settlements. The district like any other part of Kenya sometimes experience unexpected long droughts. River Umba as seen in Plate 3.1 is the only permanent river which drains in Vanga location and is the major source of fresh water for domestic use and for irrigation during drought in this area.

Plate 3.1: River Umba

3.2.3 Economic Activities

A big fraction of land in the district is covered by forest. The vegetation varies from scattered coconut plantations and low thorn bush and scrub along the coastal strip, to forests and open savannah in the hinterland. The ocean fronts are covered in very thick mangrove forests which are fed by nutrients from both the rivers and the ocean with fewer intervals of fishing beaches. Many forests found in the area constitute of former settlements *(Makaya).* These forests contain a variety of hardwood and a wide range of herbs which are still used to date but they are threatened with extinction. The area is endowed with a variety of wild animals and boast of a national reserve (Shimba Hills National Reserve) and an elephant sanctuary (Mwaluganje Elephant Sanctuary), they include elephants, bush bucks, antelopes, wild pigs, warthogs, monkeys and many others which are a menace to the locals as they destroy their farms on a regular basis. The mainstay of this district is tourism, fishing, and agriculture with huge plantations in Shimba Hills and Ramisi (Plate 3.2 - 3.3).

The major crops in this area are coconuts and cashew nuts. People in this area mostly practice agriculture and due to the swampy nature of this area, many areas are not agriculturally viable during rainy seasons so people grow rain fed rice in the swamps. They grow staple foods like maize and sorghum and also commercial fruits like mangoes, oranges, lemons cashew nuts and coconuts. Others keep livestock while the remaining groups mostly along the ocean are fishermen.

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Some of the economic activities carried out in Vanga sub-location can be seen in Plates 3.2 and 3.3.

Plate 3.2: Rain fed rice in Vanga with settlements in horizon

Plate 3.3: Fishing boats anchored during low tides in Vanga

3.2.4 The Health Sector

Kwale district is served by various hospitals, health centres and dispensaries the **majority** of which are government owned. The district has more than 40 health facilities **with** the major ones being Msambweni District Hospital, Kwale Sub-District Hospital, **Kinango** Sub-District Hospital, Tiwi Provincial Rural Health Training Centre, Vanga Health Centre, Lunga Lunga Dispensary and Samburu Health Centre. The District **Hospital is** located far out of reach of many Kwale **residents** as going there **requires** fare **of between** 500 Ksh to 700 Ksh and so many prefer to seek treatment at Coast General **Hospital**

The district has a high childhood mortality rate; the climate in this area is conducive for the breeding of mosquitoes and hence the high prevalence of malaria. The Digo believe that whenever a local bird is present within the homestead then an outbreak of malaria is eminent thus malaria attacks are referred to the local medicine men before treatment in the hospital is sought. The indigenous population of this area consults their Kaya's in cases of illnesses to try and appease the angry ancestors or offer sacrifice which is always in form of goats or chickens before they attempt to go to the hospital. This is a very common practice in this area where people believe in supernatural causation of illness. Because of this practice many lives of people with treatable illnesses like malaria, typhoid are endangered or sometimes lost because it always becomes too late for the health workers to do anything (Were *et al.,* 1987).

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The indigenous knowledge of disease causation still influences people's response to the available health services (Were *et al,* 1987). Most diseases are believed to be naturally caused. These are simple natural ailments which are brought about by god and are, therefore, treated with local herbs or in hospitals without any ceremony involved. Major ailments are believed to be caused by breach of taboos and spirits (*mashetani*) whose demands are known in the ritual dance during a trance. Other causes are *kiapo,* anti-theft device planted on people's farms, and *uchawi* (magic used to afflict people because of envy or malice). Ancestral spirits are also believed to cause affliction to those who do not pay respect to them. The types of treatment here range from sacrifice to religious therapy including verses written on metal plates and worn as talismans and rituals such as *Kayamba* dance (Were *et al.,* 1987).

3.2.5 Types of shelters

Most of the houses (living structures) belonging to the indigenous population of this area are made of mud and coconut thatch while the immigrants mainly use grass to thatch their houses. Other houses were made only of coconut leaves but in most of them there were gaps or gaping holes in the structures while others did not have proper doors (Plate 3.4).

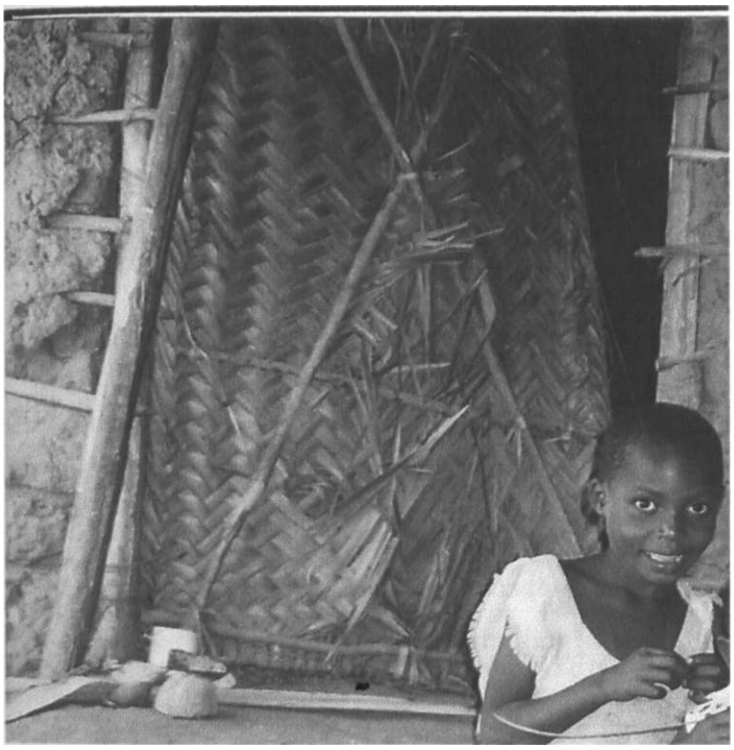

Plate 3.4: Children playing outside a Door in Tchuini

3.3 Study Design

This was an exploratory cross- sectional study which adopted both qualitative and quantitative methods of data collection for a period of three months (June, July and August 2008). Quantitative methods were used to elicit information on the community's distribution and frequency of perceptions of lymphatic filariasis and the types of healthcare options available depending on their social categorization of the disease.

Qualitative methods were used to gather data on beliefs, values, norms, traditions, **roles,** experiences, and understanding of the disease.

3.4 Study Population

The study population included members of the local community in Vanga location who have been either affected or infected by lymphatic filariasis. The study population included youths from the ages of fourteen to adults. Children below 14 years were not included in this study because the disease manifests itself on people much later in life **especially** from adolescence to adulthood.

3.5 Sample Population

The unit of analysis was the individual, living in Vanga location at the period during the study and those who worked in the government health facilities in Msambweni and Vanga Health Centre. A total number of 322 respondents participated in the study

3.6 Sampling Procedure

Those suffering from lymphatic filariasis were sampled using snowball sampling because it was difficult to identify them or were mainly staying indoors. This was done with the help of the Local Health Facility and Community Health Workers who identified most of them as the remainder introduced us to the others. Key informants were selected using convenience sampling method. Other respondents were sampled using systematic randorrf sampling method and in all villages the fifth house was selected, however, as the study progressed I realised that members of the same extended family lived in one area so I decided to adopt purposive sampling method to eliminate the chance of selecting people from one extended family and also to maximize the variation of the respondents. In cases where eligible respondents were not available from the households selected, the next immediate household was selected.

3.7 Pre-test

This study was pre-tested using a semi-structured questionnaire with a few respondents in Vanga town (four with lymphatic filariasis and 6 without lymphatic filariasis). This made it possible to allow for mistakes to be identified and corrected before the main study commenced. This helped the research assistants to familiarize themselves with the tool and ensured a clear flow of the questions and in the right order.

3.8 Methods of Data Collection

Data was collected using both primary and secondary sources. Secondary sources were used to compliment primary sources of data and they contained recent reports and statistics available on the ground.

3.8.1 Semi-Structured Interviews

These were used as the basic data collection tool to elicit information for households and for those suffering from lymphatic filariasis on their perceptions and practices and their health seeking behaviour. The respondents were interviewed using questionnaires (Appendix I and II) which were translated into Kiswahili. A total of 254 questionnaires instruments were answered with 50 of them being for people suffering from lymphatic filariasis.

3.8.2 Focus Group Discussions (FGDs)

These were conducted with those who live in the community and those who are suffering from the disease, a total of five focus group discussions were held. An FGD guide (Appendix IV) was used to collect this data. They were held to elaborate, support or contradict the findings gathered from other methods. Emerging issues and controversies were included in the FGDs especially on perception, experiences and practices of lymphatic filariasis. The participants were identified on the basis of having lymphatic filariasis, having undergone corrective surgery to remove the enlarged scrotum, being care givers or just having had an experience with lymphatic filariasis or with a person suffering from it. The discussions were tape recorded and later transcribed.

3.8.3 Key informant Interviews

These were held to elicit information on those suffering from the disease and the stake holders to know their perceptions and experiences and how this has led to their choice of treatment. A total of twenty one key informant interviews were held, they were also tape recorded and transcribed. Selections of examples illustrating various emerging issues were then used as depth wise elaboration of some of the results and observations made by the respondents and participants in this study. Key informant interview guides (appendix III and V) were used in collecting the necessary data.

3.8.4 Direct Observations

These were used to monitor and interpret the behaviour of people in Vanga concerning the care practices of those who were suffering from lymphatic filariasis and their households. The observations were recorded down in the field journal which every research assistant had and was later on used to compliment what had already been collected.

3.8.5 Secondary Data

This included data, both published and unpublished on lymphatic filariasis from archival materials, hospital records and census data and literature review. This data was used to supplement primary data it included most of the records that were available in the district on Lymphatic Filariasis.

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3.9 Data Processing Analysis and Presentation

This study used both qualitative and quantitative methods of data analysis. Quantitative data were analyzed using the Statistical Package for the Social Sciences (SPSS) computer software, to generate frequencies and distributions, while on the other hand qualitative data were analysed according to emerging themes relevant to the study. The tape-recorded data from key informant interviews and focus group discussions were transcribed and studied to identify the major categories of themes and sub-themes. Direct quotations and comments by the informants were also used to take their actual words into account.

3.10 Encountered Problems and their Solutions

This study took place in coast province where the common language is Kiswahili. This is the national language of Kenya although there was a bit of a problem in the beginning with understanding some of the words in the local dialect. Because of this reason only research assistants from Vanga were used but with time I got to understand the dialect well. The other problem was the administrative split of Kwale district into three districts Kwale, Msambweni and Kinango districts. This meant that clearance to undertake research had to be done in both Kwale and Msambweni district from the District Officer, Medical Officer of Health, and District Education Officer (to pay a courtesy call and to get permission for conducting research in the area), this delayed the inception of the study by two weeks.

The other problem was lack of transport especially within the villages and since the research was conducted during the rainy season, we were not able to stick to our work schedule as the settlements were far apart and there were flash floods. There were also very few vehicles plying the main road and they would leave after a two hour interval. The other problem was accessing the villages as we had to cross rivers at various points and the rivers are infested with crocodiles. The only available permanent bridge is situated in Jego and was too far to use on a daily basis. The problems were solved by walking barefoot in mud to reach our destinations, by praying before we crossed the rivers.

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The other problem was lack of hotel, guest houses or lodgings for accommodation in this area as the people are very strict Muslim. They do not allow for temporary accommodation facilities as they are believed to encourage immorality. The alternative was to rent a house, which was not available either, and so one of the nurses from the hospital agreed to accommodate me for the period during my research. These problems made field work take longer than anticipated but the inhabitants were very hospitable and understanding.

3 11 Ethical Considerations

Before travelling to the research site I applied for and received research clearance from the Ministry of Higher Education Science and Technology. I also received a letter of authorization from the District Commissioner in Kwale and Msambweni district to conduct the research in the Vanga location. During this study every potential respondent **was** given adequate information to make an informed decision on whether to participate or not. Every research assistant ensured that we received signed or thumb- printed **consent** from everybody who was interviewed. We ensured that if a sampled respondent **changed** their mind and did not want to be interviewed anymore then the respondent **was** automatically dropped from the sampled population. The respondents were given the mandate to terminate the interviews if they wished to do so without any explanation. Anonymity and the right to privacy of the research subjects was guaranteed because the data collected were coded to protect their identity, also any photos or materials taken for the purpose of this study were done so with their permission.

Chapter Four

Community Perceptions of Lymphatic Filariasis

4.1 Introduction

This chapter is a presentation of the results on perceptions of lymphatic filariasis in the study area. The socio-demographic characteristics of the perceptions of the respondents concerning the disease are also presented.

4.2. Socio-Demographic Characteristics of the Respondents

The respondents in this study were made up of people suffering from lymphatic filariasis (LF) and those who did not have the disease. A total number of 254 respondents were interviewed (50 suffering from LF and 204 respondents without LF). About half (50% with LF and 53% without LF) of respondents came from Kiwegu, the largest sub-location with the largest group of immigrants (Figure 4.1).

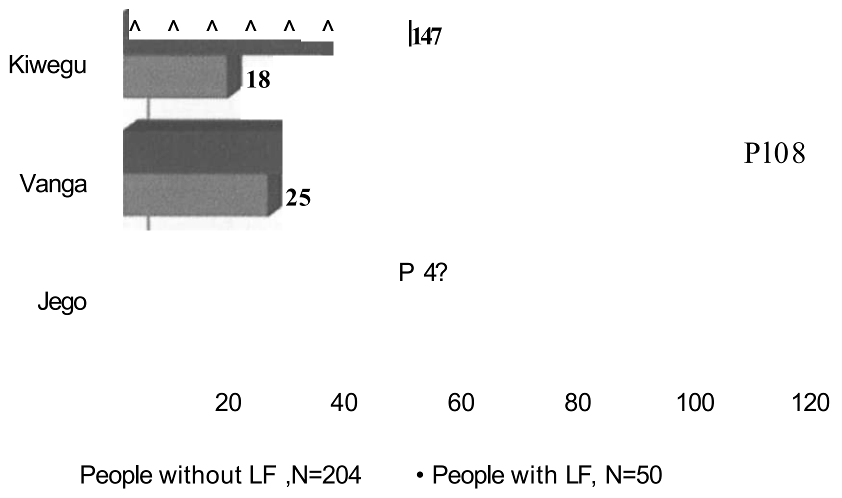

Figure 4.1 Number of respondents

Both the respondents with and without LF (30% and 29.4%, respectively) were mainly in the 30-39 years age category. The majority of the respondents in both categories were male (see Table 4.1). Most of the respondents were married as attested to by 82% (with LF) and 71.1% (without LF), respectively (see figure 4.2).

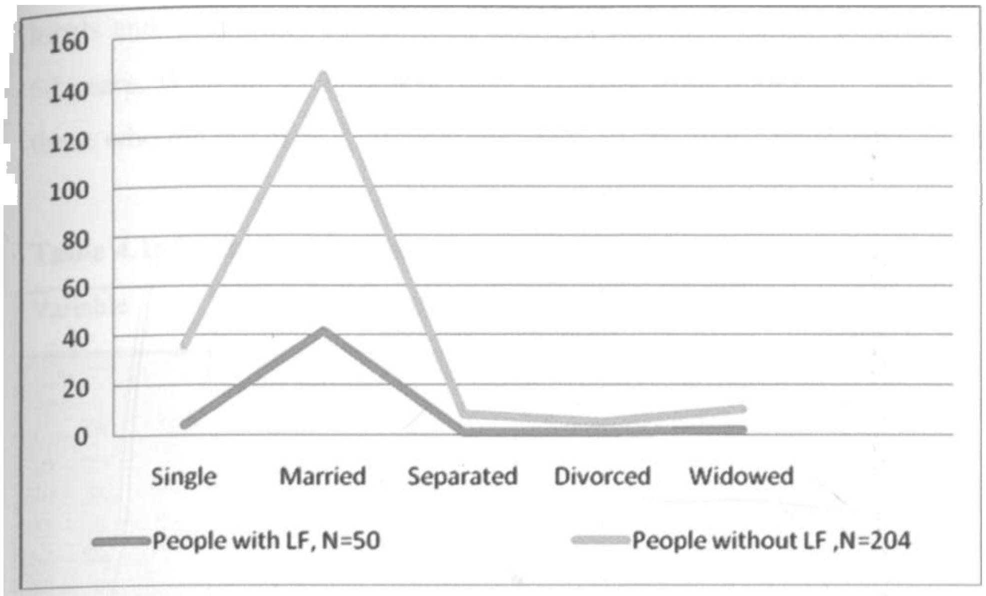

Figure 4.2 Marital Status

About half (54%) of the respondents suffering from lymphatic filariasis had no formal education at all while 58.3% of those without lymphatic filariasis had attained some level of primary education.

