Socio-Cultural Aspects of Lymphatic Filariasis and The Role of Communities in its Control in Ghana.

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Dekan

TO JOHNNY, AKOS, NANA and OBAA YAA

God bless you for being there for me

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Summary

Lymphatic Filariasis (LF) is one of the worlds most debilitating and disfiguring tropical diseases. The World Health Organization estimates that there are about one billion people at risk in about 80 countries worldwide. It is the world's second leading cause of permanent long-term disability and its prevalence continues to increase. The World Bank development report indicates that the global burden for the disease was estimated at 850,000 DALY's lost which represents only 0.23% of the global burden. In Africa, it is estimated that some 4.6million cases of lymphoedema and over 10 million cases of hydrocele occur. This represents 40% of the global burden of LF.

In 1993, an independent international task force for disease eradication identified LF as one of the only six eliminable infectious diseases. LF was selected because of recent dramatic advances in treatment methods, both for controlling transmission and for managing the disease along with remarkable improvement in techniques for diagnosing filarial infections. The principal strategy for interrupting transmission then was to identify areas in which LF is endemic and implement community wide programs to treat the entire at risk population. In terms of managing the disease, the Global Program for the Elimination of Lymphatic Filariasis (GPELF) plans that individuals already suffering from elephantiasis will be taught effective hygiene measures that can easily be carried out in the home. For men with hydrocele, surgery is the treatment choice and guidelines will be developed and disseminated on good practical surgical procedures.

Summary

The overall goal of the study was to determine the social and economic impact of LF and examine the role communities can play in its control in a country where till recently, the disease has been very low on the National Health Agenda. A number of studies were conducted in four districts in Northern and Southern Ghana that were found to be prevalent for Filariasis after a national Filariasis survey was conducted in the country in 1994. The overall prevalence in the North ranged between 20-40% and in the South between 10-20%. There were no prior studies on Filariasis neither was there a National control program in place before the conduct of these studies.

The goal of these studies was achieved using a multi-disciplinary approach, to determine how people recognize and perceive LF and the social and economic impact of the disease. This involved extensive ethnographic work, and a morbidity and economic surveillance. The information from the ethnographic phase was then used to develop Information Education and Communication techniques with the help of community members through the training of community workers and community leaders as facilitators to guide the process. To develop effective and practical methods for sustainable mass treatment of LF, two different methods of mass treatment of lymphatic Filariasis with a single dose of Ivermectin were tried. Finally, the potential role of traditional health care providers in the management of elephantiasis was investigated. Focus group discussions, observation, key informant interviews, case studies and structured questionnaires were used to elicit information from health care providers, affected and unaffected individuals. The results indicate that,

- LF is recognized as a problem in the study areas and there are specific local terms used to describe the various manifestations.
- There is the need to pay more attention to the needs of men with hydrocele.
- Each of the ethnic groups studied have different conceptions and health care seeking practices for the disease. This has implications for health education.
- Communities are capable of developing their own IEC messages with the proper guidance and building on their perceptions about the disease.
- Community directed treatment for Filariasis achieved 75% treatment coverage and can be effectively implemented through the regular health system
- By building on positive existing local treatment practices, traditional healers can be a useful resource in the management of lymphoedema through effective hygiene measures.

All these studies have been carried out in research settings. What is needed now is to come up with practical ways of up-scaling and implementing these studies in the other endemic districts in the country. This is the first time that in one report lymphatic Filariasis has been looked at from lay perceptions to practical implementations. The results contribute knowledge to the understanding of the disease in general and draws attention to the fact that the male gender also needs to be paid attention to in tropical disease research. It also raises the importance of including psychosocial aspects of disease burden in the calculation of DALY’s and adds to the body of knowledge the importance of traditional healers in particular and community effort in the global program for the elimination of LF as a public health problem. The contribution of anthropology in the study of the LF and the importance of the discipline in the study of

emerging and re-emerging infectious diseases are discussed. There are however a number of issues that need further research and they include

1. Advocacy strategies to increase awareness about the disease and to ensure sustained demand supply and distribution of Ivermectin at the National, Regional and District level for the control of the disease
2. Stigma and the burden of filariasis especially in urban areas where LF is increasingly becoming a problem.
3. We have recommended that the ComDT approach be implemented on a large scale but there is the need to address issues on how cost effective will this kind of intervention be?

Zusammenfassung

Die Lymphatische Filariose (LF), auch Elefantiasis genannt, ist eine der meist verstümmelnden und schwächenden Tropenkhrankeiten. Nach Schätzungen der Weltgesundheitsorganisation (WHO) sind über eine Milliarde Menschen in etwa 80 Ländern der Welt von der Krankheit bedroht. Als Ursache für dauernde Behinderungen steht die Krankheit weltweit an zweiter Stelle, und ihre Prävalenz nimmt ständig zu. Der Entwicklungsbericht der Weltbank schätzt die globale Bürde der LF auf 850'000 DALYs (Disability Adjusted Life Years), was aber nur 0.23% der gesamten globalen Krankheitsbürde entspricht. In Afrika werden 4.6 Millionen Fälle von Lymphödem und über 10 Millionen Fälle mit Hydrocele geschätzt. Dies entspricht 40 % der globalen Bürde der LF.

Eine unabhängige internationale Arbeitsgruppe identifizierte die LF 1993 als eine der einzigen sechs ausrottbaren infektiösen Krankheiten. Die LF wurde ausgewählt wegen den neueren grossen Fortschritten der Behandlungsmethoden sowohl bei der Bekämpfung der Übertragung wie auch der klinischen Pflege und verbesserten Diagnosemöglichkeiten. Die Identifikation der Zonen mit endemischer LF und der nachfolgenden Behandlung der gesamten dörflichen Risikopopulation war damals die Hauptstrategie zur Unterbrechung der Übertragung . Das „Global Program for the Elimination of Lymphatic Filariasis“ (GPELF) sieht vor, Patienten mit klinischer Elefantiasis Hygienemassnahmen, die einfach zu Hause durchgeführt werden können, zu lehren. Für Männer mit einer Hydrocele ist die chirurgische Entfernung die Behandlung

der Wahl. Richtlinien über gute chirurgische Methoden sollen entwickelt und möglichst breit verteilt werden.

Das Ziel der vorliegenden Studie war, den sozialen und ökonomischen Einfluss der LF zu untersuchen und zu prüfen, welche Rolle dörfliche Gemeinschaften in einem Land spielen können, welches bis vor kurzem dieser Krankheit keine grosse Beachtung schenkte. Mehrere Studien wurden in vier Distrikten im Norden und Süden Ghanas durchgeführt. In diesen Gegenden ist LF endemisch, wie eine nationale Studie aus dem Jahre 1994 zeigte. Die Prävalenz im Norden schwankte zwischen 20-40% und im Süden zwischen 10-20%. In diesen Gegenden gab es vorgehend nie Studien über die Filariose und auch kein nationales Bekämpfungsprogramm.

Das Ziel dieser studien wurde mit Hilfe eines multidisziplinärer Ansatzes erreicht, wobei untersucht, wie die Bevölkerung die Filariose erkennt und empfindet und welche sozialen und wirtschaftlichen Auswirkungen die Krankheit verursacht. Dazu wurden ausgedehnte ethnographische Arbeiten durchgeführt und gleichzeitig die Morbidität und wirtschaftlichen Bedingungen kontinuierlich registriert. Die Resultate der ethnographischen Studien wurden benützt, um mit Hilfe von Dorfmitgliedern Informations, Ausbildungs und Kommunikations Material (IEC= Information Education Communication) zu entwickeln. Dazu wurden Dorfchefs und Sozialarbeiter vorgängig als Übermittler für die Führung der IEC Arbeit ausgebildet. Für die Entwicklung wirksamer und praktisch durchführbarer Methoden zur nachhaltigen Massenbehandlung der LF wurden zwei verschiedene Behandlungsschemen mit Ivermectin Einzeldosen geprüft.

Schliesslich wurde auch die mögliche Rolle der traditionellen Heiler für die Behandlung der Elefantiasis geprüft. Die notwendige Information wurde mit Hilfe von Diskussionen mit Fokusgruppen, Einzelbeobachtungen und Gesprächen mit Schlüsselpersonen, Fallstudien und strukturierten Fragebögen bei Gesundheitspersonal sowie gesunden und kranken Personen gesammelt.

Die Resultate zeigen, dass:

- die Filariose in den Studiengegenden als Problem erkannt wird und es verschiedene einheimische Namen für die unterschiedlichen klinischen Krankheitsbilder gibt.
- die verschiedenen ethnischen Gruppen unterschiedliche Krankheitskonzepte und Gewohnheiten bei der Suche nach Behandlungmöglichkeiten haben. Dies muss für die Planung der Gesundheitserziehung berücksichtigt werden.
- dörfliche Gemeinschaften in der Lage sind, ihre eigenen IEC Mitteilungen, aufbauend auf ihrem eigenen Krankheitsempfinden und mit Hilfe einer guten Führung, zu entwickeln.
- eine auf die dörfliche Gemeinschaft ausgerichtete Filariosebekämpfung einen Deckungsgrad von 75% erreicht und wirksam durch das reguläre Gesundheitssystem durchgeführt werden kann.
- traditionelle Heiler durch den Gebrauch einheimischer Behandlungsarten und wirksamer hygienischer Massnahmen eine nützliche Rolle bei der Pflege von Lymphödemen spielen können.

Alle diese Studien wurden unter Forschungsbedingungen durchgeführt. Jetzt müssen Wege gefunden werden, um solche Studien auf grösserer Ebene und in anderen endemischen Gegenden des Landes durchzuführen. Dies ist die erste Studie, in der die Lymphatische Filariose gleichzeitig vom Empfinden des Laien bis zur praktischen Bekämpfung untersucht wurde. Die Resultate verbessern das allgemeine Verständnis dieser Krankheit und zeigen speziell, dass Eigenheiten des männlichen Geschlechts in der tropenmedizinischen Forschung berücksichtigt werden müssen. Psychosoziale Aspekte der Krankheit sollten ebenfalls berücksichtigt werden bei der Berechnung der Krankheitsbürde in DALYs. Die Studie zeigt ebenfalls, welche Bedeutung traditionellen Heilern und der Beteiligung der dörflichen Gemeinschaft im globalen Programm für die Eliminierung der LF zukommt. Der Beitrag der Anthropologie zur Untersuchung der Lymphatischen Filariose und ihre Bedeutung bei der Erforschung von neu auftretenden und wieder auftretenden infektiösen Krankheiten wird diskutiert.

Zahlreiche zusätzliche Aspekte machen eine weitergehende Forschung erforderlich:

1. Methoden zur Aufklärung, um das Wissen üdiese Krankheit zu vergrössern und um die anhaltende Nachfrage und die Verteilung von ivermectin auf nationaler, regionaler und Distrikt-Ebene für die Kontrolle dieser Krankheit zu sichern.
2. Stigma und das Leiden bei Filariose
3. Da ich in meiner Dissertation die Untersuchung dieses Leidens auf Männer beschränkt habe, wird es notwending sein, eine derartinge Studie auch bei Frauen durchzuführen. Ebenfalls ist es erforderlich, einige geschlechtsspezifische Aspekte in Beziehung zu einer dorforientierten Behandlung von Filariose zu untersuchen

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List of Abbreviations

ADL	Adenolymphangitis
AFL	Acute Filarial Lymphangitis
APOC	African Program for Onchocerciasis control
CFA	Circulating Filarial Antigen
CHPS	Community Based Health Planning and Services
CI	Confidence Interval
ComDT	Community Directed Treated
DALY	Disability Adjusted Life Years
DBL	Danish Bilharziasis Laboratories
DEC	Diethelcarbamazine
DHMT	District Health Management Team
DWHRC	Dangme West Health Research Center
ELISA	Enzyme Linked Immunoabsorbent Assay
EMIC	Explanatory Model Illness Catalogue
GPELF	Global Program for the Elimination of Lymphatic Filariasis
HRU	Health Research Unit
HST	Health Service Treatment
IEC	Information Education and Communication
ITM	Insecticide Treated Materials
LF	Lymphatic filariasis
MF	Microfilaria
NGO	Non Governamental Organization
NHRC	Navrongo Health Research Center
OCP	Onchocerciasis Control Program
SB	Smith Kline Beecham
RAP	Rapid Assessment Procedures
WHA	World Health Assembly
WHO	World Health Organisation

INTRODUCTION

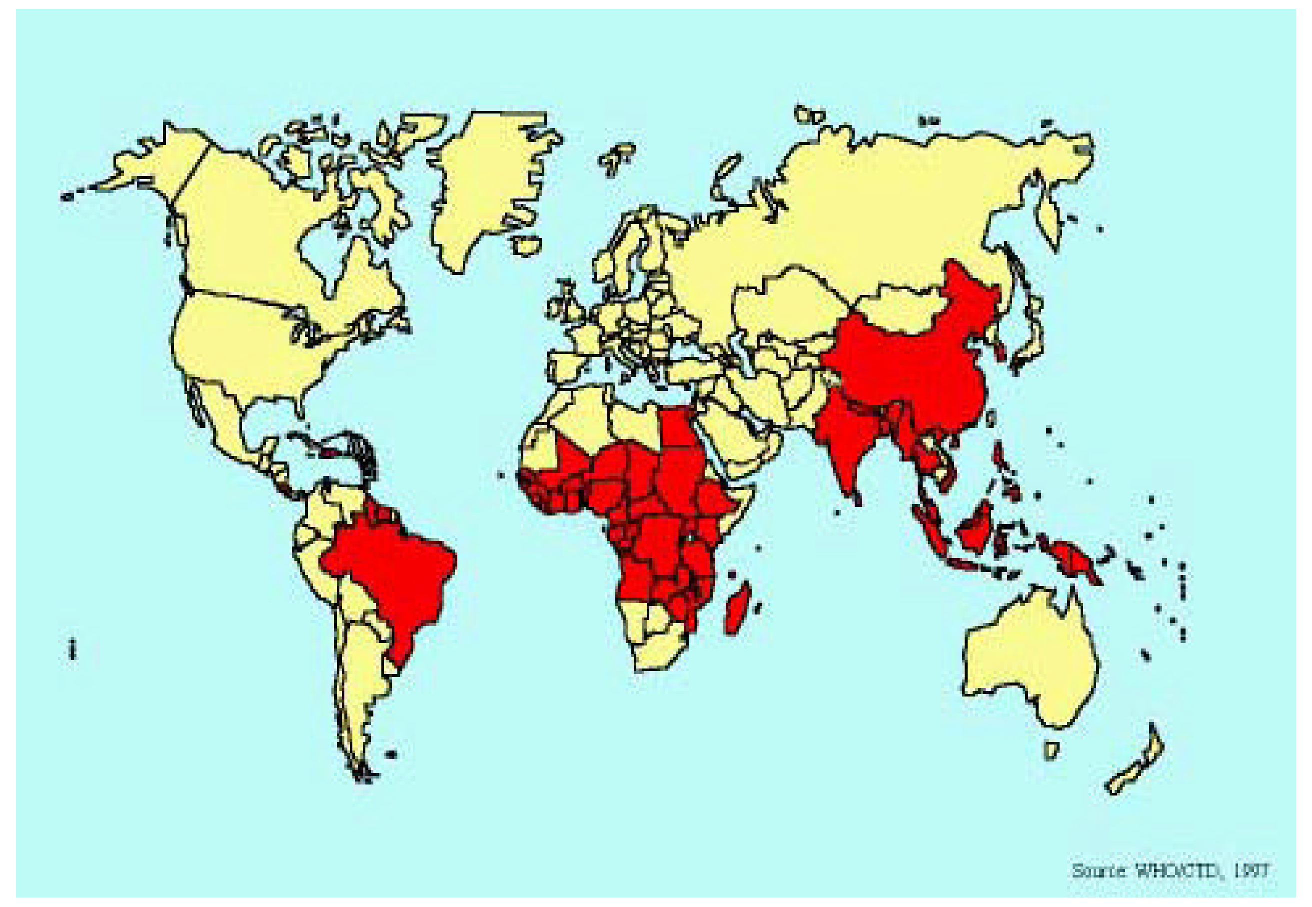
CHAPTER 1

1.0 INTRODUCTION

1.1 Lymphatic Filariasis: The Global situation

Lymphatic Filariasis (LF) commonly known as elephantiasis is a painful and profoundly disfiguring disease that has a major social and economic impact in Asia, Africa, the Western Pacific and parts of the Americas (Ottesen 1997). It is one of the leading causes of permanent and long-term disability in the world (WHO 1995). About one billion people in 80 different countries are known to be at risk of this disease (WHO 1998). Globally, the disease is known to affect about 120 million people in 73 endemic countries. (Figure 1.1).