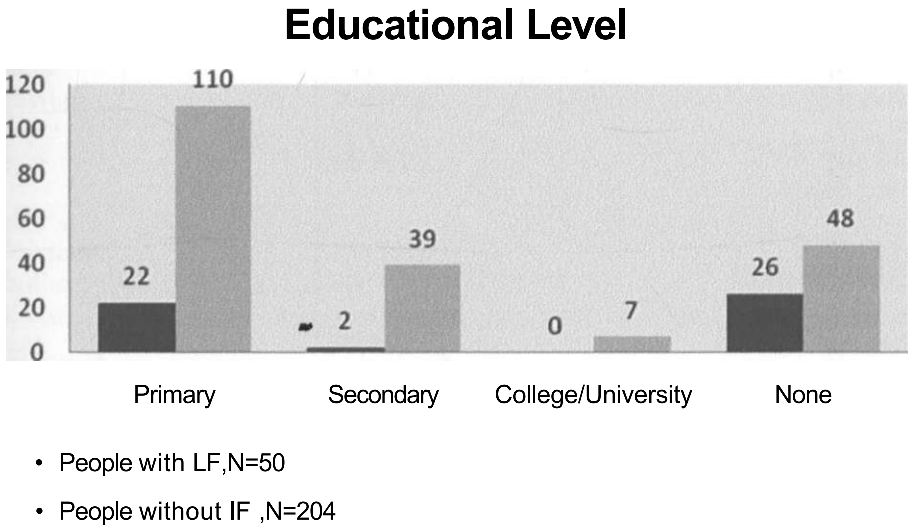

Figure 4.3 Education Level

Over a half (56% with lymphatic filariasis and 57.4% without lymphatic filariasis) of respondents were farmers. The dominant religion in this area is Islam as indicated by 60% of respondents with lymphatic filariasis and 60.8% of respondents without lymphatic filariasis, respectively (as seen in table 4.1). The respondents included both locals and immigrants to this area, majority having lived in Vanga for between 20 and 50 years. With the exception of 10% suffering from lymphatic filariasis and 17.2% of those who did not have lymphatic filariasis, all the other respondents had children.

Table 4.1: Socio-demographic characteristics of the respondents

Variable	*People with LF, N=50* *Frequency/Percentage*	*People without LF ,N=204* *Frequency/Percentage*
Age		
10-19	3 (6%)	15(7.4%)
20-29	2 (4%)	57(27.9%)
30-39	15(30%)	60(29.4%)
40-49	7(14%)	38(18.6%)
50 - 59	13 (26%)	17(8.3%)
60 +	10 (20%)	17(8.4%)
Total	**50 (100%)**	**204(100%)**
Gender		
Male	37 (74%)	117(57.4%)
Female	13 (26%)	87(42.6%)
Total	**50 (100%)**	**204(100%)**
Main Occupation		
Farming	28(56%)	117(57.4%)
Business	0 (0%)	39(19.4%)
Fishing	4(8%)	7(3.4%)
weaving	10(20%)	8 (3.9%)
Others	8(16%)	33(15.9%)
Total	**50(100%)**	**204(100%)**
Religion		
Christian	15(30%)	74(36.3%)
Muslim	30(60%)	124(60.8%
Atheist	5(10%)	6(2.9%)
Total	**50(100%)**	**204(100%)**

4.3 Community Perceptions of Lymphatic Filariasis

All the respondents knew about lymphatic filariasis. Of the 204 respondents without lymphatic filariasis, 98% knew about the disease because 89.2% of them had seen people who were suffering from the disease. Others (3.5%) had either been told about the disease or had learned about it in school, while the remainder (4.4%), were tested in the year 2000 during a research carried out in Vanga by the Division of Vector Borne Diseases.

All the respondents suffering from lymphatic filariasis knew about the disease with the **majority** having suffered from it for between 0 and 14 years as shown in Table 4.2.

Table 4.2: Number of people suffering from lymphatic filariasis

Years sufferedfront lymphatic filariasis	*Frequency*	*percentage*
	15	30
S-9	8	16
10-14	10	20
15-19	6	12
20 - 24	4	8
25+	7	14
Total	*50*	*100*

Those suffering from lymphatic filariasis included people with hydrocele (62%) and with elephantiasis (38%). Of the 38% of the respondents suffering from lymphoedema **(elephantiasis)** only 26% were female. The respondents who were suffering from lymphatic filariasis (n=50) had different reactions when they were first diagnosed of the disease. Fourteen percent of them just felt alright because their family members had it and they were expecting to have it, while 10% regretted having taken the filarial doze because that was when they started experiencing the symptoms. This is attested to by the following statement from a community health worker from Vanga.

> *When people who had no symptoms of lymphatic filariasis started having swellings in their arms, legs and scrotum, some came to me very angry asking why I advised them to take the drugs when I ktiew very well that the swelling will never go back. Some people in the village are so angry at me for having convinced them to take the filarial doze since this has made then develop the disease hence become useless.*
>
> **(Female, 42 years old, Vanga)**

Some (42%) of the respondents got scared and worried because they knew that they had to go through surgery while 32% were shocked and refused to accept their condition because they thought the doctor was not serious. At the time of the interview, 24% of the respondents with lymphatic filariasis felt that it was a normal disease like any other, while 34% of those with lymphatic filariasis were angry because their bodies have been deformed. Another 32% felt helpless because they felt that even if they had money, there was nothing much they could do, while 10 % felt sad because they experienced reduced libido with pain in their scrotum especially after sex and therefore could not satisfy their partners sexually.

4.3.1 Perceptions of the causes of lymphatic filariasis

The respondents had different ideas on what causes lymphatic filariasis, but the most common answer from people without lymphatic filariasis was mosquitoes (54.9%) this was followed by having sex with an infected partner (5.9%). One of the respondents suffering from hydrocele had the following to say:

> *When you get lymphatic filariasis people here do not believe that it has been caused by mosquitoes. They think that you had an affair with a woman whose partner had hydrocele.*
> **(Male, 28 years old, Kiwegu)**

Also 3.5% of the respondents believed that lymphatic filariasis was caused by witchcraft while 15.2% had no idea of what causes the disease. Despite the major belief that the disease is caused by mosquitoes, others believed that mosquitoes in combination with other agents cause the disease. This is because when asked what they thought caused lymphatic filariasis, they said that health workers taught them that it was caused by mosquitoes but were not satisfied with this explanation. According to them, the disease could be caused by other agents in conjunction with mosquitoes or sex. Unsatisfied with the explanation that mosquitoes cause lymphatic filariasis, male youths in an FGD were in agreement when one of them made the following statement:

> *We do not believe that mosquitoes cause lymphatic filariasis because there are other places in Kenya like Kisumu and Budalangi which also have nearly the same climate and are infested with mosquitoes. How come they do not have lymphatic filariasis even though they are bitten by the same culex anopheles mosquitoes. There has to be other causes of this disease.*
> **(Male, 19 year olfl, FGD, Jego)**

These sentiments were echoed by most of the respondents during the interviews and discussions. About 11% of the respondents believed that the disease can either be caused by a combination of agents and mosquitoes or sex. The agents mentioned include coconut foods and other products like alcohol, *madafu* (unripe coconut juice), dirty water, inheritance of lymphatic filariasis from parent(s), weak immune system, cuts to remove bad blood and fluids, and living in a hot and humid climate. Only 1% of the respondents believed that the disease was a misfortune from gods. In the focus group discussions it became apparent that most discussants believed that after mosquitoes and sex, the third most common cause of lymphatic filariasis was weak immune system. A man in an FGD for old men explained as follows:

> *You know when you have a weak immune system and you have offspring's who also have weak immune systems then they can inherit the disease from you. I have seen children or grandchildren of people with lymphatic filariasis and they get sick of the same disease as their grandparents or parents so this shows that people can inherit this disease from their family line.*
>
> **(Male, 65 year old, FGD, Jassini)**

The situation was slightly different for those who were suffering from lymphatic filariasis (n=50). Amongst these respondents, 34% did not know what caused the disease and most of them believed it was an act of god. Out of this group, only 18% mentioned mosquitoes as the cause of lymphatic filariasis while 10% believed that it was caused by witchcraft. Eight percent of the respondents believed that lymphatic filariasis was caused by sexual intercourse with infected partners or a woman who was in her monthly periods. Others (16%) believed that it was caused by eating burned or cold foods while 10% believed that it was caused by taking the filarial doze distributed in endemic areas. One key informant from Vanga health centre had the following to say about filarial doze:

> *Those who had filarial worms in their blood experienced increased cases of swelling of the lymph nodes, the spermatic codes, (structure in the tubes where sperms are stored) and pains in the testicles after taking the filarial doze. Some of the swellings never went back and hence they developed lymphatic filariasis. Therefore some of the residents have refused to take filarial doze again this year (2008) for fear of developing the symptoms again or of getting either hydrocele or elephantiasis.*
>
> **(Male, 39 years old, Vanga Health Centre)**

The remaining 4% believed that it was caused by not being sexually active for a very long time. However, most of the respondents (74%) believed that everybody's lymphatic filariasis is caused by a different agent. This is further illustrated by one of the informants suffering from lymphatic filariasis in the following quote:

> *I believe that the cause of my disease is ubovu (weak immune system) but other villagers tell me that my disease has been caused by witchcraft and other traditional things.*
>
> **(Female, 58 years old, Jego)**

There were varied reasons for **the belief** that **lymphatic filariasis is caused** by mosquitoes and sexual intercourse with infected partner(s). Most of the people who said that the disease is caused by mosquitoes and sometimes other agents gave varied reasons. Twenty two point one per cent said that they had been taught during awareness campaigns by the Community Health Workers. Other respondents (10.8%) believed that mosquitoes only transmit their worms to humans during feedings (blood meal) after 10 pm. Another 10.3% believed that the area is ideal for breeding of mosquitoes since the place is marshy, humid, hot, swampy and bushy. Another group of respondents (6.4%) **who** believed that mosquitoes caused lymphatic filariasis equated it to unclean environment around the area. A similar percentage believed that most people who do not use treated nets are the ones who are infected by this disease. The last group who gave mosquitoes as their answer had learned about it in school or read about it in the print media or books.

The respondents (7.8%) who believed that sex, sometimes in conjunction with other agents caused lymphatic filariasis argued that those who had lymphatic filariasis had partners who also suffered from the disease. Others (10.3%) however, reported that they heard people in the village attribute lymphatic filariasis to sex. The remaining respondents (2.9%) argued that the disease is caused by coconuts and its alcoholic product such as *mnazi.* This is because most people who use oily foods and especially men who drink alcohol made from coconuts (*mnazi or mchuchula)* are the ones who suffer most from this disease. In female immigrants FGD the participants agreed that coconuts can cause lymphatic filariasis,

> *I believe the disease is caused by foods locally found here especially coconuts and its products mainly madafu and alcohol because that is the only thing that cannot be found where I come from. So I totally forbid my children especially my sons from eating madafu.*
> **(Female, 34 year old, FGD, Bondeni)**

Another 2.9% believed that the disease especially elephantiasis was caused by witchcraft because it has no treatment, while 1.5% of the respondents believed that it was caused by witchcraft.

4.3.2 Perceptions of the Transmission of Lymphatic Filariasis

Over a half (56.4%) of the respondents believed that lymphatic filariasis can be transmitted from one person to another. The transmission can be through mosquito bites from the affected to unaffected person (22.1%), or having sex with an infected partner (17.6%)

Other respondents (8.8%) believed it is transmitted through having sex and mosquitoes while 3.9% believed that it can be transmitted by inheriting bad blood (infected blood) from parents. The remaining respondents believed that the disease could be transmitted through alcohol (*mnazi*) and bad luck, not using treated nets and unclean environment. Some respondents believed that lymphatic filariasis was contagious because patients with it were isolated. During an FGD with old men, the participants were in agreement and supported the argument that mosquitoes only transmit filariasis to those who have weak immune systems. This they argued was because in a household you find that people are bitten by the same mosquito but only one or two of them end up getting hydrocele or elephantiasis.

Almost half (46.6%) of the respondents without lymphatic filariasis (n=204), believed that men were more at risk of being infected with lymphatic filariasis than women. Also in an FGD involving women in Jego there was an agreement amongst the discussants concerning the belief that men were more at risk of getting LF as one explained:

> *I believe that men are more at risk because men drink till late past 10 pm, when the mosquitoes with filarial worms start biting and some stay out till late sometimes up to 2 am. While drunk most men do not sleep under insecticide treated nets so they are likely to be bitten by mosquitoes than others. With these habits how can they protect themselves against lymphatic filariasis?*
> **(Female, 45 year old, FGD, Jego)**

Other respondents (32.8%) believed that all adults have the same risk of suffering from lymphatic filariasis while 9.3% believed that both men and women are equally at risk. Only 1.5% believed that women are more at risk. Others (3.4%) believe that children are more at risk, 5.9% believed that everybody was at risk while only 0.5% believed that people who did not sleep under insecticide treated nets are in danger.

Chapter Five

Experiences of People Suffering from Lymphatic Filariasis

5.1 Introduction

This chapter presents the findings on the experiences of those suffering from lymphatic filariasis and their care givers in Kwale district.

5.2 Manifestations of lymphatic filariasis

In Vanga all respondents were aware of lymphatic filariasis and had seen those who suffered from it. More than a half (62%) of the respondents who had lymphatic filariasis (n=50) knew other people who also had this disease. Amongst the respondents without lymphatic filariasis (n=204) slightly more than a half (51%) had family members who suffered from lymphatic filariasis. Out of these, 40% had family members manifesting elephantiasis, 43% had hydrocele, while the remaining 17% had manifested both hydrocele and elephantiasis.

5.3. Symptoms/ manifestations of lymphatic filariasis.

The symptoms of lymphatic filariasis given by respondents represented the stages and the type of lymphatic filariasis suffered. Forty per cent of the respondents suffering from lymphatic filariasis were in the second stage of lymphoedema.