Figure1.1 Global distribution of filariasis



Source: WHO/CTD, 1997

Estimates from the 1993 World Bank Development Report (which uses Disability Adjusted Life Years as a measure for comparing the public health impact of diseases) indicate that, LF accounts for 850,000 DALYs lost. This represents only 0.23% of the global burden of parasitic and infectious diseases (World Bank 1993).

In sub Saharan Africa, it is estimated that about 512 million people are at risk of the infection and about 28 million are already infected. Of this number, there are 4.6 million cases of lymphedema and over 10 million cases of hydrocele. These represent about 40% of the global burden of the disease (Michael et al 1996).

Until recently, little could be done to relive the suffering and disability caused by this disease. Today however, significant advances have been made in understanding both the disease and its control. As a result of these advances, the independent International Task Force for Disease Eradication identified LF in 1993 as one of the only six eliminable infectious diseases (Ottesen 1995). This decision was followed in 1997 by the adoption of Resolution WHA50.29 by the World Health Assembly calling for the worldwide elimination of LF as a public health problem by the year 2020 (WHA 1997). Following the adoption of this resolution, WHO with support from organizations and donor countries began developing a coalition to eliminate the disease. In 1998, the coalition was given a powerful boost when Merck and Co., Inc. pledged to expand its Mectizan Donation Program for onchocerciasis to cover the treatment of LF in Africa where the two diseases occur together. In the same year, Smith Kline Beecham (SB) announced its commitment to form a unique private-sector/public-sector collaboration with WHO to support the global program.

The aims of the global program are to reduce and eliminate transmission of LF, reduce and prevent morbidity in affected individuals, through the use of albendazole (provided free of charge by Smith Kline Beecham), which will provide a de-worming benefit to endemic populations and provide strengthening benefits to the health services (WHO 1999).

The principal challenge of the Global Program for the Elimination of Lymphatic Filariasis (GPELF) is to deliver treatment to populations of high-risk communities and to sustain this delivery and high treatment coverage for a sufficiently long period of time to bring about the elimination of the disease. In line with this discussions have been going on about the possibility of integrating LF elimination with oncocerciasis control. The reasons being that

1. The Onchocerciasis control program (OCP) and the African Program for Onchocerciasis Control (APOC) have experience with mass drug delivery in the region.
2. OCP and APOC have established a rapport with the participating countries and already have the drug procurement in place.
3. This plan will enhance collaboration between health workers and communities and would be cost effective.

Some issues that need to be addressed with regards to this cooperation are commitment of the national governments, the need for local expertise in LF, mapping the distribution of LF and the development and adaptation of Information Education and Communication (IEC) messages and training materials (Gyapong & Amuyunzu 1999).

1.2 Cause and Transmission.

Lymphatic Filariasis is caused by long thin filarial worms (*W. bancrofti, B. malayi* and *B. timori*) that live in lymph channels in the human body. In most endemic countries, it is transmitted at night by the female *Culex* and *Anopheline* mosquitoes through the process of taking a blood meal from individuals infected with microfilaria (mf) which are millions of larval forms produced by paired adult worms. The mosquito ingests the mf over a period of about 12 days. The mf progress through several larval stages to an infective stage, called the L3, which breaks out of the mosquito mouth parts, escapes, and finds its way into the human bloodstream during another blood meal. The L3 matures into an adult worm within the human host between 3 to 15 months, migrating to the lymphatics, where it pairs with an adult of the opposite sex and initiates a fecund infection with the production of mf. The adult worms may live up to 8 years on the average but there have been reports of some worms living beyond 20 years (WHO, 1984; 1992a; 1996a).

1.3 Clinical Manifestations.

As a result of the parasitic infection described above, the lymph channels get damaged and blocked thereby preventing the proper flow of lymph fluid through the body. The accumulation of lymph fluids leads to the chronic manifestation of LF in the extremities of the body namely elephantiasis of the upper and lower limbs, which affects about 4.6 million people in Africa. Hydrocele is another manifestation of LF and is also known to affect about 10 million men in Africa alone (Michael et al 1996). Women have been known to have infections of the breast and female genitalia but these are rare. In terms of sex differences, Brabin (1990) has noted that the intensity of infection, and clinical disease are higher in men than in women. Similar findings have also been reported in India (Ramiah et al 1996a) and other geographical sites (Pani et al 1997). In Ghana however, more women than men seem to be infected (Gyapong et al 1994). Manifestation of LF begins with acute attacks (ADL) characterised by fever, general malaise, pain tenderness and swelling. In Tanzania and Ghana, the incidence has been found to be closely associated to rainfall patterns (Gyapong et al 1996a, Gasarasi et al 2000). Studies in India however found no seasonal pattern in the occurrence of the ADL episodes (Ramiah 1996a)

Acute attacks have been known to recur at irregular intervals from once a month to less than once a year and may continue to do so, often until the end of life. The frequent inflammatory attacks are known to leave some residual swelling over the years, and thus lead to the recognised chronic disease states associated with LF mentioned above. The literature however indicates that in some endemic countries, there are individuals who do not develop obvious chronic disease but may have had a history of long standing recurrent acute attacks (Gyapong JO *et al.*, 1996a; Pani *et al.*, 1995; WHO, 1992a).

Early studies on ADL assumed that it was a result of human immune response to parasite products released by the adult worm or by microfilariae (Addis *et al.*, 1994; Chan *et al.*, 1984; Kar *et al.*, 1993; Ottesen, 1984; Partono, 1987). Recently, Dreyer et al (1999) identified two types of acute attacks, which occur in residents in Brazil. One is caused by the death of the adult filarial worms and its clinical presentation varies from asymptomatic to the syndrome of acute filarial lymphangitis (AFL). The second type they found out is due to secondary bacterial infections, which cause acute dermatolymphangiodenitis (ADLA). Studies in India and Ghana have also confirmed the finding of bacteria being a cause of ADL attacks (Shenoy 1998, Gyapong JO *et al.*, 1996a, Rajagopalan 1990).

1.4 Diagnosis.

Early surveys for LF depended on the examination of blood films, which in most areas had to be collected around midnight because of the periodicity of mf in the blood. Alternative methods using immunodiagnosis were not satisfactory since they failed both to distinguish between active and past infections and had problems with specificity owing to their cross reaction with gastrointestinal parasites (Ottesen 1984). Two diagnostic tests were recently developed. The first to appear on the market was Trop Bio test made by Tropical Biotechnology Pty Ltd in Australia. This test uses a monoclonal antibody Og4C3 in a sandwich enzyme linked immunoabsorbent assay (ELISA) to detect Circulating Filarial Antigens (CFA) in serum specimens (More and Copeman 1990). This test raised serious concerns with respect to sensitivity and reliability.

The second test, the ICT test card produced recently by ICT Diagnostics in Australia, has been found to have a high sensitivity and specificity, can be used during the day and at night, is field usable and is currently commercially available at $1/test for public health programs (Weil et al 1997).

Simonsen et al (1999) recently compared the above diagnostic tools (together with a Trop Bio for filter paper specimens) based on the detection of specific circulating antigens. They conclude that the tests have various qualities for application in different settings and for different purposes. In their opinion, the ICT card test can be performed by technical staff after a minimum of training with laboratory facilities and seems ideal for diagnosis in clinical laboratories and for surveillance in large control programs when only a negative or positive result is required. The Tropi Bio tests they found provided a graded response probably reflecting the load of the adult worm infection but require more advanced laboratory equipment and well trained laboratory staff.

The use of Ultrasound for the identification of adult worms was also developed in Recife, Brazil. In this, procedure, lymphatic vessels, show peculiar aleatory movements (“filaria dance sign”). To confirm that the observed structures were living *Wuchereria bancrofti* adult worms, a segment of the lymphatic tract containing these mobile intraluminal structures was surgically removed from the left spermatic cord of one individual and checked. The results were positive (Amaral *et al*, 1994 Dreyer *et al*, 1994). This filarial dance sign was also seen for the first time in Africa at a meeting organised by the Danish Bilharziasis Laboratories (DBL) with the use of a portable ultrasound machine and demonstrated by Peter Bernhard (Simonsen 1997).

In another development, Gyapong et al (1998a) found that it is possible to obtain reliable and valid estimates of the community burden of LF by using the prevalence of hydrocele as a rapid diagnostic index.

1.5 Control of Lymphatic Filariasis.

In terms of the control of LF three main options are available. Vector control, morbidity control and mass chemotherapy (Ottesen et al 1997).

1.5.1 Vector Control

Vector control has traditionally played an important role in the control of LF. Earlier studies in Liberia used residual spraying (Zielke & Chlebowsky 1980). In Zanzibar polysterine beads were used in wet pit laterines (Maxwell et al 1990). There are now new improved techniques for enhancing the effectiveness of vector control which include the use of insecticide-treated materials

(ITMs), mainly bednets and curtains, and residual spraying. The use of these and other techniques has enabled the elimination of LF in Japan, Taiwan, Solomon Islands, South Korea and some parts of China (Webber 1979, WHO 1996a). These methods of reducing human vector contact still provide useful supplements to the effects of treating the human population to reduce transmission. They should however not be relied on exclusively and should be combined with other control strategies.

1.5.2 Mass Chemotherapy

Early studies on treatment of LF was based on the selective treatment of patients with single annual doses of DEC (6 mg/kg) which decreases mf by 90% and decrease adult worms by 50%. In some parts of the world, it was used as a medicated salt (Gelband 1994, Meyrowitsch 1996, PIPD Shantung 1976). Due to advances in research, there is a growing shift to the use of mass distribution programs with single or combined doses of ivermectin, albendazole or DEC. Even though the use of DEC remains the mainstay of treatment in most endemic countries. Its use is limited in communities in which onchocerciasis and loaisis are endemic due to severe adverse reactions in people infected with these parasites. Ivermectin, which has been very successful in treating onchocerciasis, is now approved as a single dose or in combinations with DEC or albendazole following several studies that have shown its effectiveness as an annual dose. Plaisier et al (1999) have shown that a dosage level of 400 micrograms/kg of ivermectin as a single dose irreversibly reduces mf production by 65%. With a dosage of 200 micrograms/kg, the reduction is at least 35%. Beach et al (1999) in a study, which combined albendazole and ivermectin for the treatment of intestinal helminth, and *Wuchereria bancrofti* in school children report that combination therapy reduced the prevalence of *Tricuris* and the prevalence of mf more than placebo or ivermectin alone. Shenoy (1999) using combinations of

DEC and ivermectin also found similar reductions in mf density. Other studies include those by Addiss et al (1997), Ismail et al (1998) and Ottesen et al (1999).

Throughout the world therefore, the recommended approaches to be used except in the loasis or onchocerciasis zones of Africa are

1. Once yearly single dose treatment (for 4-6years) with either a two–drug regimen of 200micrograms/kg co administered with either DEC (6mg/kg) or albendazole (400mg).
2. DEC fortified salt (0.2-0.4 % w/w) substituted for regular cooking/table salt for 6-12 months.

For endemic zones where onchocerciasis or loasis exists, once yearly single dose administration (for 4-6years) of either a two drug regimen of ivermectin (200micrograms/kg) + albendazole (400mg) or one drug regimen of ivermectin(400mg) alone.

The added benefit of the two drugs as potential anti-helminth for intestinal parasites makes it an excellent public health tool. Developing effective drug distribution mechanisms will be key to the elimination of the disease since most health services in Africa on their own, may not be able to deliver drugs to entire populations on a yearly basis. A Community Directed Treatment (ComDT) approach involving the community and other partners in the drug distribution as described in chapter 8 is therefore essential.

Morbidity Control

Morbidity control aims at reducing the suffering of already diseased persons, making them as functional as possible and preventing the progression of their condition to worse states. Until recently, it was not appreciated as to how much could be done for individuals who were suffering from the chronic manifestations of lymphatic filarial disease. In most instances, a sense of hopelessness inhibited any active intervention. As a follow up to their studies on ADL mentioned earlier, Dreyer (1999) and Shenoy (1998) suggest that basic hygienic practice such as regular washing of elephantoid limbs with soap and water reduces the incidence of acute attacks and the progression of elephantiasis. The formation of “elephantiasis clubs” in Brazil where members share experiences and help one another with washing of elephantoid limbs has been found successful in reducing suffering and psychosocial problems associated with the disease. The relieving and prevention of suffering and disability is therefore one of the targets of the GPELF (WHO 1999). In line with this target, multi country studies are currently going on in Ghana, Tanzania, Kenya and Nigeria to look at community based management of lymphedema and ADL. In addition, a training of trainers’ course on the management of the lymphedema and ADL was held for Filariasis.

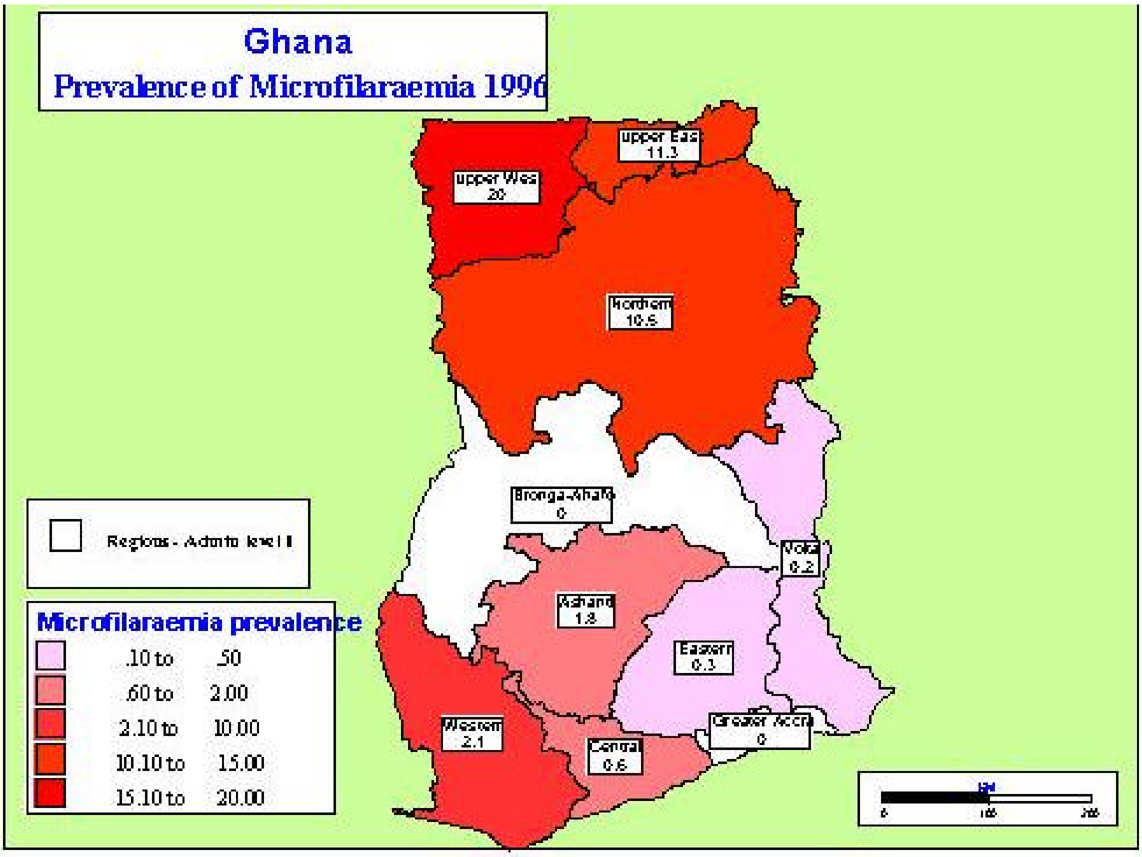
Surgical intervention for men with hydrocele is also an important component of morbidity control. The GPELF hopes to disseminate as broadly as possible the most practical surgical techniques appropriate for the care of patients with hydrocele.