All the respondents (n=204) had seen a person with lymphatic filariasis and described the varied manifestation of the disease. The details of the symptoms are presented in Figure 5.1

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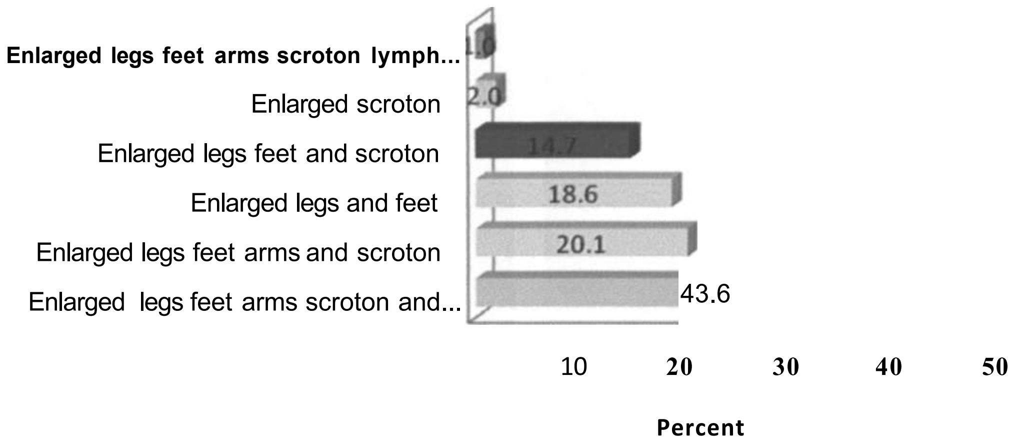

Figure 5.1: Manifestations of lymphatic filariasis

The symptoms or manifestations for those who suffered from lymphatic filariasis were similar with those without lymphatic filariasis. The only exceptions were symptoms like fever, abdominal pains, change in urine colour, loss of fertility and vomiting. Those who had lymphatic filariasis (n=50) said that the symptoms of the disease include pains and swelling of the legs (30%), pains and swelling of the scrotum (26%) and enlargement of the legs and retention of water in the legs (14%) as shown in Plate 5.1. Others included enlargement of the scrotum (12%), swelling and pain in the testis, abdomen and high fever (8%), and fever, vomiting and enlargement of the scrotum (4%). The remaining respondents said that the symptoms of lymphatic filariasis included enlargement of the scrotum and swelling of the testis (2%) as shown in Plate 5.2, swelling of both testfs and both legs (2%), and enlargement of the scrotum, loss of fertility, and change in urine colour (2%).

Plate 5.1: Elephantiasis of the Leg

Plate 5.2: Hydrocele of one Scrotum

5.4 Experiences of People with Lymphatic Filariasis

People suffering from lymphatic filariasis experienced a lot of problems due to their illness. Some of these experiences were due to societal misconceptions and perceptions of the disease. This sometimes led to victimization, stigmatization and even isolation in their families and the community.

5.4.1 Marriageability

A majority (82%) of respondents suffering from lymphatic filariasis believed that having the disease does not destroy a person's chances of getting married. The remaining 18% believed that the disease affected their chances of getting married. This can be explained by the following sentiment expressed by a respondent suffering from hydrocele:

> *If a man gets hydrocele or elephantiasis before marriage it is highly unlikely that they will get a spouse except maybe if it is arranged or if they are rich. A betrothed can refuse to get married\ but if she agrees maybe the man is rich and is able to cater for her and maybe her family's needs. Otherwise the family will wonder "what their daughter would like to do with a man with a 'load'.*
> **(Male, 50 years, Jassini)**

Ten percent of those who believe that the disease affected their chances of getting married (reported that a partner can leave one immediately one gets deformed as noted by the following key informant:

> *The other day I was called in to arbitrate on a case where a young girl wanted to leave her husband who had developed an overgrown hydrocele. It became apparent that they were not having sex. She was also the fifth wife of this old man and he had paid a lot of dowry for her and her family could not afford to pay it back. The old man insisted that she had to remain in his family if the dowry was not returned. We resolved to let her remain in the family but instead of living with the old man we resolved to let her get married to his grandson who was mature but had not married[so the girl remained in the family.*
> **(Male, 45 years old, community health worker, Jego)**

Others (8%) believed that it can also make one experience reduced libido. The following statement from a female discussant in an FGD illustrates the attitudes of some women towards marrying a man with hydrocele

> *Why should I marry a man who is already a woman? I can only marry a man with hydrocele if there is something that I can gain like money. Otherwise I can only marry a person with elephantiasis or hydrocele if I am also infected.*
> **(Female, 36 years, FGD, Jego)**

The responses were more or less the same for those without lymphatic filariasis as majority of them (88%) believed that people with lymphatic filariasis can marry or get married as long as they love one another. However out of the remaining 12 % (n=25), half of them rejected this notion of love because they believed that a person can only marry before the disease^ manifests itself or after hydrocele surgery. Others (16.7%) believed that only people with elephantiasis can get married, while 8.3% believed that marriage to people with lymphatic is only possible with orphans, divorced partners or forced /arranged marriages. A few (8.3%) believe that men with hydrocele cannot get married because they are shy in bed since their penises are characteristically embedded in the voluminous scrotum and under such conditions the penis cannot have proper erection for sexual intercourse. About (17%) of the respondents believed that people with lymphatic filariasis should not marry since they can transmit this disease to their partners and offspring. This was further explained in a focus group discussion with young men as follows:

> *People have developed this disease because they got it from either or all of their parents and sometimes their partners. This is because most people with this disease have partners, parents and grandparents who have this disease. So they should not get married because they can also transmit it to their children or their partners.*
> **(Male, 19 year old, FGD, Jassini)**

Only 3 respondents of those suffering from lymphatic filariasis (n=50) thought that it would be difficult for their family members who did not have lymphatic filariasis to get a spouse. They said that this is attributed to the fact that people think that families of people with lymphatic filariasis are also infected with the disease.

5.4.2 Bearing of children

Most (88%) of the respondents believed that men with enlarged scrotum can father a child provided he is fertile, while 3% believe that they can only father a child if they marry early depending on the size of the scrotum. Other respondents (6 %) believed men with hydrocele cannot father a child once the penis is shrunk /embedded in voluminous scrotum since they cannot achieve an erection or be sexually active. Others (3%) also believed that they cannot father a child since their blood and their spermatozoa have already been infected by filarial worms.

An overwhelming majority of the respondents (96.6%) believed that women can get pregnant provided they are fertile. This can be seen in this statement by a female informant with elephantiasis.

> *I have three children and all were born when I was already like this (nilikuwa na ubovu tayari.)*
> **(Female, 27 years old, Kiwegu)**

Others (1%) believed that even though they can get pregnant they can only give birth through caesarean. Only 2.4% believed that they cannot get pregnant because the worms are already mixed with their ovaries.

5.4.3 Effects of lymphatic filariasis on relationships

During the study **some** of the **respondents acknowledged** that lymphatic **filariasis caused** a strain in the relationship between those suffering from the disease and their spouses, their children, their families and members of the community, as seen in Table 5 .2.

Table 5.1: Effect of lymphatic filariasis on people's relationships

"Strained Relationship with	**N=204 (People without LF)**			**N=50 (People with LF)**	
	Yes (%)	**No (%)**	**Don't know (%)**	**Yes (%)**	**No (%)**
Spouse	**27.5**	**69.1**	**3.4**	**10**	**90**
Children	**10.8**	**87.7**	**1.5**	**14**	**86**
Other family members	**10.3**	**88.2**	**1.5**	**8**	**92**
Community	**11.3**	**87.3**	**1.5**	**6**	**94**

5.4.3.1 Relationship with a spouse

Slightly more than a quarter (27.5%) of respondents without lymphatic filariasis thought that lymphatic filariasis can cause a strain in relationships, while 25% of them believed that enlarged scrotum can reduce a man's virility and sexual performance. This is exemplified by the following excerpt from a discussant in an FGD

> *When your husband has hydrocele he cannot be sexually active/ 'play ball' (hawezi kucheza ngoma). As for those who have gone for surgeries they come back when they are useless (wana ubovu).*
> **(Female 28 years old, FGD, Jego)**

Also 21.4% believed that the disease is in the genes/blood and can be inherited and were constantly accusing their spouses of transferring the disease to their children. Others (17.8%) believed that the disease can cause mistrust amongst the couples when promiscuity is suspected to be the cause of the disease. A similar percentage, (17.8%) believe that wives can cause their husbands to go for surgery especially when they feel ashamed or uncomfortable about their spouses' condition. Other (14.2%) respondents said that some people leave their partners immediately they get deformed while a small percentage of the respondents (5.6%) believed it is painful to deal with this disease when a spouse gets acute attacks thus straining the relationships.

Ten percent (5) of the respondents who had lymphatic filariasis thought that the disease caused **a** strain in their relationship. Reasons for this included lack of sexual **satisfaction,** jeering from neighbours causing embarrassment to a person's spouse, high expenditure in treatment seeking causing a drain in the **family**'s resources and desertion ofones spouse

5.4.3.2 Relationship with children

A few (10.8%) of the respondents without lymphatic filariasis believed that the disease can affect a person's relationship with their children. Amongst this group of respondents, 22.7% believed that the sick might refuse treatment options available which can cause a strain in their relationship with their children. The other 27.2% thought that the children would feel ashamed of their parents and ignore them if they were sick, a similar percentage (27.2%) believed that children can inherit lymphatic filariasis from their parents and this can also cause problems in their relationships. Other respondents (13.6%) believed that this disease can cause poverty in the households due to loss of work hours and purchase of constant medications. This diminishes the family's capacity to meet their daily needs, thereby making the children take up odd jobs to try to supplement the income and, in most cases, drop out of school. The remaining 9% believgd that children can talk behind a person's back without letting them know.

For those suffering from lymphatic filariasis, 14% believed that lymphatic filariasis can affect a person's relationship with their children. This is because 28.6% said that they had been abandoned by their children because they were suffering from filariasis, a similar percentage also said that people laughed at their families because of their illness. This made the family vulnerable to isolation and stigmatization. This has led to children blaming and hating their parents for what the society is putting them through because of their illness. This can be illustrated by the following admission from an informant with elephantiasis:

> *My son does not listen to me anymore. Ever since I developed this disease he started becoming distant and now he lives in Lunga Lunga with his wife and family. Can you imagine I have not seen my grandchildren? He blames me and my illness for his dropping out of school. He even says that he could not marry the lady he loved because of me and my legs. He says that I am an embarrassment to them because my legs are swollen and smelly. He once told me that I would infect his kids. Can you imagine that?*
> **(Male, 65 years old, Kiwegu)**

Another 28.6% said that their families spent their money on medications instead of food and this put a strain on the family's resources and thus their relationships. The remaining 14.2% said that their children had inherited the disease from them and are now blaming them for the misfortune that had befallen them.

5.4.3.3 Relationship with family members

Respondents without lymphatic filariasis who believed that the disease can affect a person's relationship with other family members were few (10.3%). Amongst this group 15% believed that they can be infected by those having filarial worms, 20% believed that other family members can make fun of those who have hydrocele. The other (35%) believed that the family can feel ashamed of people with lymphatic filariasis and ignore them due to their illness. Of the remaining respondents, 15% said that people with LF feel inferior and are seen as inferior to other people, a similar percentage said that some people with hydrocele fear death during surgery and resist going for treatment and this embarrasses their families who sometimes abandon them.

Of the respondents suffering from lymphatic filariasis only 8% (4 respondents) admitted that the disease can affect a person's relationship with their family members. Reason for this included abuse and neglect from family members. This can be summed up in a statement by this male discussant:

> *Sometimes when we have no money in the house, my family members would joke by telling others to ask me for money by saying "si uulize huyo mwekahazina akupatie kitu". Sometimes this made me so angry." since I was a cashier* (equating hydrocele swelling to money kept in a bag/bags used in the market to keep money)

> **(Male, 40 year old, Kiwegu)**

5.4.3.4 Relationship with the community members

A small number of respondents (10.3%) believed that lymphatic filariasis can affect people's relationship with community members. More than a half of them (54.4%) said that people made fun of those who have lymphatic filariasis openly or secretly, while 27.2% felt scared that those with lymphatic filariasis can sleep with their partners and transmit the disease to them. The remaining 19.4% believed that those who suffer from lymphatic filariasis developed inferiority complex and felt ashamed of their condition and thus were embarrassed to relate with others in the community. This can be exemplified by this discussant excerpts from an FGD:

> *Some people with hydrocele have a very low self esteem that if one tried talking to them about their disease or advise them to seek help. They turn violent and try to even beat up a person. They can pick a fight with a person for no apparent reason. Some people are also so poor that they cannot afford the surgery, but even if they get the money they get scared that they will not fend for their families or perform their spousal duties. Others do not go for surgery because they are afraid that their families will leave them.*
> **(Male, 23 years old, FGD, Jassini)**

Most of the respondents who suffer from lymphatic filariasis do not believe that the disease affects people's relationship with community members. Of the three respondents two said that people always complain about their sadness during acute pains and one said that people use their legs as an example to illustrate or describe the disease to others while laughing at them. This can be illustrated by the following statement from a discussant in an FGD:

> *If you pass where a group of people are seated they make fun of your legs saying "ndovu huyo yuapita"* (there goes the elephant) *some even laugh at you.*
> **(Female, 26 years old, FGD, Jego)**

Some of the respondents suffering form lymphatic filariasis (26%) admitted to concealing their condition (illness) by the way they dress. This is because people laugh at them secretly and openly. The degree of attempts to conceal ones condition can also be summed from the following statement made by an informant with hydrocele:

> *When you have this load (hydrocele), it can be seen very clearly as if you are carrying a fruit in a basket than in a bag. So it is convenient for me to wear kanzu (long religious loose robe/ gown) than a normal tight trouser and shirt.*

> *When one live in a society like this one, one must try to hide ones condition especially when one does not have money, until one saves enough to pay for the surgery. I do not want to be like other people who when they realize they have this disease they start feeling like they are not a part of human race so they even forget about their hygiene and they do not dress well.*
> **(Male, 48 years old, Jassini)**

Those who conceal their condition do so for fear of stigma (30.8%), shame in being noticed (30.6%), and fear of being mocked or laughed at (38.6%). They conceal their condition by wearing napkins, religious clothes (kanzu), baggy trousers, loose shirts and long loose dresses. Most people with elephantiasis do not remove their shoes because they do not want their feet to be seen especially when they are in the first two stages of elephantiasis as highlighted by the following excerpt from a respondent with elephantiasis:

> *When you pass where people are you get a feeling that they are inwardly laughing at you, but when it comes to friends they say that one has a weak body that is why one got this disease. But I thank god that men with lymphatic filariasis are sort of more respected than women as women are teased much more.*
> **(Male, 65 years old, Jassini)**

And from this comment from a key informant:

> *Sometimes when a person has elephantiasis especially when he is a man, he wears long religious clothes (kanzu) to cover his legs. Some other men also wear more than three layers of trousers. What kind of suffering is that?*
> **(Male 54 years old, traditional healer, Jego)**

5.5 Participation in community functions

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An overwhelming majority (95 .6%) of the respondents believed that those who suffer from lymphatic filariasis should participate in social functions. Those who believed that people with lymphatic filariasis should not participate in social functions reported that they could not be of much help much since they are sick and because they could get embarrassed.

All the respondents with lymphatic filariasis said that the community allowed them to participate in all activities or community functions. The majority (94%) did not stay away from social functions. Those who stay away from social functions (2.3%) did so because they had not had sex with their wife for years and did not want people to know. A similar percentage did not want to be discriminated upon, while the remaining 2.3% felt ashamed of the condition. The degree of social exclusion in this society can be summed up by this discussion in a male FGD.

> *People who have lymphatic filariasis can participate in most activities but not all. For example, they cannot play football as the hydrocele will be too heavy for them to run and also there is no room for movement. The most common elephantiasis is for the legs and they cannot run like other people so they are excluded from activities that involve a lot of walking and running.*
> **(Male, 20 years old, FGD, Jassini)**

5.6 Family's reaction to members suffering from lymphatic filariasis

When asked how the family reacted when they learned that they had lymphatic filariasis respondents with lymphatic filariasis gave varied answers. Twenty six per cent said that their families said nothing, 18% took it as a normal ailment, while 32% were advised to go to a hospital for surgery. Other respondents (16%) said that their families sympathized with them as the remaining 8% said their families were shocked and abandoned them.

These reactions made 38% of the respondents with lymphatic filariasis feel that they were a burden to others, while (34%) felt useless as their spouse did all the work and supported the family. Some (18%) felt that they could not fulfil their marital obligations due to loss of fertility resulting from lack of erection and penetration. The remaining 10% said people often wonder why they could not just go for surgeries and get better. This can be emphasized by this story from a discussant in an FGD:

> *Some people are so scared of going for surgeries that even if they have money they refuse. So their children play a trick on them by taking them to hospital for surgery when they suffer from acute attacks when they wake up their load is already gone. For example, there was an old man in Gathini village who had a very big hydrocele that whenever he would sit down he used two chairs one for himself the other for his hydrocele. He did not want to hear anything about hospital but would only spend money on witchdoctors. Early this year he got very sick and his children took him to the hospital. He was first carried in a wheelbarrow until the main road when he woke up in the hospital he found that his load (hydrocele) was gone. Now he walks upright while a long time he used to walk bending. Villagers nowadays make fun of him by asking him why he did not die in the operating table and on how young he is looking.*
> **(Male, 58 years old, FGD, Jego)**

5.7Community reaction to those sufTering from lymphatic Filariasis

In this community people feel sorry for those who are suffering from lymphatic filariasis because there is no treatment. Over a half (55.5%) felt sorry for them because there is no treatment for this disease. Some (20.1%) advised them to seek help because they can infect others while 10.3% see it as a disease like any other. One per cent suspects they had an affair and are now suffering while 1.5% says they have inherited the disease from their parents. Two per cent felt that if they had gone to the hospital early they would not be sick while 3.4 % avoid contact with them so as not to get the disease. The concern from the villages can also be seen in this except from an interview the key informant:

> *When people see a person with hydrocele especially if he is a young man people talk in low tones asking why he can't go to the hospital for surgery as he is still a young man with no family. Others openly tell them to go to hospital for surgery just like an intervention and this sometimes makes others go for surgery. For example there was a young man here called Rashidi. He was told by his friends to go to hospital and be operated on. He could not even walk, so he agreed and now he is well. He even has a wife. Some of them are so scared that if they go for surgery they will die so they opt to carry the load. You know when you refuse to go to hospital and you have hydrocele, it reaches a point when it takes all your strength such you are unable to perform your manly duties or even work. You become useless as a human being and begin to depend on other people's their good will.*
>
> **(Male, 54 years old, Traditional healer, Jassini)**

More than a half (54%) of the respondents suffering from lymphatic filariasis said that the society acted favourably towards them. They reported that the community members did not discriminate against them (30%) and also sympathized with and advised them to seek treatment (24%). Others said that they were not treated fairly because people make fun of them openly and secretly (28%) or ignore them because they are seen as useless (18%).

When asked how they are treated by their fellow villagers, respondents with lymphatic filariasis had the following to say: 56% said that they were treated the same as everyone else, 10% said that some people sympathized with them while 12% said that they are always advised and helped by family and friends when they are sick. The remaining

22% said that people were openly disgusted with their presence and always laughed at them secretly or openly.

Most of the respondents interviewed said that the society calls them names. Further discussions during the FGDs and KII revealed that these names describe lymphatic filariasis by depicting the shape of deformity that develops due to this condition. For example discussants further gave the following names to depict hydrocele. B*usha, mabushe, ruja, football, ngiri maji, mshipa wa kutserera* are the common. However, they have names that make distinction between the two types of hydrocele, for hydrocele of both testes (round hydrocele) the names include: cashier, *tajiri* (rich fellow) *mzigo,* (load), *pakacha* (basket for carrying mangoes at the coast), *mweka hazina* (treasurer), and *paw paw mkubwa* (big paw paw). Hydrocele of one scrotum is referred to as *jug,* or *kitungi cha sita* (3 litre container). They use the following names to depict elephantiasis *matende, ndovu yua pita* (an elephant is passing) *ndovu* (elephant), *vibuti* (gumboots) and *kigingi* (tree stump).

Sixty per cent of the respondents with lymphatic filariasis reported that the disease has had some effect on their role as community members. Amongst these roles 40% said that they were embarrassed to be with members of the community because people talk about them and laugh at them. On the other hand 20% said that it reduces sexual pleasure and makes someone weak while 15% said that they were afraid of spreading the disease to members of their community. The remaining 25% said that they could not work like they used to do before.

All the respondents agreed that those with lymphatic filariasis should work. However, the respondents without lymphatic filariasis categorized the kinds of work that the society should allow people with LF to carry out. These include any work as long as they were capable of doing it (74.5%), any work that is light and does not involve walking for long distances (13.7%). Others (5.9%) believed that they should only be allowed to do fishing and farming while the remaining 3.4% said that they should only participate in weaving and plaiting. But during a focus group discussion with young men, there was a consensus that people who ride bicycles for long have a greater chance of developing lymphatic filariasis than other groups because of the long distances that they sometimes travel.

5.8 Prevention of lymphatic filariasis

The prevention of lymphatic filariasis depends largely on the perceptions of the causes of the disease, major ones being mosquitoes and sex. Amongst the respondents (52.5%) who stated that lymphatic filariasis was caused by mosquitoes, 34.8% believed that the disease could be prevented by sleeping under insecticide treated nets to prevent mosquito bites. A key informant from Vanga health centre believes that:

> *The only way we can prevent more people from contracting this disease is by distributing more insecticide treated nets and educating people on their importance. This can help in preventing the spread of this disease.*
> **(Male, 39 year old, Vanga Health Centre)**

Others (10.8%). who linked the causes to mosquitoes believed that using mosquito nets, clearing bushes, draining stagnant water and covering ponds would help prevent lymphatic filariasis but as can be seen from plate 5.3 the paths and bushes around the homesteads are overgrown. Amongst this group 6.9% believed that taking the filarial doze and sleeping under mosquito nets could also prevent this disease and, lastly, 1.0% believed the use of mosquito nets and going to the hospital both for tests and treatments can help prevent people from suffering from this disease.

Plate 5.3: Bushy path in Bondeni

Respondents who cited sex as the cause of lymphatic filariasis believed that in order to prevent this disease, people should avoid sexual intercourse with infected partners or abstain from sex (17.2%), be faithful to partner(s) (3 .4%), clean their environment and also be faithful to their partners (6.4%) and avoid drinking *mnazi* and be faithful to their partner(s) (1.5%). The remaining (14.7%) respondents had no idea on prevention and only trusted on god's protection. Only 1.5% believed the disease cannot be treated as it is found in the genes/blood.

Some (18.6%) of the respondents believed that in order to stop the spread of lymphatic filariasis, everyone should sleep under insecticide treated nets. Others (20.1%) believed in the provision of yearly filarial dozes and education of the community on lymphatic filariasis. While 23.1% of the respondents believed that people with hydrocele should go for surgery. Others (8.8%) believed in keeping their environment clean, avoid drinking *mnazi* (6.3%) and visiting health facilities or traditional healers for treatment (7.8%). Only 1% believed people should keep off foods like beans and coconuts, and cold foods. The remaining 14.2% of the respondents believed that the disease cannot be treated as it comes from god and it is exacerbated by the coastal climate.

5.9 Awareness of National Programme for Elimination of Lymphatic Filariasis

According to the Public Health Officials in Kwale, the campaign for the elimination of lymphatic filariasis in Kwale district started in 2003 at the same time as it did in other lymphatic filariasis endemic districts in Coast Province. The aim was to distribute *diethlcarbamazine* and *albendazole* to all households living in lymphatic filariasis endemic areas in the province. The campaign was supposed to take five years (2003-2007) to stop the infection but it stopped after two years (2003-2004) due to budgetary constraints. The summary of the distribution can be seen in Table 5 .2

Table 5.2: Summery of drug distribution in Vanga location

Sub-location	**Drug distribution**	**Year**		
		2003	**2004**	**2007**
Vanga	Total number of people registered	4054	5041	4267
	Total number of people who took medications	3624	3971	2513
	Total number who never took medications	644	1560	1054
Jego	Total number registered	3048	3503	4163
	Total number of people who took medications	2526	2629	2044
	Total number who never took medications	723	1135	1236
Kiwegu	Total number of people registered	2132	2590	2555
	Total number of people who took medications	1706	1564	1915
	Total number who never took medications	340	1026	640

Source: Vanga Health Centre campaign for elimination of lymphatic filariasis record books

According to the public health officials the only groups exempted from taking drugs are pregnant women, children under two years and the very sick. This is because no research has been done to verify the effects of these drugs on these categories of people. The effects of the drugs on humans include headache, bodyache, fever, dizziness, low appetite, nausea, itching, vomiting and wheezing. Other effects includes, swelling of the lymph nodes, spermatic cord, and structure in the tube where the sperms are stored. It also causes pains in the testicles.

The majority (90%) of respondents suffering from lymphatic filariasis were actually aware of drug distribution in the area, and (86%) of them received and took the drugs during the distribution. The respondents also reported that only 12% (6 people) of their family members never took filarial doze because they were away (8%), were pregnant (2%) and lack of information (2%).

During this study the majority (93.1%) of the respondents that did not have lymphatic filariasis said they were aware of the drug distribution that took place in Vanga. The majority (88.2%) of these respondents received these drugs but only 84.8% took them. They also acknowledged that 15.6% of their family members never took the drugs and gave the following reasons, increase the size of hydrocele (6%), pregnant (16%), fear of developing hydrocele (3%), used for family planning (9%), lack of information (29%)

and were away (37%). Also key informants reported that during the drug distribution a number of people never took filarial doze either because, they were pregnant, very sick, under age, absent at the time of the drug distribution or simply because they did not want these drugs.

Nearly two thirds (65.7%) of the respondents interviewed had heard about the National Programme for Elimination of Lymphatic Filariasis (NPELF). Of this group (n=134), 53 .2% said that their work included distribution of filarial doze to all people in endemic areas, 11.8% said that they train community health workers to create awareness and distribute drugs to the community, while 4.7%.said they conduct blood tests, give filarial drugs and perform surgeries. Others (7.9%) mentioned distributing filarial drugs, eradicating mosquitoes and providing mosquito nets. The remaining 10.5% said they trapped and collected mosquitoes, while 11.9 % said they cleaned ponds and wells and distributed filarial dozes to the community.

In Vanga 65.7% (n=134) of the respondents who had heard of the organization said that the National Programme for Elimination of Lymphatic Filariasis (NPELF) has done the following in order to control and prevent the spread of lymphatic filariasis. Distribute yearly filarial doze (45.4%), conduct massive blood screening (12.9%). Train community health workers to sensitize people on control prevention and treatment of lymphatic the disease (12.9%). Eradicate mosquitoes, and provided treated mosquito nets (20.8%) and performed surgeries on people with hydrocele (8%).

However, the respondents agreed that all these efforts are not enough to control and eradicate this disease. They said that more campaigns need to be conducted to create awareness on lymphatic filariasis. Also funding should be increased to help alleviate the suffering of people in endemic areas. The government should also be consistent with drug distribution and provide free mosquito nets to the entire community. They also felt that the government should conduct free surgeries or subsidize hydrocelectomy for those suffering from hydrocele.

Chapter Six

Practices in Relation to Lymphatic Filariasis in Kwale

6.1 Introduction

Different people have gone through a lot and used various methods of health seeking in order to try and deal with lymphatic filariasis. They have visited traditional healers, modern health facilities, attended prayers and used local herbs in diagnosis and treatment of the disease. They have also undergone different hygiene routines and care practices to try to manage their conditions. This chapter describes the health seeking behaviour of people with lymphatic filariasis beginning with the diagnosis, choice of health care system, and the type of treatment sought by people in order to deal with their conditions. It also highlights the practices relating to prevention and treatment of the disease both at home and in hospital.

6.2 Diagnosis of lymphatic filariasis

The diagnosis of lymphatic filariasis has proved to be a challenge to most of the health workers in the region as lymphatic filariasis is not rated amongst the priority diseases by the government as reported by a key informant in Kwale. This is because the disease is rarely fatal and mainly causes deformities which are sometimes irreversible. The degree of this challenge can be summed up in the following statements by key informants:

> *The symptoms present themselves like those of malaria or typhoid which are endemic in this arjta, and unless you notice the swellings you will think it is malaria. Sometimes when you refer them to Kisambweni for more investigations and treatment, the majority of them are too poor to even afford the fare (Ksh 600 to andfro) to take them to the hospital.*
> **(Male 42 year old, Vanga Health Centre)**
>
> *Diagnosis for lymphatic filariasis is very hard because the symptoms presented are like malaria or typhoid and since this area is a malaria prone area we initially treat for malaria. When the symptoms persist we refer them to the Division of Vector Borne Diseases (DVBV) lab in the hospital because our lab does not have the antigens to test for the disease. Another challenge that we face is that most of the patients come here when it is too late to do anything, when their limbs and scrotum are already swollen and have sometimes reached an irreversible stage.*
> **(Male 39years old, Msambweni District Hospital)**

> *By the time somebody comes to the hospital in this area, most of them would have already gone to many of the traditional healers. They only visit the health facility when they realize that things are not working. And by that time it is sometimes too late as the swellings are already irreversible.*
> **(Male, 45 years old, Vanga Health Centre)**

It is equally hard for those who suffer from lymphatic filariasis to know what they are suffering. This is due to the ambiguous nature of its symptoms. They first deal with the known like malaria, typhoid or fever before the symptoms present themselves. The majority (84%) of the respondents suffering from lymphatic filariasis became aware of their conditions only when they started manifesting the symptoms of lymphatic filariasis. Others (8%) started manifesting the symptoms after taking the filarial doze, while 2% became aware of their conditions when they were pregnant and developed irreversible swelling. Only 6% became aware of their condition when they were tested for lymphatic filariasis.

Despite the tell tale symptoms that these respondents had, less than a half (42%) accepted that they had lymphatic filariasis after diagnosis in hospital. Others (36%) were told by their families and friends, 14% were diagnosed by traditional healers/herbalist while 8% relied on their symptoms. Amongst all the respondents, only 25.5% had been tested for lymphatic filariasis. The majority of these respondents were tested during a research carried out in 2000. Only 20% of those who had undergone the test had been personally Aested in Msambweni District Hospital. They confessed that during these tests they were anxious and scared but were very glad to go for the test. Unsatisfied with the number of diagnosis of lymphatic filariasis done in Kwale a key informant said:

> *Filariasis is a problem in this district but tests are not done in Vanga Health Centre or other Health Centres in the district. The case of diagnosis is very rare as the only place to undergo this test is in Msambweni district hospital. But according to doctors in Msambweni tests for lymphatic filariasis cannot be carried out in the hospital lab. This is because they do not have the antigens to do so. When they suspect that people have lymphatic filariasis they refer them to the DVBD laboratory in the hospital.*
> **(Male, 48 years old, Vanga Health Centre)**

6.3 **Treatment of lymphatic filariasis**

Respondents who suffered from lymphatic filariasis (N=50) used different kinds of treatment to try to heal themselves or reduce the swellings. Most of the respondents had gone to both traditional healers and hospitals to try and find a cure for this disease. Some had even gone for traditional surgery in Tanzania and Kenya which involves making incisions in the elephantnoid legs or arms to remove excess water and piercing of hydrocele using bicycle rim wires or needles to remove excess fluids as confirmed by discussants in the FGDs. They also made poultices using local herbs mixed with coconut oil or sometimes petroleum jelly, and ointments like *Cussons Robb* or *Vicks Vapour rub* or *Kaluma* to massage or cover the swelling. They sometimes took painkillers, herbs or concentrated black tea to numb the pain as confirmed by those suffering from lymphatic filariasis. The kinds of treatment sought by various respondents with lymphatic filariasis can be seen in Table 6.1

Table 6.1: Treatment of lymphatic filariasis

Kinds of treatment	**Where from**	**Frequency**	**Percentage**
Medications	Hospitals and shop	10	20.0
Antifilarial, albedazole	Community health workers	9	18.0
Herbs, antifilarial, antihistamines	Shop, hospital and home	7	14.0
None		7	14.0
Tablets and Injections.	Hospital	4	8.0
Antifilarial, antihistamines.	Hospital and home	2	4.0
Herbs	Medicine men	3	6.0
Herbs, antihistamines, antifilarial.	hospital ,shop and Tanzania	2	4.0
Traditional surgery	Tanzania(traditional healer Tanga	1	2.0
Surgery	Hospital	2	4.0
Herbs, medicine,	hospital and medicine men	1	2.0
Tea leaves, antihistamines, Shop	Shop	2	2.0
Total		**50**	**100.0**

Discussants in the FGDs and in depth interviews revealed that the painkiller brands commonly used included *Hedex, Panadol, Paracetamols, Maramoja* and *Action*, which are mainly bought over the counter. And *Brufen* which was given sometimes during visits to the community health workers (CHWs) or the local health facility. The local herbs that were mainly used could be bought from traditional healers or just picked from the bush. Those suffering from lymphatic filariasis reported that they were mainly given anti-malarials and Paracetamols in hospitals, to relieve acute pains and reduce fever. But during this time everybody with lymphatic filariasis sleeps near a fire to reduce incidences of cold and shivers.