1.6 Filariasis in Ghana.

Until recently, very little work had been done and documented on LF in Ghana. Anecdotal clinical reports since the early 1990’s indicated that elephantiasis of the leg and hydroceles were very common, especially in the northern regions and the western part of the coastal belt.

The management of hydroceles in the hospitals was by hydrocelectomies, while elephantiasis was managed with antibiotics and analgesics when there is a super-infection. The first population-based survey of elephantiasis of the leg in northern Ghana in 1990 showed that out of 5846 compounds visited by trained field workers. 735 (12.6%) of the compounds had at least one resident compound member with visible or reported elephantiasis of the leg (Gyapong et al 1995). This study was initiated at the request of the Regional Health Administration because of a simple observation of cases of leg elephantiasis in the market places, and also because hydrocelectomies accounted for more than 20% of all surgery done in the district hospital. After this survey, two other community-based surveys were conducted. The first one by the Ministry of Health examined all people above ten years. The second one conducted in collaboration with DBL, examined the total population. Both surveys showed an average mf prevalence of 41% (Gyapong et al 1993, 1994). At about the same time as the above surveys were conducted, a press release concerning the outbreak of elephantiasis in the western region of Ghana, led the Ahanta West district to collect baseline data and identify the vectors responsible for transmission of the disease. The main vectors found were *Anopheles gambiae* and *Anopheles melas* and the parasite identified was *Wuchereria bancrofti.* Parasitological surveys showed an mf prevalence of 10% (MOH 1993). Similar studies by Dunyo et al (1996) along the coast of Ghana, showed similar vectors and an mf prevalence of between 9.2-25.4%. Results from detailed ethnographic studies in the northern section of the country coupled with findings from the surveys mentioned above, prompted the Ministry of Health to conduct a national survey as a basis for designing a national control program. Figure 1.2 shows the distribution of filariasis in the country.

Figure 1.2 Distribution of filariasis in Ghana



Even though the prevalence of reported elephantiasis was 0.6% (95% CI 0.3-0.9%), the findings from the clinical examination however, revealed many more people with elephantiasis. The prevalence was 2.1% (95% CI 1.6-2.6%) ranging from 0.0% to 11.8% in the Upper East Region. Few females (2.1%) had chronic lymphoedema of the breast (95% CI 1-5-2.7%), with a range of 0.6% in the Brong Ahafo Region to 6.6% in the Upper East Region. The prevalence of hydrocele among males was 5.5% (95% CI 4.3-6.7%) ranging from 0.0% in the Brong Ahafo Region to 19.5% in the Upper East Region.

The prevalence of infection was statistically much higher in males than in females, but the prevalence of elephantiasis was higher in females than in males, although not statistically significant.

A detailed multi centre study on the social and economic impact of the disease played a key role in unravelling the burden of the disease. Other community related studies have since been conducted in the country and form the main chapters in this thesis. Today, the country has a national filariasis control program in place.

1.7 Economic aspects of filariasis.

Although LF is not fatal, the chronic symptoms often afflict individuals in their most reproductive stage of life and therefore impose a significant social and economic burden on society. Lost productivity due to lympoedema, genital damage and ADL caused by LF costs millions of dollars each year. At a recent meeting in the Hague, in relation to discussions about incorporating LF into APOC/OCP, Haddix (1999) presented figures on the economic impact of filariasis. These figures indicated that while APOC countries may loose $1.3 billion due to each year lost in productivity, OCP countries lose about $350 million due to each year lost in productivity. She added that over 80% of this loss is due to disability in men with hydrocele.

Surgical treatment for hydrocele has been known to impose a tremendous burden on the health care systems in endemic areas and on the sufferers of the disease. In Ghana, one-third of all surgeries is for hydrocele repairs. In Ghana, a hydrocele operation costs US $30 representing over a month of income for the average worker. In India, a hydrocele operation represents up to three months in wages. It has been conservatively estimated that filariasis in India, where one-third of cases occur, costs over one billion dollars each year in lost productivity. In some communities in India, 7-8% of male labor is lost because of chronic LF, primarily hydrocele. The Chinese now estimate that every US dollar invested in filariasis control has produced more than US $15 in benefits (WHO 1999). The direct cost of the disease on affected individuals and on productivity is grave (Ramiah et al 1997, 1998, 1999, 2000). In a study by Ramu et al (1996), the productivity of male weavers with chronic LF was found to have reduced by as much as 27.4% in the cloth weaving industry and thus reduce wage earning. In China where LF has been eliminated, the primary motivation behind the elimination campaign was the impact of the disease on agricultural productivity (WHO 1999). Even though grave, the direct cost on treating the disease is low since very few people travel to seek treatment for their condition. This is mainly due to treatment seeking behavior related to local concepts on the perceived cause of the disease (Ramiah 1996b).

1.8 Socio-cultural aspects of filariasis

Several studies have examined filariasis related cultural concepts and beliefs though, few have been found to enhance the understanding of LF to a very large extent. The earliest of these studies of the social aspects of the disease were by Muhondwa (1983) in Tanzania, Lu et al in the Philippines (1989) and Hunter (1992) in Ghana. After these came research on the large-scale social and economic impact of filariasis initiated by WHO/TDR. These were the first multi center studies, and they had a significant ethnographic component in which researchers spent a year in the field learning about local beliefs and disease concepts. At the same time, a few other studies were underway on the same topic in other parts of the world (Ramiah 1996b, Ramu et al 1996, Amuyunzu 1997, Ahorlu 1999, Eberhard et al 1996).

This research has shown that, according to local illness concepts, the disease is unrelated to the mosquito and the different manifestations are seen as different disease entities. Treatment is mainly by self-medication or by consulting a traditional healer. Although the disease is not fatal, the chronic symptoms often afflict individuals in their most productive stage of life, and it therefore impose a significant social and economic burden on society and a heavy psychosocial burden upon affected individuals. Persons with hydrocele and lymphoedema are often shunned and become isolated within their communities. For people with this condition, the chances of finding a spouse are slim, and since they are often unable to work, they become dependent for care and financial support, leading to further insecurity, shame, isolation and economic loss. (see chapters 4 & 6).

The importance of the above findings in the control of LF cannot be overemphasised. However, only few ethnographic studies on tropical diseases have provision for their results to influence control programs. The need to do that motivated the studies in the subsequent chapters. They show how findings from an ethnographic study have influenced the development of further work with communities in districts in Ghana where filariasis is a major problem.