Most of the respondents with lymphatic filariasis reported having tried various methods of treatments, only 14% reported having not tried anything yet. Those who had tried any form of treatment said that they (20%) sought help from both hospitals and traditional doctors. Others (38%) had received treatments in hospitals, bought painkillers and anti-malarials over the counter (14%) and taken the filarial doze given during mass drug distribution (8%). Others (8%) drank concentrated black tea or a concoction called *subiri* (Black bitter powder mixed with water and sold in most shops at the coastal towns in Kenya) and other traditional herbs. Only 6% had undergone surgeries as shown in Table 6.2.

Table 6.2: Number of hydrocele surgeries performed in Msambweni District Hospital from 2004-2008

Month	**Year**				
	2004	**2005**	**2006**	**2007**	**2008**
January	12	9	2	7	3
February	3	6	3	2	4
March	7	7	4	7	4
April	7	5	2	1	7
May	5	5	4	4	6*
June	4	3	4	1	
	2	-	6	4	
August	7	2	6	8	
.September	4	1	2	5	
October	6	2	1	3	
November	18	8	2	4	
.December	5	1	1	3	
[Totir	**80**	**49**	**37**	**49**	**24**

Source: Msambweni District Hospital surgical register.

*2008 records were only available up to the month of May well trained to handle all diseases. Others (1.5%) would visit community health workers for advice, 3% would go to the hospital and community health workers. The other 2.5% would only visit traditional healers, (2%), would visit the hospital only if they develop hydrocele while the remaining 1.5% would not consult anybody as they believe there is no treatment for lymphatic filariasis.

Most (72.6%) of those who had lymphatic filariasis were still optimistic and consulted the hospital to get help for their condition because they had well trained personnel. Others (16.2%) had given up and did not consult anyone anymore but they believed that more research needs to be done to a find cure. Other respondents (6.4%) would only get filarial doze during drug distribution. Only 2.5% would visit hospital in case of hydrocele and consult traditional healers in case of elephantiasis. The remaining 3.3% would consult traditional healers to remove bad fluids to relieve pain because they have generational remedies as highlighted by this excerpt from a key respondent in Vanga:

> *Most people in this area visit the Kayas (ancestral shrines) to pray and offer sacrifices. This they do by slaughtering chickens and goats to pray to the ancestors to make them happy, appease them and ask them to remove their ailments. When they realize they have any ailments, they then visit traditional healers to treat their ailments and if this fails then they try the health facilities. This is very common in cases of lymphatic filariasis where diagnoses are always late and always made with the onset of the overt symptoms.*
> **(Male, 35 years old, Vanga Health Centre)**

Most of respondents without lymphatic filariasis believed that the disease can be treated as shown in figure 6.1.

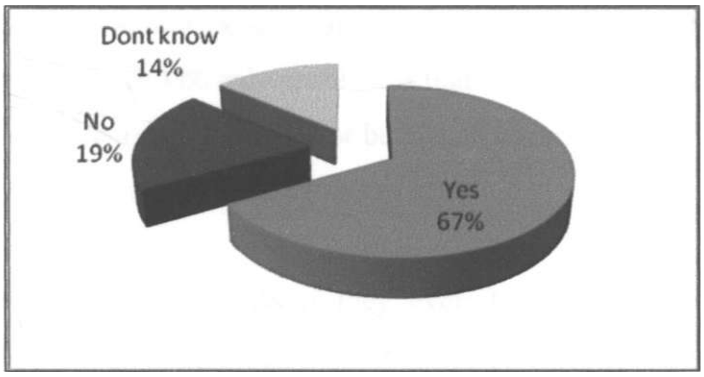

Figure 6.1: Treatment of lymphatic filariasis

Respondents have tried various methods of treating lymphatic filariasis. But **some have** given up all together and this can be seen from the following statement by a female informant suffering from elephantiasis in an in depth interview:

> *I have taken a lot of traditional medicine, gone to the hospital and nothing has happened but when I get acute attacks I still go to the hospital where I am only given painkillers like paracetamols, injections and Fansidar (anti-malarial). The symptoms are just like malaria I lack strength when I get acute attacks I cannot even walk, I shiver, I even urimte there and then because my abdomen aches and I cannot even carry up my legs. If I get an infection on the infected leg and I begin to heal I get acute pains but the last one I got was almost a year ago.*
> **(Female, 78 years old, Jego)**

The same sentiments were also echoed by a male respondent suffering from elephantiasis during the following discussion:

Moderator: *"You have said that nowadays you do not do anything to try and treat the swelling in your feet and arms so now when you get acute attacks what do you do?"*
Respondent: *"Right now even now if I get acute attacks I do not visit the hospital anymore because if I visit the dispensary they usually give me those drugs and if I try to take them I feel very bad and I begin to vomit right away. So if I get feverish right now I just let it be, 1 do not go at all".*
Moderator: *"You do not take medications? "*
Respondent: *"No I do not even try the medications from over the counter. "*
Moderator: *"So you are used to the pain? "*
Respondent: *"Yes I believe I am used to the painful attacks nowadays "*
(Male, 48 years old, Jego)

In terms of treatment, a key informant revealed that the numbers of hydrocele surgeries have not been high. According to a health official in Vanga and confirmation from focus group discussions, people try to treat hydrocele by using sharp bicycle wires to prick the hydrocele to let out excess water. This can be done by the sick themselves or by experts in this method. The only problem is that the pricked areas become septic, and sometimes cause infection to the blood or bust open causing pain or even death if one is not taken to hospital or is taken when it is too late.

When asked what they would do if they ever developed lymphatic filariasis, the majority (89.8%) of the respondents without lymphatic filariasis reported that they would go to hospital for further check up and treatment. This is because the doctors are

Among the respondents who believed that lymphatic filariasis can be treated, 39.7% believed it could be treated in the hospital, 23.5% mentioned the use of a combination of *Albendazole* and *Diethylcarbamazine* (DEC). Twenty one point two per cent believed that only hydrocele can be surgically removed in the hospitals but there is no treatment for elephantiasis (lymphoedema). Other respondents (5.8%) believed that for hydrocele the treatment is surgery while for elephantiasis it is taking a filarial doze (a combination of *Albendazole* and *Diethylcarbamazine).* Others (4.3%) did not believe in treatment of lymphatic filariasis but in prevention of mosquito bites using insecticide treated nets. The remainder 3.9% believed in taking a filarial doze in the initial stages of infection in combination with traditional and hospital treatments (surgery for hydrocele and small incisions to drain bad water from elephantnoid legs).

Among the respondents who had lymphatic filariasis (n=50), the majority (78%) believed that lymphatic filariasis can be treated. Ten percent of those interviewed sought help from traditional healers, hospitals shops and drug stores, while 36% visited hospitals or health centres. On the other hand 12% used herbs or went to traditional healers, and the remaining 42% sought help from community health workers, shopkeepers, chemists, hospitals and health centres. Most of these respondents sought help from these healers because it was affordable (78%), family's choice (10%), healer's reputation (6%), and convenience (8%).

Amongst the respondents without lymphatic filariasis who believed that lymphatic filariasis cannot be treated (N=68), 52.8% believe that nobody with the disease has ever been successfully treated as illustrated by this female discussant in an FGD:

> *I have never seen anyone getting cured from elephantiasis or hydrocele. Those with elephantiasis, their legs continue to increase in size while people with hydrocele even after surgery develop the disease again. This is because one man underwent surgery in Msambweni and now again has developed a swelling in his scrotum. Having hydrocele I believe is not normal.*
> **(Female, 45 years, FGD, Kiwegu)**

But a key respondent from Msambweni explained that the recurrence of hydrocele is °nly possible in cases where one has undergone hydrocelectomy on one scrotum. This is due to re-infection which can occur and lead to the development of hydrocele on the remaining scrotum. Others (30.9%) believe there is no cure for elephantiasis while hydrocele can be operated on. The remaining respondents believed that treatment would depend on the stage of the disease in ones body. Others believe hydrocele can recur even after surgery because it is found in the blood which is contaminated.

More than a half (52%) of the respondents reported that their treatment was normally paid for by their families while 48% paid for their own treatments. The average cost of treatment per month for lymphatic filariasis was Ksh500 as reported by 54% of the respondents with lymphatic filariasis. Only 22% of the respondents had spent Ksh 1000-5000 on treatment in a month.

Respondents with lymphatic filariasis preferred different types of treatment, 18% said that they preferred traditional healers because they are cheap, 34% preferred hospitals because they have qualified staff while 26% would love surgery to remove or reduce the swelling of both hydrocele and elephantiasis. Of the remaining respondents, 16% preferred painkillers because they are cheap, others (6%) did not prefer any of the treatments because they did not believe there is a cure for lymphatic filariasis.

6.4 Care practices for people with lymphatic filariasis

People with lymphatic filariasis need daily care and hygiene of the swollen or the affected parts of their bodies. Those who were immobilized and could not help themselves agreed that they needed care givers to help maintain hygiene of their bodies and their surroundings.

6.4.1 Hygiene Routine

Most of the respondents with lymphatic filariasis believed that taking care of the affected body parts can help to reduce infections and acute pains. About two fifth (42%) of those suffering from the disease clean the affected areas of their bodies with soap sometimes using hot water at least twice a day. Some respondents (18%) do not walk or work a lot and also clean the affected areas twice or three times a day. Another 18%

clean and elevate their limbs during acute attacks while 10% avoid being pricked by anything as this can trigger acute attacks. The remaining 22% use coconut oil, sometimes mixed with herbs, *Cussons robb* or *Vicks vapour rub*[x] to massage or cover the affected areas.

6.4.2 Care for People with Lymphatic Filariasis

Forty per cent ofthe respondents with lymphatic filariasis are cared for by their families during acute attacks, while 36% are cared for by their wives. This was explained in a discussion by an informant suffering from elephantiasis.

> ***Moderator:*** *"So who takes care ofyou when you get acute attacks? "*
>
> ***Respondent:*** *"Like the other day I got an attack when I went to Tanga in the morning. You see ifI get an attack this leg (points at his right leg) it has reached a stage that I cannot even move my legs or walk. So ifI am at home in my house I do not even leave to go to the toilet, I am brought a basin and ifIfeel pressed to go to the toilet Ijust do it there and my wife throws it in the toilet. But the other day when Igot it awayfrom home. "*
>
> ***Moderator:*** *"What didyou do? "*
>
> ***Respondent:*** *"when I woke up in the morning I went to the toilet but on coming back to my room Ifell down I cannot even explain it myself I wasjust shocked that I was already on thefloor. During this time I lost consciousnessfor some time and my nephew came in asking, "what is it uncle "?, I told him that I was ok and that it was a normal thing with lymphaticfilariasis and that I would get up on my own. Later on I got up and went to bed. That was the second time that I had collapsed in a hotel awayfrom my wife, and the way I look at it this disease will kill me awayfrom home one* ***dtjy.*** *That is why right now ifIget an attack I do not want to leave and go to relieve myselfIprefer to use a container which my wife can empty later. "*
>
> ***Moderator:*** *"So it isyour wife who takes care ofyou whenyou are sick? "*
>
> ***Respondent:*** *"Yes, she is the one who helps me. "*
>
> **(Male, 48 years, Jego)**

The others (12%) are taken care of by their husbands while the remaining 12% take care ofthemselves because they have been abandoned or are alone.

The majority (77.5%) of people without lymphatic filariasis (N=204), believed they would interact with, care for, participate in family things together, and live with them and use the same household goods. Others (13.8%) said they would interact with them and participate in family functions, while 7.4% would take care of them, participate in family affairs together and even live with them. Only 1.5% said they would not want anything to do with them completely.

Chapter Seven

Discussions, Conclusions and Recommendations

7.1 Introduction

The discussion on the findings of perceptions, experiences and practices of people with lymphatic filariasis in Vanga location of Kwale district are presented in this chapter. This is followed by conclusions and recommendations.

7.2 Discussion

In as much as lymphatic filariasis afflicts both males and females in the community, gender distribution in the study showed that the numbers of males with lymphatic filariasis were more than women. The study also showed that the burden of hydrocele was greater than that of elephantiasis. This proves that the incidences of lymphatic filariasis in men are more than that of women. These findings support similar findings observed in other studies of lymphatic filariasis. In a Haitian study, Lammie *et al.,* (1994) found that more males were infected than females and the incidence of disease was higher in males. On gender as a risk factor for lymphatic filariasis prevalence in adult populations, Brabin (1990) found a predominance of infection among males. The 120 million cases of Lymphatic filariasis included 83.63 million cases of microfilaria carriers, 16.02 million cases of lymphoedema, and 26.79 million cases of hydrocele; this clearly shows that the burden of genital manifestations in filariasis in terms of hydrocele is greater than ffiat due to lymphoedema. Also in a multi-centric study conducted by the Programme for Research and Training in Tropical Diseases (TDR) in 1992-1995, on clinical epidemiology of lymphatic filariasis in India, Ghana, Tanzania, and Philippines, the prevalence of lymphoedema was lower than that of hydrocele in all study areas (WHO 2002).

7*2.1 Local knowledge about lymphatic filariasis

In this study the respondents were aware of the various manifestations of lymphatic filariasis ascertaining that people in Kwale know about the disease. This is because the majority of people in this area live with, have relatives or know people who suffer from lymphatic filariasis. People who suffered from lymphatic filariasis included both men and women, majority being men with hydrocele. The disease is also not discriminative as it attacks both residents and immigrants to this area and many households are taking care of those who are either suffering from hydrocele or elephantiasis.

The widespread knowledge of lymphatic filariasis is based on the outward manifestation of hydrocele and elephantiasis and also on the acute attacks suffered by those with outward manifestation of the disease. Similar findings have also been seen in Papua New Guinea where the bio-scientific definitions of lymphatic filariasis made it very difficult to explore the nuances of the local names, definitions and descriptions of the disease. The widespread use of the word *"pom"* to describe lymphatic filariasis strongly indicated that local understandings of the disease were confined to outward gross manifestations of elephantiasis (Carron *et al.,* 2007). In a multi- centre study carried out by Gyapong et al (2000) in Kenya and in Ghana it was found that in Kenya the majority (99%) of the community members interviewed reported they had heard about elephantiasis and hydrocele

7.2.2 Perception on the causes of lymphatic filariasis

The concept of causality in Africa is very complex as it goes beyond the scientific western explanations of the causes of a phenomenon, be it death, disease, accident, good harvest, drought. In Africa, there exists a belief in the dualist system of disease causation the natural and the supernatural (Imperator 1976). In this study the perception of the causes of lymphatic filariasis was very important in understanding the health seeking behaviour of people with the disease. The perceptions of lymphatic filariasis have remained multi-factorial and have been influenced by the traditional and superstitious beliefs that are found in this community. The majority of the people attributed the cause of lymphatic filariasis to mosquitoes as they had been taught by community health workers and in school. Also this area is a low lying swampy area covered with shrubs, bushes and mangrove forest with huge tracks of uninhabited land. This makes the area a perfect breeding ground for mosquitoes.

In Kwale the perceived causes of lymphatic filariasis include mosquitoes, sexual intercourse with infected partners, coconuts and its products, witchcraft, weak immune system, dirty water, inheritance, foods, filarial doze and god's will. This indicates consistencies with other studies in areas affected by lymphatic filariasis. Studies by Gyapong (1996) Ahorlu *et al* (1998) and Amayunzu (1997) have shown that beliefs about the cause of lymphoedema include heredity, supernatural and spiritual causes, and natural causes such as injury, standing in cold water, stepping on insects, and ingesting unhygienic food or drinks. While the causes of hydrocele vary by culture and geography, they can be grouped into supernatural causes (including witchcraft and sorcery), heredity, exposure to extreme heat or cold, excessive sexuality, and consumption of certain foods or drinks. According to Addiss and Brady (2007) few studies mention mosquitoes even in regions where mass drug administration and health education have occurred.

Despite the fact that over a half (54 .9%) of the respondents said that lymphatic filariasis was caused by mosquitoes, a majority also mentioned other agents other than mosquitoes and this came out quite clearly during the FGDs. Quite a number attributed the cause of hydrocele to sex with infected partner(s). This is consistent with an earlier study carried out in the same area (Amayunzu, 1997). Another study carried out in Papua New Guinea suggested that sorcery and witchcraft are the cause of elephantiasis (Wynd *et al,* 2007). In a study carried out in the Southern Pacific Ocean Archipelago of Vanatu, 56% of the people surveyed knew that filariasis was transmitted by mosquitoes while 26% said they did not know how it was transmitted. Other answers included by mosquitoes, by sexual transmission, through the MDA drugs, by swimming in dirty rivers, through food, and cultural related beliefs such as stepping in someone's footprint or sleeping by a certain stone (Amos *et,al.,* 2005).

Other findings of this study suggested that infidelity especially on the part of the mother, was to be blamed for incidences of hydrocele or elephantiasis in offspring. If a child whose family has no history of lymphatic filariasis develops the disease, the mother is always blamed for moving outside the marriage because she might have been contaminated with filarial worms during her sexual encounter. This implies that the society relates lymphatic filariasis to a punishment for infidelity. Similarly in a study carried out in Nigeria, one of the causes of lymphatic filariasis was punishments from gods because of promiscuity and infidelity (Nwoke *et al*., 2000). On the contrary a study on influence of maternal filariasis on childhood infection and immunity, showed that Kenyan children whose mothers are infected with the filarial parasite *Wuchereria. bancrofti* have an increased risk of filarial infection compared with children whose mothers were not infected (Indu *et al.,* 2003). This could possibly imply the existence of congenital transmission of lymphatic filariasis. Other studies have also indicated that children of both *microfilaramia*-positive mothers and fathers are more likely to be *microfilaramia* positive than children of *microfilaramia* negative parents (Das *et al.,* 1997).

Other people attributed alcohol from coconuts to be the cause of lymphatic filariasis. This is because a majority of people who suffer from lymphatic filariasis also drink the local brew made from coconuts. The major reason why this belief has persisted could be because most of the people who drink this local brew stay out in the open drinking till late in the night. This increases their chances of being repeatedly bitten by *microfilaremia* carrying mosquitoes and so become infected with the disease. Others also get so drunk that they sleep in the open or do not use insecticide treated nets. This could be the reason that immigrants to this area would use to prevent their families from eating coconuts, food cooked in coconut juice, or drinking alcohol made from coconuts. According to Ahorlu *et al.* (1999) excessive drinking of palm wine is one of the factors that is perceived to enhance the development of hydrocele in Ghana. Other studies have also indicated that people believe that lymphatic filariasis is caused by the type of foods that people eat. In a Malaysian study by Haliza and Mohd (1986), consuming contaminated food or drink was commonly implicated as the source of infection.

In a study carried out in Ghana (Ahorlu, *et al.,* 1999) the respondents did not accept the mosquito theory of transmission, but believed in other physical, spiritual and hereditary causes. This is because in most African societies when people cannot understand the cause of a disease they do not ask for how it happened but for why it happened. In this case one of the logical explanations is witchcraft because people will rest assured that at least they have found a way of explaining the illness. Witchcraft has also been one of the causes of lymphatic filariasis in this study. Initially it was believed to cause both hydrocele and elephantiasis, but ever since people realised that hydrocele can be surgically removed, witchcraft has been mainly linked to elephantiasis. This is because once the deformity occurs in elephantiasis it becomes irreversible as there is no cure. The reverse is the case in a study in Eastern India where a high proportion of people knew that mosquitoes were the reason for the spread of elephantiasis, but fewer people were aware of the cause of hydrocele and the association between elephantiasis and hydrocele (Babu *et al,* 1999).

This study also noted that a few of the respondents believed that suffering from lymphatic filariasis was due to destiny as they had been selected by god. It is for this reason that the Mijikenda resort to have Kaya's to pray and ask for god's protection and help. A study conducted in both the Dominican Republic and Ghana also revealed that people turned to god or prayers in the hope of healing, comfort, and strength when suffering from lymphatic filariasis (Addiss *et al,* 2008).

Our findings also revealed that the respondents believed that the disease can either be inherited or can be due to a weak immune system. Results from studies conducted in Ghana also showed that people believed that lymphatic filariasis is hereditary (Gyapong *et al,* 1996). This is because most of the people who suffered from lymphatic filariasis have had generations of family members suffering from either hydrocele or elephantiasis. Others have either parents or siblings suffering from the same disease, so they and the community conclude that it is a generational disease which is inherited or passed down from one generation to another. In a study carried out in Ghana some respondents believed elephantiasis could be hereditary because the disease was found across generations in particular households. It is also believed that hydrocele runs in the family because it is transferred from father to son through the semen during sexual intercourse (Gyapong, 2000). Others believed that they get lymphatic filariasis because they have a weak immune system. This was justified by the fact that in a household where people live under the same roof and eat the same foods, some members develop the disease while others do not. They describe this situation as *kmva na mwili mbovu* (having a weak body).

7.2.3 Experiences of People Suffering from Lymphatic Filariasis

The study population is well aware of the outward manifestations of lymphatic filariasis because the disease is manifested at the extremities including elephantiasis, hydrocele, and *Adenolymphangities* (ADL) attacks. And the fact that all respondents could describe in detail the symptoms of the disease suggests that the community was well aware of the symptoms of the disease. This high level of awareness of the symptoms of the disease could be linked to the fact that the area is endemic to lymphatic filariasis and more than a half of the respondents had experienced the disease themselves or in their families. Wamae *et al,* (2006) also relate the high awareness of lymphatic filariasis in the coastal region to the endemicity of lymphatic filariasis in the region since 1910. Other studies in endemic areas also associated filariasis with the chronic signs of lymphatic filariasis, including hydrocele, *Adenolymphangities* (ADL) and elephantiasis (Wynd *etal.,* 2007)

In African societies a person can only be counted as a member of the society when they marry and have children. This way, they can leave a legacy or can be remembered through their descendants-These two stages of life can be affected if an individual is suffering from either elephantiasis or hydrocele. Thus some people in the study area believe that people with lymphatic filariasis should not marry or have children and that those who marry and have children should do so before the disease manifests itself or after hydrocele surgery. This came out clearly during the FGDs. Men who suffer from hydrocele were seen as or saw themselves as useless (*wana ubovu).* Similar findings have also been seen in other studies, in a health related stigma study among women with lymphatic filariasis in Dominican Republic and Ghana, many women thought less °f themselves after suffering from lymphatic filariasis than before this condition (Addis et Ql, 2008). That is why some partners leave as soon as the other starts developing the disease. Once a person has hydrocele or elephantiasis they can only be allowed to get married to orphans, divorcees or in arranged marriage especially when the partner or the family is rich. Similar findings have also been seen in Ghana where women only marry men with lymphatic filariasis in arranged marriages because they have little choice about whom they marry and also because want to please their families (Gyapong, 2000).

Additionally, men with hydrocele avoid marriage because they are shy in bed and sometimes have reached a stage where they cannot participate in sexual intercourse because the penis has been embedded in the voluminous scrotum. According to a study carried out in India (Babu *et ai,* 2009), the most worrisome effect of hydrocele for patients and their wives was the inability to have a satisfactory sexual life. The majority of patients (94%) in this study expressed their incapacity during sexual intercourse, and another majority (87%) reported pain in the scrotum during intercourse. Others in the community believed that they should not be allowed to marry as this will transmit and spread the disease to others in the community through their wives and their offspring. This has made people in this society believe that family members of those suffering from lymphatic filariasis will have a hard time getting spouses. Others are also scared that they will get sick and therefore disrupt the labour and utilization of family resources. This belief is also found in other societies for example a study carried out in Ghana (Gyapong, 2000), revealed that unmarried people have a problem getting married when they have filariasis. In the Ghana situation, men, revealed that they would never allow their daughters to marry men who have hydrocele because their daughters might not have children. Also men were adamant that those who marry women with filariasis would have to pay for their treatment and care while receiving no significant help from them (Gyapong *et ai,* 1996) thus they were considered useless economically.

Although some of the community members believed that people with lymphatic filariasis could not father a child, most of them acknowledged that this was only Possible when the hydrocele has become so big that it has covered the whole penis They say that if they marry during the early stages of hydrocele when the penis is still intact and only the scrotum is swollen then they can father as many children as they like. In Ghana for example (Hunter, 1992) men conceal and deny having hydrocele and all those who acknowledge their infection eagerly point to their offspring as evidence to their continuity virility while in the Philippines (Lu *et al,* 1988) hydrocele was considered serious only when overgrown. Also the majority of these respondents believed that women could get pregnant as long as they were fertile because they only suffered from elephantiasis. But for those who believed that elephantiasis is found in the blood, the majority believed that those who had lymphatic filariasis had their sperms or their ovaries mixed or affected by filarial worms because they attack places with lymphatic systems and the sperms and ovaries are located near these regions in the body. This, they believed can make an individual infertile and hence incapable of fathering children or conceiving. The situation is similar to that in India (Bandyopadhyay, 1996) where women who considered the disease hereditary blamed themselves for passing the disease to their children. Similarly in Ghana (Gyapong *et al.,* 1996) women also believe that their offspring developed the disease because it was transferred from father to son during intercourse.

According to this study, lymphatic filariasis was noted to occasionally cause a strain in the relationships of the sufferers with other members of the community. This could sometimes cause marriages to break or lead to distrust. It could also lead to problems with ones children family or the community, leading to disagreements and sometimes abandonment or underhanded behaviour.

Other respondents acknowledged that lymphatic filariasis affected relationship between the spouses. This was mostly true in cases of hydrocele, where the enlarged scrotum can reduce a man's virility and sexual performance which interferes with sexual satisfaction. In Ghana (Ahurlo *et al.,* 1999, Gyapong *et al,* 2000), both community members and men with hydrocele reported that hydrocele impeded sexual intercourse, sometimes leading to divorce. In Brazil, Dreyer *et al* (1997) reported several concerns of men with urogenital disease, including hydrocele, which ranged from lack of intimacy in marriage to thoughts of suicide.

Lymphatic filariasis was also believed to cause mistrust amongst couples because some would claim that the partner has been moving out with other partners and has been contaminated, and therefore responsible for the disease. Also when a child develops the disease the mother will be blamed for being promiscuous unless it is found in the family. Ever since the community learned that hydrocele can be surgically removed, wives force their husbands to go for surgery but some men are scared because they think they would die in the operating table. Many wives persuaded their husbands to remove hydrocele by surgery (Babu *et al*2009). This brings a lot of problems between them as some spouses feel ashamed and uncomfortable with their conditions. Others will insist that they go for surgery because other community members embarrass their family because of the spouse's condition. Others also leave because they cannot handle the painful acute feverish attacks that plague people who suffer from this disease as they are not sick like them. They also make this decision because the cost that they incur during treatment put a strain on family's finances and sometimes drain all the family resources, so most partners decide to leave before they get into financial troubles.

Relationship with children was sometimes strained as some abandoned their parents when they developed this disease as they were ashamed of them. This was because members of the community would mock and even isolate them due to their parent's condition. Some of the children believed that the disease caused a strain in the family resources because most ofjhe finances were spent on medication instead of food and maybe school fees. Others also made this decision as not to take care of their parents or their needs and just ignore them completely. This situation was also found in the Philippines where Lu *et al* (1988) report that family members always feel the impact of the illness more because they are stigmatised along with their ill father. In Ghana (Persons *et al.*, 2009) children of women with lymphoedema were often the subjects of courtesy stigma, teased and insulted about their mother's condition due to association with her. In Haiti (Addiss *et al.,* 1998) patients reported that their children had the most difficulty in coping, as they were often teased or embarrassed about the mothers'

Some family members abandon their own because they are afraid of being infected with filarial worms and thus they lack anyone to take care of them when they are sick. Others abandon them because they feel ashamed of their conditions and ignore them as they did not want to be associated with them. Those who suffer from lymphatic filariasis said that the disease can cause a strain with family members because some use abusive words against them and also make fun of them. These findings are also similar to those in the Philippines where men are teased about carrying their wealth in their enlarged scrotum (Lu et al, 1988). This is because they neither care nor are bothered by their condition. People with lymphatic filariasis are also seen as inferior or see themselves as inferior to others in the society and this makes it very difficult for them to get along with others. According to Gyapong (1996), hydrocele threatens the integrity of male bodies by devastating an organ that is associated with self esteem, fertility and masculinity which can render any man inferior or have low self-esteem.

The findings of this study show a common belief in this community that if a person with lymphatic filariasis has sex with anyone that they will infect or transmit LF to them. People are always suspicious of LF sufferers and thus choose not to associate with them. This has led to a situation whereby people mock those who have LF and make fun of them. This is very common and has led to some developing inferiority complex. Similar findings can also be seen in Ghana and the Dominican Republic (Persons *et al.,* 2009) where respondents reported being teased, shunned, marginalized, gossiped about, and discriminated against. Such treatment often resulted in labelling, public rejection, forced exclusion from social situations, and differential treatment in educational and health care settings

Due to the stigma associated with this disease people with lymphatic filariasis admitted to concealing their condition by the way they dress and walk until they get money to go for surgery in case of hydrocele. Those who had elephantiasis admitted to concealing their conditions while looking for cure until the elephantnoid limb reaches a stage when they can not hide it anymore. Since having lymphatic filariasis is seen as unnatural, people feel ashamed to reveal their condition. In a study done in the study area (Amayunzu 1997) most patients felt that their physical appearance influenced community reactions towards them. These reactions varied from sympathy to neglect. To protect themselves, men with hydrocele wear nappies to prevent hydrocele from hanging, they would also wear baggy clothes and religious clothes. Those with elephantiasis wear shoes for as long as they can, they even increase the shoe size as the disease advances. In a study carried out in Ghana, Hunter (1992) also noted that men conceal and deny having enlarged or scrotum elephantiasis.

People that live in this area are close knit and are bound by kinship. They are all required to participate in all functions together; people are not discriminated against on whatever basis. Since this is a requirement people with lymphatic filariasis are allowed to participate in any activity they so wish to. However some people in the community still do not approve of their participation, while those with LF sometimes feel that they cannot contribute much to the preparations and subsequent activities as they are always sick or are hampered by their deformities. Others are afraid of being discovered or made fun of by their colleagues. But most of the people with this disease confessed that they particularly like dancing and singing which is a very integral part of coastal culture. A study on lymphatic filariasis related perceptions and practices on the coast of Ghana (Ahorlu *et al.,* 1999) established that, generally, victims of clinical manifestations of lymphatic filariasis were accepted, sympathized with and cared for in the communities. They were allowed to attend and contribute at community gatherings, but most of them hardly attended because they felt ashamed of themselves. But Nwoke *et al* (2000) reported that villagers in some parts of Nigeria expressed fear and insecurity towards people with filarial skin lesions and men with genital complications and elephantiasis of the extremities.