CHAPTER 2

2.1 Theoretical orientations in Medical anthropology and its application to filariasis.

Medical Anthropology is concerned with how people in different cultures and social groups explain the causes of ill health, the types of treatment they believe in and to whom they turn if they get ill. It is also the study of how these beliefs and practices relate to biological, psychological and social changes in the human organisation in both health and disease. The discipline lies at the intersection of the social and natural sciences and benefits from insights of both disciplines (Helman 1994). According to Foster and Anderson (1978), it is a bio-cultural discipline concerned with both the biological and socio-cultural aspects of human behaviour, and particularly with ways in which the two have interacted throughout human history to influence health and disease. The discipline is heavily based on theory (as in other areas of anthropology) which provides a conceptual framework for research and interpretation of culture.

The interpretive theories give precedence to the study of meaning rather than a decontextualised, positivist account. They tend to explore metaphors of health and illness and the symbolic uses of the human body in various cultures. Interpretive theories have often been used in the analysis of healing rituals and typically constitute micro studies of the interaction between patients and practitioners. In addition, interpretive theories frame accounts of ill health and serve as a focal point for teaching clinicians to elicit the sick persons point of view in the context of clinical work. (Eisenberg and Good 1978, Janzen 1978)

The political economic theories bring into focus the health consequences of global power relations. The central concepts are social class and social relations and are useful in drawing attention to factors of social class, poverty and power as determinants of health, illness and health care. These theories look at a condition within a wider social context. In other words, an effort to understand health issues in the light of the larger political and economic factors that pattern interpersonal relationships, shape social behaviour, generate social meaning and condition collective experience (Singer and Baer 1995, Scheper Hughes 1992).

Ecological and bio-cultural theories, influential in the early 1970’s view the human species as part of environmental systems interacting with other animal and plant species in energy exchange cycles. The ecological perspective grew in prominence through multi-disciplinary projects such as the studies of the high altitude populations of the Andes and the peoples of the Kalahari Desert. With increasing reliance on mathematical modelling, ecological theory continues to shape research on hunting-gathering and agricultural systems and there is a growing interest among human biologists in applying an ecological perspective in urban settings. Townsend and Mc Elroy (1992) find that ecology is still a logical and productive framework for investigating human reproductive patterns, epidemiological change, and differential access to health care resources.

The cognitive approach deals with the study of beliefs and practices associated with illness by persons from diverse cultures. It suggests frameworks for studies of lay health beliefs and care seeking (Good 1994). Whilst a number of studies have used this framework in health problems like diabetes (Greenhalgh 1998), colds and infections (Helman 1978) Guinea worm (Brieger 1992), acute respiratory infections (Nichter 1994), epilepsy (Good 1994) diarrhea (Nichter M 1988) and high blood pressure (Garro 1988), other studies indicate the problems arising from inattention to cognitive approaches (Kendell and Martorell 1984, Illegbodu et al 1986, Edugbola 1984).

2.2 Ethnographic Health Systems research

Health systems provide the critical interface between life-saving, life-enhancing interventions and the people who need them. If health systems are weak, the power of these interventions is likewise weakened, or even lost. Health systems thus deserve the highest priority in any efforts to improve health or ensure that resources are wisely used (WHO 2000).

A health system in Kleinmans words includes patterns of belief about the cause of illness, norms governing choice and evaluation of treatment, socially legitimated status roles, power relationships, interaction settings and institutions (Kleinman 1980). A Health system is not a static phenomenon. It is in a continuous process of change due to pressure from both outside the system and from within. Every society to one degree or the other has a multiplicity of health systems (not many systems but rather complex health systems with many components) a situation, which may be termed as medical pluralism. This term is usually related to the presence of different cultural or ethnic groups within one society, each adhering to its own medical tradition. Medical pluralism accounts for the range of therapeutic choices and the diversity of health-seeking behavior. No health system is watertight. When various systems come into contact, they generally exert an influence on each other. For example, in recent years, traditional healers in some parts of the world have incorporated western pharmaceuticals into their practice of healing. Alternatively, in Western Europe, some biomedical doctors have started using acupuncture and other healing techniques. In Ghana, there have been talks on getting traditional health care practices into the formal professional regular health care system, and this has been discussed in chapter 6. In addition, there is nearly always a hierarchical order between the various medical traditions based on power and prestige. This is likely to result in stronger systems imposing themselves on weaker ones or repressing them altogether. In many countries, the biomedical health system has become the official system with other indigenous medical traditions being dismissed as mere quackery.

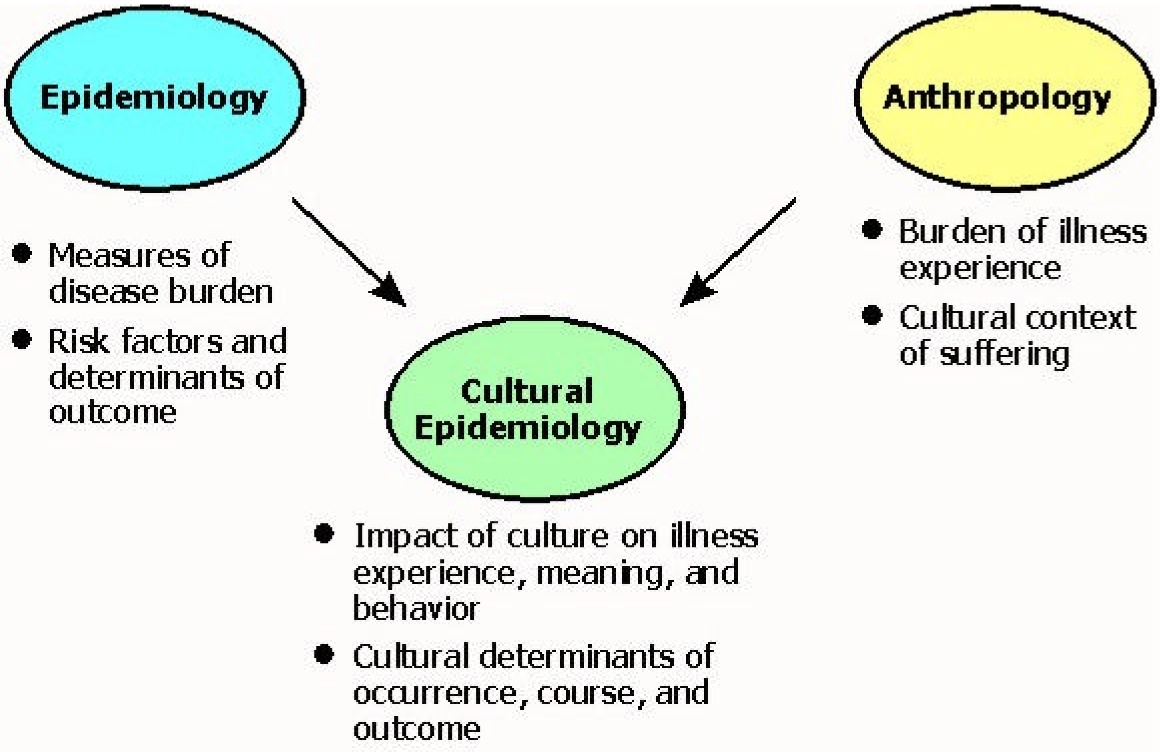
Within a health system, one may distinguish various levels of organization, starting from the household as the lowest level at which people organize their ideas and activities to maintain or restore health. One may consider higher levels, such as the local community, the district, the region, the national level and finally the international level. Political power and economic resources to improve health are distributed extremely unevenly over the various levels making access to and provision of health care services difficult. Recently, a study on Community Directed Treatment with Ivermectin for Onchocerciasis control, found that in mass drug administration, higher coverage is achieved if the community rather than the health sector took the responsibility for drug distribution. The low coverage achieved by the health sector was as a result of some of the problems outlined above. A similar approach of Community Directed Treatment was tried out with lymphatic filariasis and is presented in chapter 8.