The reactions of community members to those suffering from lymphatic filariasis were diverse. The majority of people generally sympathized with those who were suffering from lymphatic filariasis and even offered advice and help to alleviate their situation. Most of the respondents suffering from lymphatic filariasis acknowledged that some people were disgusted by their appearances and called them names, they were also openly laughed at and made fun of. This made them so insecure and angry, and sometimes it led to altercations with other community members. Some people in the community saw them as totally useless and ignored them because they were hampered in many ways and sometimes could not help much when it came to physical activities. Persons *et al.* (2009) also noted that women in Ghana and Dominican Republic, reported being teased, shunned, marginalized, gossiped about, and discriminated against. Such treatment often resulted in labelling, public rejection, forced exclusion from social situations, and differential treatment in educational and health care settings. The women described emotional responses of feeling anger, shame, humiliation, and emotional and psychological distress when coping with gossip, teasing, rejection, exclusion, and differential and poorer treatment in institutional and community settings.

People with lymphatic filariasis felt that their roles as members of this community had been affected because of their deformities. Due to embarrassment most of them avoided communal gathering or associating with other community members because they were afraid of being the subject of conversation every time. In Ghana Ahorlu *et al.* (1999) found that patients with chronic manifestations were not permitted to become chiefs, because these are supposed to be without deformity. It was also reported that patients with chronic disease were subjected to ridicule and teasing in the community. Others avoided communal gatherings because they were afraid that they would transmit the disease to other community members who came into contact with them. This isolation affected their relationships with others and also their contribution to the welfare of the society. Others complained that lymphatic filariasis robs a person of sexual satisfaction and pleasures and sometimes renders a man totally unable to have sex. Similar findings have been seen in Ghana where lack of sex or sexual satisfaction due to hydrocele has led to some cases of divorce (Ahorlu *et al.,* 1999).

Most patients feel useless because they cannot contribute to the wellbeing of their families. The understanding that they cannot work like they used to in the farms to feed their families also lowers the income of the household and renders them useless as members of that household. Most of them end up being dependants and this really hurts. Kumari *et al.* (2005) also noted people with lymphatic filariasis could not work the way they used to due to ADL attacks, and weight and size of hydrocele and elephantiasis which made movements strenuous and painful. This limited the time they would spend on their work and sometimes incapacitated them completely sometimes making many of them switch to less demanding occupations. Simple things like sitting down and getting up from the toilets were extremely painful; these conditions caused severe anxiety and depression.

The reaction of family members influenced the experiences of those who were suffering from lymphatic filariasis. This study found that most of the families were sympathetic and tried to help their members who had the disease by offering advice, especially on treatment options. The patients were also happy that their families considered the disease normal and treated them like any other person. The study also found that some families did not react at all to this condition, maybe because it is a common ailment in the area. Nevertheless, a number of patients were abandoned by their shocked families. So a person can have favourable experiences or not depending on their family's reaction in cases of lymphatic filariasis. In a study conducted in Ghana, Hunter (1992) found that when community members were asked about their reactions to men with hydrocele, those who had family members with hydrocele expressed understanding and sympathy, while others tended to joke about it

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Due to their experiences as seen in this study most of the respondents having lymphatic filariasis were in a state of helplessness. This was because some felt that they were a burden to others as they were being taken care of physically and financially, especially during acute fever attacks. Others felt that they were useless because their spouses had to do all the work as they were unable to contribute or perform their duties. Others felt useless because they could not fulfil their marital obligation and this can hurt any marriage. Some patients especially those with hydrocele felt that people around always Pass judgement on them. Some believed that people wonder why they cannot just go for surgery and remove the hydrocele. This makes them suspicious of anybody looking at them or just talking and laughing. This is because the topic is all about their condition and this has made them paranoid and sometimes cruel to others. Some studies suggest that people with lymphatic filariasis develop suicidal tendencies due to stigma which causes anxiety and depression Gyapong *et al.* (2000). Indicated that men with hydrocele often describe themselves as frustrated, losing hope and even become suicidal.

7.2.4 Prevention of Lymphatic Filariasis

From this study it came out very clearly from the respondents who believed that mosquitoes cause lymphatic filariasis, that vector control and eradication of mosquitoes was the most important factor in the fight against the disease. This they are doing by clearing bushes, draining stagnant water, spraying their houses with insecticides, and sleeping under treated nets. The government on the other hand is engaged in free distribution of insecticide impregnated nets for pregnant women and mothers with children under five, and selling of mosquito nets at a subsidized price of Ksh 50 per net in the health facilities. Apart from these campaigns, the government has also funded the distribution of *diethylcarbamazine* and *albendazole* in endemic areas by setting aside a vote in the Ministry of Health budget while WHO provided the drugs.

Despite the steps the government has taken to provide treated mosquito nets either cheaply (Ksh 50 per net) or free to pregnant women and children in mosquito endemic zones, not all species of mosquitoes can be eradicated using these nets. Studies have shown that permathrin treated mosquito nets are only effective in reducing only *anopheles gambiae* to 5% (Mbogo *et al.,* 1996). That *Anopheles fenestus* is only irritated by the nets and changes its feeding habits to ruminants and birds and also its resting place to outside (Borg *et al.,* 1998). And that *Culex quinquefasciatus* are less susceptible to permathrin impregnated nets and other insecticides (Magesa *et al.,* 1991, Borg *et al.,* 1998). and that while their indoor resting patterns are not changed, the nets marked a shift from feeding on humans to feeding on ruminants (0.4%) and birds (85.2%) proving that *Culex quinquefasciatus* is maintained even when human blood meal is restricted. These studies have demonstrated that not all mosquitoes can be controlled or eradicated using insecticide treated nets.

7.2.5 Health Seeking Behaviour of People with Lymphatic Filariasis

The outward manifestation of lymphatic filariasis contributes to the understanding of people's health-seeking behaviour and factors influencing their decision to self-report with lymphatic filariasis related signs and symptoms. The findings suggest that people suffering from lymphatic filariasis explored popular, folk and professional sectors in seeking cure and treatment. The choice of their health care was determined by the perceived causes of the disease. It also became apparent that they explored two or all the three sectors of health in seeking treatment. Some of the respondents used two or three sectors of health in their search for treatment. From the focus group discussions, it became evident that most of the respondents first used known local herbs available in this area to treat the symptoms of the disease which were mainly in the form of acute attacks. The families were very influential in this case as they would fetch and prepare these herbs for use. The head of the family would also offer prayers and sacrifice in their family Kaya to request for good health in their families. This would sometimes be done in conjunction with over -the -counter pain relievers like *Panadol, Hedex, Maramoja, Action* and *Brufen* to relieve pain and fever and antibiotics to reduce infection. When this fails the family or the individual would then decide to go to visit either a traditional healer or the nearest hospital or sometimes both to look for diagnosis.

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A similar study by Gyapong *et al* (1996) found that patients seek treatment from local health centres, traditional healers, and self-medication. The study revealed that modern medical care is often avoided due to lack of interest from health care workers and a belief by patients that lymphoedema treatment requires spiritual interventions (Gyapong *et al,* 1996). In contrast, in areas of India with networks of public healthcare facilities, most patients seek care from modern medical practitioners, although a minority consult Ayurvedic doctors or use home remedies first (Suma *et al.,* 2003). According to this study, access to care is not necessarily universal, as young women in India may not seek treatment because of social constraints, such as the paucity of female doctors.

Due to this duality in the search for treatment, there occurs sometimes an overlap of two or three health sectors as described by Kleinman (1980) and more than 40% of our respondents in this study have used all the sectors at the same time. According to this study the most common sectors used here were an overlap of the popular and the professional sector, where people bought painkillers to relieve pain during acute attacks and antibiotics to reduce infection. They also visited hospital to try and find treatment for their condition or get medications especially injections to reduce infection.

Diagnosis of lymphatic filariasis is a problem as the hospitals in Kwale are not well equipped to handle the early diagnosis of this disease. In this area it was evident that the majority of the people learned that they had lymphatic filariasis when they started manifesting the symptoms of the lymphatic filariasis. Knowing that one is suffering from this condition becomes problematic as the disease is common among the large number of infected persons who do not have overt clinical symptoms. Most respondents only knew their actual condition after experiencing the swellings in their limbs or scrotum. The situation was also similar to that found by Addiss and Brady (2007) in Papua New Guinea where Misima islanders associated lymphatic filariasis infection only with the chronic visible manifestation of filariasis and other unrelated diseases.

Upon diagnosis most people with lymphatic filariasis, especially hydrocele, got scared because they knew that they had to undergo surgery in order to remove the swelling. This was because of the fear of dying on the operating table, becoming impotent or having reduced libido. According to Gyapong *et al.* (2000) a study of men with hydrocele in Ghana noted that their fear of "temporary death" while under anaesthesia prevented them from going to the hospital. Though the greatest desire for a man with a hydrocele in the study area was to have surgery, the fear of death and cost of the operation seemed to be a problem. However the situation was totally different for those suffering from elephantiasis as there was no surgical relief for their deformity. Most of them felt a lot of pain and anger because they were going to live with their deformities for the rest of their lives. It did not matter whether one was rich or poor, because there is no treatment or cure for it. This has led to a situation where most of the people with lymphatic filariasis especially elephantiasis, are resigned to their fate. However some of them have developed a positive attitude as they see it as a disease like any other.

7.2.7 Treatment of Lymphatic Filariasis

Every respondent suffering from lymphatic filariasis had gone through varied methods and utilized all the three sectors of health in seeking treatment. Some even went across the border in Tanzania trying to find a cure for elephantiasis. The most common treatment given locally was the removal of excess fluids by making incisions or using sharp hollow wires or needles on the elephantiasis and hydrocele respectively by experts or individuals who suffer from the disease. This only offers short term relief and is very dangerous as these instruments are never sterilized and have led to painful infections that can cause hydrocele to bust and sometimes lead to death if not treated. People use this method because they are afraid of surgery or of being discovered by their peers to be suffering from this disease. However the method is very dangerous because it can lead to injury and damage a patients' reproductive organ. The infection can also become septic and lead to death, or impede treatment when one opts for surgery at a later date after a long period of fluid letting. This is because the skin becomes thickened and this can be challenging during surgery. There is a possibility that objects used during fluid letting (razors, surgical knives, wires and needles) of being used on different people at different times and without sterilization this can be a source of transmission of diseases such as HIV/AIDS from one person to another. The other documented folk surgery was in the Philippines by Lu *et al.* (1988) who noted that folk surgery was performed by a patient turned healer in the process of discovering a cure for his ailment. This he did by putting his scrotum in two bamboo splits and incising it with a blade to remove the fluids and then putting it back together, applying the juice of the *dapdap* leaves while taking penicillin twice a day. The other documented folk surgery was by Bandyopadhyay (1996) in India where women decided to operate on themselves to remove swollen nodules from their breasts with a sharp instrument.

Since self-medication is a worldwide phenomenon (Haider & Thaver, 1995), there was a very extensive use of painkillers both traditional and conventional to relieve pain during acute attacks. The traditional healers use an assortment of roots, leaves and barks of trees to treat people, as seen in Plate 2.4 (pg 16). There was also a very widespread use of painkillers, antimalarials and antibiotics that are sold over the counter by both shopkeepers and community health workers. This made it easier for anyone who felt pain to obtain medication to numb pain until the end of acute attacks, especially for those with elephantiasis. In the absence of these, people use concentrated black tea or ground herb called subiri found in most shops. This was done in conjunction with sleeping near ongoing fire for the duration of acute attacks to reduce pains and shivers. Also in northern Ghana Gyapong *et al* (1996) also noted that most people with ADL tended to treat themselves. They would normally buy analgesics and antibiotics from drug peddlers in the market place, apply '*Chinese Robb*' to the leg and hydrocele or use herbal preparations recommended by family and friends.

Despite the fact that hydrocele can be removed through surgery to remove the swollen sacks that retain fluids around the testis, very few people had undergone this surgery in the period 2004 to May 2008 in Msambweni District Hospital which is the major hospital in Kwale district see table 6.1. As at 2008 hydrocele surgeries were charged at KSh 2500 plus five hundred shillings for bed occupancy and other hospital charges for four days before the patient was allowed to go home. This comes to Ksh 3000 which in most cases is out of reaclf of most of the patients. This is also compounded by high transport cost which is about Ksh 1000 to and fro per person.. The situation is also the same in other parts of the world where lymphatic filariasis is endemic studies by Gyapong *et al* (2000) in Ghana, Lu *et al* (1988) in the Philippines, Ramaiah *et al* (1999) in South India revealed that hydrocelectomy is too expensive for a majority of people who are inflicted with this debilitating disease. Therefore many who would otherwise undergo this surgery avoided it.

The other reason for lower surgery rates are that hydrocele is not life threatening and some people who have it can still perform their duties so they would rather use the money scheduled for surgery on other things that can bring benefit to their families. Psychologically most people are not prepared to undergo surgery for fear of death, and will put off the surgery even if they have the money. Similar findings were also noted by Gyapong, (1996) in Northern Ghana where respondents reported that surgical operations irrespective of how minor they may be are considered a matter of life and death and for this reason surgery is not popular.

Another reason why so many people who can afford surgery do not opt for it is because there have been cases where one has undergone surgery and developed hydrocele again. This is because when one has hydrocele on one scrotum and it is removed there are chances that the other side can also be infected if a person still has filarial worms in their system. This has made some people believe that lymphatic filariasis cannot be treated as it can recur. So they have opted not to seek any form of treatment to remove hydrocele because they think it is a waste of money. Similar findings were encountered by Amayunzu (1997) where, 90% of respondents with lymphoedema and/or hydrocele believed their disease was incurable. This may have been influenced by the experience of two elderly men in the area who had a recurrence of hydrocele after surgery.

The study also showed that most people with lymphatic filariasis maintain a high level of hygiene by bathing at least twice a day. This might also be occasioned by the type of weather that is found in this area which is hot and humid. But this was challenged during the focus group discussions where people admitted that maintaining hygiene was a problem amongst people with severe lymphoedema as most of them depended on their families for care as they had difficulty in mobility and could not even fetch water for bathing. When they develop acute attacks or are incapable of performing their duties as they used to, their families assume the responsibility of caring and supporting them.

7.3 Conclusion

Since sustainable health gains depend on understanding and accommodating local beliefs, this study has explored the common perceptions, experiences and practices of people with lymphatic filariasis in Vanga location of Kwale district. People in this area know about lymphatic filariasis as the majority have lived with or seen people with this disease throughout their lives. Despite the fact that most people cited mosquitoes as the cause of lymphatic filariasis, people here believe in a plurality of causes and this also leads to multiplicity in health seeking behaviour.

The cause of lymphatic filariasis is still ambiguous as most people, even those who claimed to know that the disease was caused by mosquitoes, do not really believe in this explanation. This is because other parts of the country are also endemic to mosquitoes but have no cases of lymphatic filariasis. This has made people doubt the linkage between the cause as mosquitoes and lymphatic filariasis and to hold on to the belief that it is caused by other agents.

Early diagnosis of lymphatic filariasis is almost non existence in the local health facilities. This is because the tests can only be done at Msambweni district hospital which has Division of Vector Borne Diseases Laboratory. The ambiguous symptoms of lymphatic filariasis normally lead to late diagnosis of lymphatic filariasis often in the irreversible stage of the disease. This is because the symptoms always look like those of common diseases which are endemic to this area like malaria, typhoid, and fever and hernia. As such misdiagnosis is very common since the worms have nocturnal periodicity and can only be detected at night. During the day, people present malaria parasites in their blood in endemic area in endemic areas and not filarial worms. The hospitals do not use the ICJ card test which can present the worms during the day. It is unfortunate that lymphatic filariasis disfigures people because of misdiagnosis and inappropriate treatment causing untold suffering to those involved.

Some methods of management or treatment of lymphatic filariasis undertaken by those suffering from the disease and their families cause more damage or leads to further infection. Practices like removing excess fluids using bicycle wires and syringes can lead to further infection which can cause death or even the spread of infectious diseases like HIV/AIDS through the use of contaminated instruments.