A contribution to the study of health seeking behavior comes from ethnography through anthropological focus on micro-level factors that affect household decision making that has led to the consideration of intra cultural and intra community factors (Pelto and Pelto 1990). These Factors make behavior intelligible by describing both the context in which people reach their decisions and by clarifying health seeking behavior as sometimes health planners wish them to do. Their description of the emic rationality of peoples therapeutic choices may encourage health workers to adopt a more positive appreciation of peoples low utilization of health services. Having more respect for patients' views undoubtedly improves the quality of their services. In biomedicine, these levels are yet to be well developed. In the traditional system, it is not that way. Different individuals have different sometimes even conflicting beliefs about the cause of illnesses and appropriate therapy. The relationship between biomedicine and local traditions of health care to date has been hostile but efforts are being made to salvage this. Some suggestions regarding how traditional healers can be incorporated in health worker training for filariasis control is discussed in chapter 6.

2.3 Cultural Epidemiological Framework

Research activities at the Swiss Tropical Institute have been developing conceptual underpinnings and a theoretical framework for an emerging field of Cultural Epidemiology. This is a discipline, which encompasses an ethnographic agenda and the use of a semi-structured interview framework known as the EMIC to develop an epidemiology of illness representations. Collaborative research at the Institute is studying illness related experience, meaning and behavior and the priority of its research is to develop ways of integrating anthropological and epidemiological methods.

Figure 2.1 Cultural Epidemiology Framework.



The figure above, reproduced from the 1999/2000 annual report of the Swiss Tropical Institute, shows that the two disciplines have a common interest in explaining ill health. Whilst Epidemiology measures disease burden, risk factors and determinants of outcome, Anthropology is interested in the burden of illness and the cultural context within which the suffering takes place. The cultural epidemiological framework makes use of the EMIC to look at the impact of culture on the illness experience meaning and behavior and the cultural determinants of occurrence, course and outcome of illness.

Whilst the discipline of anthropology uses the emic approach, which is rooted in the ideologies of local communities, the field of Epidemiology uses the etic approach, which is based on the ideology of professionals outside the local communities. The concepts and opposition represented by emic and etic perspectives, provide a framework for understanding the relationship between biomedical models and patients experiences.

Apart from an interest in ill health and resort to health care, epidemiology and anthropology according to Koss and Hewlett (1997) have other things in common. Both struggle with the value of the distinction between applied and basic research. Both are concerned with helping people. Both conduct research in tropical zones and both often wish to understand what is happening on the ground. The focus on the web of factors and qualitative research methods that may be used to arrive at a better and more valid understanding of it may be the major contribution of anthropology to the required cultural epidemiological approach for tropical public health. In tropical public health, we can also talk about the need to establish therapeutic or public health alliances with the communities in which we work. This obviously includes bridging cultural and socio-economic differences a process that recognizes an understanding of the charismatic norms of the people concerned, of their particular problems and the particular context of their lives.

According to Sommerfeld (1998), there is a widespread recognition that biomedical, biological and environmental approaches to disease control are only one side of the coin and socio-cultural and behavioral factors are crucial determinants for the success or failure of disease control efforts. As a consequence, over the course of the past two decades, a complex terminology has emerged on the implementation of the principle that health programs should start with people as they are and the community as it is, both in anthropology as well as in public health. They include community participation, community needs assessment, participatory rural appraisal and rapid anthropological procedures, focused ethnographic study guides and EMIC interview guides. True interdisciplinarity can emerge from an integration of in-depth anthropological and epidemiological research. This is shown in the studies presented in the book by Inhorn and Brown (1997) and some other studies mentioned in the next section. To date, rapid assessment methodologies while they may meet time and resource constraints remain limited in their explanatory capacity. Future interdisciplinary work needs to bridge existing conceptual differences in anthropology and infectious disease epidemiology. Combining qualitative and quantitative data in a single design is the most effective way to balance the collection of in-depth data with counts based on a representative sample of a particular population. Several anthropological studies have done this (Nations 1986, Sarti et al 1994). An ethnographic approach to the collection of cognitive and behavioral data is necessary to set the stage and design survey instruments that are culturally valid and reliable, and which reflect the reality of the members of a local community in which a control program will be developed. The most effective approach is for planners to design their own investigation using some of the conceptual (theory based) approaches, methodological perspectives and specific techniques mentioned above.

2.3 Contributions of anthropology to disease control

A community base is a key element in the design of effective disease control programs. However, persons involved in control programs have reported problems with mobilizing community involvement in such programs. There are however a number of issues that need to be considered. The first one is the fact that in each society, community is a cultural domain and community relationships are culturally patterned. Each community is unique and the social structures, housing patterns and other political, social and economic issues need to be looked at in detail. This approach was used in the implementation of the study on community directed treatment described in chapter 8.

A search through the literature indicates that there is currently a growing interest in the incorporation of anthropology in public health (Hahn 1999, Inhorn and Brown 1997). This growing interest has arisen because very few of the studies on perceptions and beliefs are conducted by anthropologists and the methods used are rapid and tend to loose a lot of contextual information. The tropical disease that has had a lot of attention with regards to anthropology/social science is malaria. Here, the areas of interest have been in terms of perceptions and treatment seeking behaviour, (Haussmann 1998, Agyepong 1992, Mwenesi 1995, Aikins 1994, Ahorlu 1997). Similar areas of interest have been found in studies on Onchocerciasis (Ovuga 1995, Amazigo 1993, Hewlett 1996). With regards to Tuberculosis the concern has been on socio-cultural aspects and compliance to treatment (Khan 2000, Liam 1999). From the anthropological perspective, concepts of illness, treatment and control must be appreciated from the human centered perspectives situated in particular locales, and resulting from the complex web of forces that bind us all within our natural environments. Roosenfield (1992) labels these forces social determinants and catalogues them under the rubrics of individual household, community and broader social conditions. In her paper, she focuses on some anthropological contributions to the control and prevention of tropical diseases focusing on methodological issues.

Manderson (1998) in concluding her paper on anthropology in infectious disease control notes that, anthropological research in infectious disease control has often focused on the specifics of illness, especially cultural perceptions of illness entities, understanding local perceptions of the cause of particular diseases and treatment seeking. The ethnographic details of this work reported in various publications typically serve academic interests rather than informing practical interventions. In contrast there is relatively little which demonstrates this use partly because the interventions are frequently government or NGO initiatives, where program reports are internal documents and accountability is to funding agencies rather than accountability to an informal public. While anthropological input in terms of community perceptions of illness including local taxonomies and etiology, have value in developing health educational materials to support interventions, a more sophisticated understanding of cultural and social dimensions of illness and disease draws attention to the structural barriers to change and to the difficulties of introducing and sustaining community interventions. Anthropological involvement ensures that some account is taken of knowledge, cultural influence on the patterns of disease and structural barriers to good health. Although the social cultural and political contexts in which people experience illness and seek to recover is a small section of a more complicated puzzle, interventions that overlook these components risk failure as the structures around it crumble.

Hewlett and Cline(1997) also looked at anthropological contributions to Schistosomiasis control. They used ethnographic data to help them understand treatment seeking behavior and issues related to cost of health care. Ethnographic information helped educators to modify their educational material to be in line with beliefs regarding delay in seeking health care. Ethnographic studies also contributed to the snail control efforts that were put in place. This approach was used in chapter 7 in the development of health education strategies. They used the trans disciplinary approach which was also used in all the papers from chapters 4-8. The need for anthropologists and people working in disease control to work hand in hand cannot be over emphasized.

Gubler (1997) notes that in order to achieve substantive successes in disease prevention and control, there is the need to include social scientists in the control process primarily due to demographic and societal changes that have contributed to the transmission and spread of infectious diseases. Secondly, the top down approach of interventions was found to be unsustainable last but not the least, the unavailability of funds to support such programs. To be more sustainable, disease prevention and control programs must involve the citizens in the community where the problems occur and health officials must be able to understand the ethno cultural diversities that occurs and to communicate with the different segments of the lay population (Chapters 4&6). The ethnographic methods take time and care must be taken not to oversimplify them.