People who suffer from lymphatic filariasis undergo a lot of stigma because of their illness. Their experiences make it hard to have a normal relationship with other people as they are looked down upon and are regarded as less than others in the society. They spend a larger part of their income in seeking diagnosis and treatment which, in most cases, are dangerous and life threatening. Some get resigned to their situation as they are too poor to afford surgery to remove hydrocele. To add on this, surgery can only be carried out in Msambweni district hospital. Those with elephantiasis have given up hope on ever getting better and are now just resigned to their fate. This issue of helplessness has arisen because of lack of treatment in cases of elephantiasis and also due to recurring cases of hydrocele in the society. It has also been made worse by the expenses that people incur when suffering from this disease and also the stigmatization that people experience from the society, family and even friends.

The government and stakeholders are not doing much to stop the spread of this disease and help those who are already suffering from it. The fight against this disease is not going on as directed by the World Health Organization as drug distribution was discontinued for three years due to lack of funds. Also government directives on control of mosquitoes were only carried out in selected areas raising eyebrows on whether it is serious in eradicating mosquitoes

Despite the current medical advances that have taken place in the country and the numerous programmes that the government has initiated to tackle lymphatic filariasis. The majority of people who suffer from this disease still seek treatment in all three sectors of health. The most common one being the folk sector but at any given time people consult either two or three sectors to find cure of relief to alleviate their suffering.

Lymphatic filariasis though not fatal is a debilitating disease which cuts across people of different ages, sex and status in the community. It is stigmatizing to both the victims and their families and sometimes leads to abandonment of those who are sick. It also reduces productivity and income of the families due to the man-hours lost as a result of acute Adenolymphangities and increase in size of the limbs. It also leads to considerable suffering amongst those who have it and very often leads to poverty due to the enormous resources spent on the prevention and treatment of this disease. Most families are rendered poor because of the amount of money is spent on buying medications during acute attacks, Unless control and prevention measures necessary to eradicate this disease are adhered to, poverty levels will rise leading to low literacy levels and isolation of the community.

7.4 Recommendations

The following are the recommendations that were drawn from this study:
There is need for increased advocacy including awareness and sensitization about the disease including its causes and management at the community, health sector and national level.

The government should develop a policy for filariasis endemic zones to test every patient who presents with malaria like symptoms for lymphatic filariasis. The testing facilities should also be expanded to include health centres and later on scaled down to the dispensary level to reduce cases of delayed diagnosis in the area.

The government should also intervene by offering free or subsidised surgeries on those with hydrocele. This should be accompanied by intense awareness campaigns to educate the public and to» lobby for more funds from individuals and development partners to eliminate lymphatic filariasis.

More studies should be done to find out whether or not people developed resistance to *diethylcarbamazine* and *albendazole* when the mass drug therapy was discontinued.

Studies should also be carried out to find out if there is some genetic predisposition that makes some individuals in the households not susceptible to lymphatic filariasis.

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APPENDIX I

Household Questionnaire

Biographical Data

1. Name of the respondent.................................Signature.........Date ../.../
2. Location
3. Village
4. Year of birth
5. Sex
    1) Male
    2) Female
6. Marital status (please circle)
    1) Single
    2) Married
    3) Separated
    4) Divorced
    5) Widow/widow
    6) Others (specify)
7. Educational background
    1) Primary
    2) Secondary
    3) College
    4) University
8. How many children do you have
9. Occupation
10. Religion
11. Tribe
12. How many years..........and or months..........Have you lived in Kwale?

Perceptions of the communityj)n lymphatic filariasis

13. Do you know of a disease called Lymphatic Filariasis (use local name?)
    1) Yes
    2) No
14. How did you learn about it?

15. Have you seen a person with this disease?
    1) Yes
    2) No
16. If yes how does it look like?
    1) Enlarged legs and feet
    2) Enlarged arms
    3) Enlarged scrotum

4) Swollen lymph nodes
5) Others (specify)

17. What causes Lymphatic Filariasis?

18. How does one get this disease?

19. What is the reason for your answer?

20. Can this disease be transmitted from one person to another?
    1) Yes
    2) No
    3) Don't know.
21. If yes how?

22. Whom do you think is more likely to get this disease[9]
    1) Male
    2) Female
    3) Both
    4) Adults
    5) Children
    6) Others
       (specify)
23. Do you know the symptoms of this disease?
    1) Yes
    2) No
24. If yes what are the symptoms of this disease
    1) Headache
    2) Fever
    3) Aching of the whole body
    4) Swelling of extremities
    5) Dizziness
    6) Other (specify)
25. How long does the symptoms last?

26. Do you know how this disease is diagnosed?
    1) Yes

2) No
3) Don't know

27. What is the diagnosis of Lymphatic Filariasis?
1) Blood examination
2) Urine examination
3) Physical examination
4) Others (specify)

28. Can this disease be treated? **(If no go to question 31)**
1) Yes
2) No
3) Don't know

29. If yes what kinds of treatment do you know of?

30. Why can it not be treated?

31. How can you prevent yourself from contracting this disease?

32. What control measures can you take to prevent Lymphatic Filariasis?

33. Does killing mosquitoes help in controlling Lymphatic Filariasis?
1) Yes
2) No
3) Don't know

34. Have you ever been tested for Lymphatic Filariasis?
1) Yes
2) No

35. What did you feel when you were being tested?

36. Whom do you think you will consult if you get Lymphatic Filariasis?

37. Why will you consult this person/ health sector?

38. What do you think when you see a person with Lymphatic Filariasis?

39. Do they conceal their conditions by the way they dress or any other way at all?
    1) Yes
    2) No
    3) Don't know

40. Do people make fun of them?
    1) Behind their backs.
    2) In their face.

41. Can this person still marry or get married? **(Probe further)**

42. Can a man with hydrocele father a child? **(Probe further)**

43. Can a mother get pregnant when she has Lymphatic Filariasis? **(Probe further)**

44. Do you think this disease can affect a person's relationship with a spouse?
    1) Yes
    2) No
    3) Don't know

45. If yes how

46. Children
    1) Yes
    2) No
    3) Don't know

47. If yes how

48. Other family members
    1) Yes
    2) No
    3) Don't know

49. If yes how

50. Members of the community
    1) Yes
    2) No
    3) Don't know

51. If yes how

52. Should they participate in the social functions of the community?
    1) Yes

2) No

53. If no why

Attitude towards lymphatic filariasis (probe for all the answers)

54.1 will read to you the following statements and I want you to answer sincerely using the following choices.

1) strongly agree
2) agree
3) **neither agree nor disagree**
4) disagree

Statement	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
55. If my parents have lymphatic filariasis, I will also have lymphatic filariasis.					
56. If I wear charms and amulets I will not get lymphatic filariasis.					
57.1 cannot sit in a place where a man with hydrocele has sat before.					
58.1 believe that lymphatic filariasis is caused by mosquitoes.					
59. The enlargement of scrotum and feet are due to a curse from god.					
60.1 prefer to go to a traditional healer if I have lymphatic filariasis.					
61. People with lymphatic filariasis should live alone because they can transmit the disease to other people.					
62. Having hydrocele is advantageous because it can make you marry more women					

Practices

63. Does any one in of your family have Lymphatic Filariasis?
1) Yes
2) No

64. If a member of your family has Lymphatic Filariasis do you?
1) Use the same household goods.
2) Do you interact with him/her?
3) Do you care for them when they are sick?
4) Do you participate in family activities together?

    5) Live under the same roof?

65. What kinds of foods do you give them?

66. What kinds of work are they allowed to do?

67. What can be done to prevent this disease?

68. What can the community do to prevent this disease?

69. Are you aware of any drug distribution for lymphatic filariasis in the district?
    1) Yes
    2) No
70. If yes have you ever received any?
    1) Yes
    2) No
71. Did you take them?
    1) Yes
    2) No
72. Did other members of your family take them?
    1) Yes
    2) No
73. If no why?

74. Have you ever heard of national control programme for Lymphatic Filariasis?

75. If yes what do they do?

76. What have they done to Help in control and prevention of Lymphatic Filariasis in your area^9

APPENDIX II

Questionnaire for People with Lymphatic Filariasis

Biographical Data

1. Name of the respondent..........................Signature..............Date.../.../...
2. Location
3. Village
4. Year of birth
5. Sex
    1) Male
    2) Female
6. Marital status (please circle)
    1) Single
    2) Married
    3) Separated
    4) Divorced
    5) Widow/widow
    6) Others (specify)

7. Educational background
    1) Primary
    2) Secondary
    3) College
    4) University
8. How many children do you have
9. Occupation
10. Religion
11. Tribe
12. How many years..........and or months.....Have you lived in Kwale?

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Illness history

13. State the stage of Lymphatic Filariasis
14. Is the respondent suffering from?
    1) Hydrocele
    2) Elephantiasis?
15. How long have you suffered from this disease?
16. When did you become aware that you had this disease?
17. How did you know you had this disease?
    1) At the hospital
    2) Traditional healer / herbalist
    3) Family
    4) Friends
    5) Others (specify)

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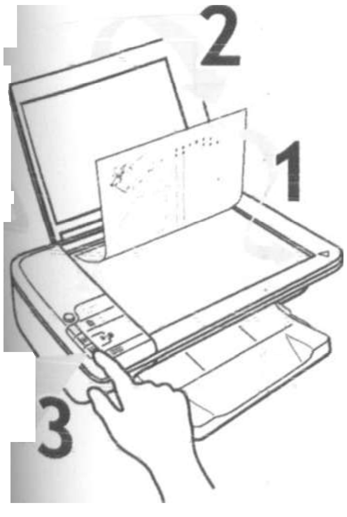

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18. What did you think you had when you first noticed the swelling of your legs or the enlargement of your scrotum?

19. What did you think you had before you were diagnosed with Lymphatic Filariasis?

20. How did you treat it?
21. When did you first know that you had the disease?
22. How did you feel when you were first diagnosed by the disease[9]

23. How do you feel about your condition now?

24. What are the symptoms of this disease?

25. What do you think caused your disease?

26. Is your disease caused by the same agent as other people with the same disease elephantiasis or hydrocele?

27. What kinds of treatments have you received so far? (Name all)

treatment	Place received

28. What kinds of medications/ remedies do you take or use to relieve pain attacks?

Remedy/medications.	Where from

29. Can this disease be cured/ treated[9]
    1) Yes
    2) No

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Care

30. How do you take care of your (mention the infected part of the body) so as not to get infections?

31. What is your daily hygiene routine?

32. Where do you go to seek help for your condition?
    1) Health worker
    2) Traditional healer
    3) Drug store /chemist
    4) Health centre
    5) Hospital
    6) Private practitioner
    7) Others specify
33. What are your reasons for choosing this kind of help?
    1) Convenience
    2) Affordability
    3) Family's choice
    4) Healers reputation
    5) Others (specify)
34. What kinds of treatment do you receive?

35. Who pays for these treatments?
36. What is the cost?

37. What kind of treatment do you like best and why?

Effects on personal life

38. Do you stay away from social functions?
    1) Yes "
    2) No
39. If yes why?

40. Do you conceal your condition by the way you dress?
    1) Yes
    2) No
41. If yes why?

42. Describe peoples reaction to your condition

43. What effect does this disease have on your role as a member or your community?

44. Do you know other people in this community who have this condition?
    1) Yes
    2) No
45. Has the disease affected your chances of marriage or your marriage life?
    1) Yes
    2) No
46. If yes how?

47. How did your family react towards you when they realised you had Lymphatic Filariasis?

48. Has this condition affected your relationship with your spouse?
    1) Yes
    2) No
    3) Don't know
49. If yes how

50. Children
    1) Yes
    2) No
    3) Don't know
51. If yes how

52. Other family members
    1) Yes
    2) No
    3) Don't know
53. If yes how

54. Members of the community
    1) Yes
    2) No
    3) Don't know
55. If yes how

56. Who takes care of you when you are sick?

57. Do you think your condition is a burden to others'?
    1) Yes
    2) No
58. If yes why?...

59. Do you think it is hard for anyone in your family to get a spouse now that you have this disease?
    1) Yes
    2) No
    3) Don't know
60. If yes why?...

61. How are you treated by your fellow villagers? (P**0be)

62. Are you allowed to participate in things in the community?
    1) Yes
    2) No
63. If no why?_

64. How many hours did you spend on your work before you were diagnosed with Lymphatic Filariasis?_
65. How long do you spend in your work now? (If still working)

Control programmes
66. Do you know of any way to prevent this condition?
    1) Yes
    2) No
67. Are you aware of any drug distribution for lymphatic filariasis in the district?
    1) Yes
    2) No

68. If yes have you ever received any?
    1) Yes
    2) No
69. Did you take them?
    1) Yes
    2) No
70. Did other members of your family take them?
    1) Yes
    2) No
71. Do you know of national programme for elimination of Lymphatic Filariasis?
    1) Yes
    2) No
    3) Don't know
72. What do they do?

73. What have they done in this community so far to help in control and eradication of Lymphatic Filariasis?

74. What role do you think you can play in this community to help in prevention and control of this disease

Direct observation (Interviewer must observe in cases of elephantiasis)

1. Size of lymphoedema
2. General cleanliness of the patient (especially the odour coming from the infected leg) and the house
3. If the respondent has elevated his/her leg during the interview

APPENDIX III

Key Informants Interview

a) Biographical data

- Name
- Location
- Sub-location
- Village
- Age
- Sex
- Marital status
- Education background
- Position in the household
- Size of the household
- Occupation
- Religion
- Tribe

b) Involvement with Lymphatic Filariasis

- What kind of health care provider are you?
- Where do you work?
- Have you undergone any type of training?
- What illnesses do people usually see you for?
- Do you think Lymphatic Filariasis is a problem in Kwale district
- Do you treat people with lymphatic filariasis? How?
- How many years, and or months have you been involved with Lymphatic Filariasis?

c) Attitudes and Perceptions^ Lymphatic Filariasis

- What are the perceived causes of lymphatic filariasis in this community?
- In your opinion what causes lymphatic filariasis?
- Who is more likely to get lymphatic filariasis?
- Do people who come to you with these conditions know that they have lymphatic filariasis?
- What is the communities' attitude towards people with this lymphatic filariasis?
- Are men who have lymphatic filariasis treated differently from women?
- Do people with lymphatic filariasis live a normal life in the society?
- What happens to people with lymphatic filariasis who do not seek treatment?

d) Management and Control of Lymphatic Filariasis

- How do you manage lymphatic filariasis in Kwale?
- How much if any do you think these management services cost?
- How can people deal with this problem in the district?

What kinds of measures are being taken to control the disease in the district right now?
What are the challenges faced by the stakeholders in the fight against Lymphatic Filariasis?
Do you know about national control of Lymphatic Filariasis?
What is their role in the control and eradication of Lymphatic Filariasis
What is the society's response to their work?

APPENDIX IV

Focus Group Discussion (FGDs) Guide

Perception on lymphatic filariasis

1. Aetiology of disease in this community
2. Aetiology of lymphatic filariasis in this community
3. Local terms used to describe lymphatic filariasis
4. Causes of lymphatic filariasis
5. Manifestations of lymphatic filariasis
6. Group at risk of getting lymphatic filariasis
7. Treatment and cure of lymphatic filariasis
8. Places for seeking treatment from lymphatic filariasis
9. Available treatment options for those suffering from Lymphatic Filariasis
10. Effectiveness of these treatments
11. Community's attitude towards people with lymphatic filariasis
12. Prevention and control of lymphatic filariasis.
13. Government, community and individual role in eradication of lymphatic filariasis

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APPENDIX V

In-Depth Interview Guide for People with Lymphatic Filariasis

1. Aetiology of lymphatic filariasis
2. Causes Lymphatic Filariasis
3. Illness history
4. Caused of your illness
5. Population or people at risk from Lymphatic Filariasis
6. Early symptoms of Lymphatic Filariasis
7. Manifestations of lymphatic filariasis
8. Experiences on marriage, family life and relationships.
9. Treatment options available
10. Treatment and cure for lymphatic filariasis
11. Type of health sector sought so far and why
12. Advantages and disadvantages of these health sectors?
13. Care practices used in management of lymphatic filariasis?
14. Family's attitude towards your condition?
15. Society's attitude towards your condition?
16. Community's treatment for people suffering from lymphatic filariasis.