CHAPTER 3 PART I

STUDY AIM AND OBJECTIVES

3.1 Study aim and objectives

The overall aim of the studies was to determine the social and economic impact of lymphatic filariasis in Ghana and examine the role communities could play in its control in a country where the disease has been very low on the National Health agenda.

The main objectives were

1. To determine how people recognise and perceive filariasis, the social and economic impact of this disease on daily life and perceptions of the disease with reference to other diseases.

   Specifically, this objective sought to determine

   a. The community's definition of filariasis and their knowledge, cause and transmission of the disease
   b. The community's attitude towards individuals with filariasis particularly evident chronic disease
   c. Treatment seeking practices at the various stages of the disease

2. To examine concepts of causation and treatment practices among traditional healers.

   Specifically this objective examined

   a. What health care providers think about the disease
   b. The kind of treatment they give to patients
   c. Their reasons for referring patients to another source of care
   d. The potential role of traditional healers in filariasis control

3. To develop Information Education and Communication (IEC) techniques on the cause, transmission, and treatment of lymphatic filariasis (based on previous

ethnographic work) with the help of community members to facilitate an effective control program.

The specific objectives were to

a. Train health workers and selected community members in IEC techniques and to come up with a manual for future training sessions on the same subject.
b. Draw on information gathered from previous studies to design IEC techniques with active community involvement.
c. Develop and field-test the educational materials on the cause, transmission and treatment of the disease.
d. Raise awareness on the cause of the disease and the availability of effective treatment options.

4. To develop, implement and assess the process and effectiveness of a system of Community Directed Treatment of Filariasis, involving existing health services.

The specific Objectives were

a. To design, on the basis of the results of Phase I, a system of ComDT which involves the HS at the level of implementation.
b. To sensitize existing health system to the ComDT approach for filariasis control, and to train health system personnel to initiate and support ComDT
c. To encourage the health system to launch ComDT
d. To describe the process of ComDT implementation

5. To make appropriate recommendations to policy makers and to follow up and make sure the recommendations are implemented.

It is worth noting that the studies described in the subsequent chapters are based on research conducted between 1995 and 2000.

CHAPTER 3 PART II

STUDY DESIGN AND METHODS

3.2 Study area

Ghana is a tropical country on the West Coast of Africa, bordered on the west by Cote d'Ivoire, on the north by Burkina Faso and on the east by Togo. The national capital, Accra, is located on the eastern coast. The country is divided into ten regions and 110 districts. Each district has a population of about 100,000 people. The total land area of the country is about 238,537 sq. km. The country's agro-ecological zones include the drier tropical Savannah in the northern half of the country, the forest belt and the coastal Savannah in the country's southern half. Temperature ranges from 21^0C to 33^0C. The studies in this thesis were conducted in mainly one district in the North of the country and another district in the south: the Kassena Nankana district and the Winneba district. For the study on community directed treatment (chapter 8), we worked in four districts (two in the North and two in the South in which LF was found to be prevalent after a national Filariasis survey was conducted in 1994 (see fig. 1.2).

3.2.1 Field work in the Northern sectors

The Kassena Nankana district and the Builsa district in the North of the country have populations of 140,000 and 90,000 respectively. The two districts in the Northern sector are characterized by Guinea Savanna type of vegetation. The people are mainly farmers who grow crops like millet, guinea corn, groundnuts and beans. There is a large dam with canals for irrigation during the Dry season and several small dams, which the inhabitants use to water their animals. The people in this sector of the country practice mainly ancestral worship. The prevalence of filariasis ranges from 20%-40%. For elephantiasis it is 3% of the population and hydrocele affects 20% of the men. The Kassena Nankana people have no word for the supernatural; boundaries between reality and imagination do not exist. The gap between mortals and ancestral spirits is bridged by the medium of soothsaying. Every lineage (a line of family descent which includes the whole extended family) is headed by a patriarch who practices religious rites for contacting spirits to explain events of the past, forecast the future, or guide decisions of current concern to families in the lineage. Soothsaying guides the most mundane decisions of daily life. In most soothsaying encounters, little discussion takes place between the soothsayer and the client. Incantations are believed to establish communication with spirits allowing the client to interpret the questions on his mind in consultation with his ancestors. However, at the end of the session, soothsayers impart advice on auspicious actions for the client to pour libations to the ancestors and often convey other general advice. Usually a sacrifice is prescribed as an offering at an ancestral shrine, which is present in every Kassena Nankana compound. The Kassena Nankana belong to the Mole Dgbani cultural groups, one of the major ethnographic groups in Northern Regions of Ghana and neighbouring Burkina Faso. In this sense, the Kassena Nankana are more closely related to the cultures of neighboring Sahelian countries than they are to peoples of coastal Ghana.

About 51% of the district population speaks Nankam, 47% speak Kassim and the rest speak Buli, which is the principal language of the Builsa people. Although these languages differ, the cultural groups share a common custom of religion, lineage, marriage and family structure. Every lineage is headed by a patriarch who employs soothsayers for contacting ancestral spirits to explain the past, interpret the present and forecast the future on matters of current concern to his lineage (Adongo 1997). The Kassena Nankana people are a patrilineal/patriarchal society with 9 paramount chiefdoms. Male dominance is assured by family custom and one third of the families are polygynous. Women are viewed as property of males and domestic power relationships assure male control over family resources and health-seeking behavior. In fact, all decision-making is vested in males. Religion is traditional and includes ancestor worship. Soothsayers control access to ancestors and only men can consult soothsayers. The religious traditions of the Kassena Nankana reflect the dominant social role of male compound heads and lineage leaders and the importance of the lineage to social organizations.

Since the principal author did not understand the language, of the Kassena people, a one-year period was spent doing participant observation while trying to understand the language and learn about the people at the same time. This period in the field was useful and helped in building a very strong relationship with people in these communities especially with men as required by the subject we were dealing with. Initially, it was difficult to get men to talk however, a year after being in the field, men would pull down their pants to show a swollen scrotum without hesitation and indicate their distress.

3.2.2 Fieldwork in the southern sectors

The Winneba district and the Ahanta West district in the South have populations of 110,000 and 125,000 respectively. In the Southern sector the vegetation is the coastal Savannah type with stretches of mangrove swamps. The inhabitants are mainly fishermen and farmers and grow crops like cassava, plantain and other vegetables. The overall prevalence of filariasis is 10-20% while 2% of the population have elephantiasis and 10-

15% of the men have hydrocele. The people from Ahanta and Winneba are Akans and have similar beliefs and practices. The principal language of the people from Winneba is Effutu and the language spoken in Ahanta West is Nzema, however, Fanti is commonly spoken in both areas. The community members are basically traditionalists. Generally, they believe in ancestral worship. Libation is poured regularly to the ancestors in praise and in supplication of their blessing for the community. In times of trouble, they are called upon to heal the land. Their priest and priestess healers are highly respected and deal with "spiritual" problems in the community." Both physical and spiritual protection is sought from them in the form of talisman powders and so on. In addition, they are staunch church members. Despite the influence of the so called Zionist churches and capitalism, people still turn to their traditional gods in time of "trouble" Some of the churches include the church of Pentecost, African faith Tabernacle, Awoyo and so on. Migration and inter marriage has therefore contributed greatly to the downfall of the local tradition. Today large numbers of the people in the village who have migrated to other places come together only annually to celebrate their annual festivals held at the end of August.

The main sources of formal health care are hospitals, health centers and community clinics. However access to these formal health facilities leaves much to be desired. Both registered and non-registered Traditional Birth Attendants (TBA) exist in the study communities. Since the principal author is a Fanti, a much shorter time was needed in the communities to learn the language and to understand the culture of the people.

3.3 District Health Management Teams

The health system in Ghana is set up such that, all districts are managed by a district Health Management team headed by a District Director of health services (DDHS). This person is usually a medical doctor who may have had a years training in public. The team consists of a Public health nurse, a nutrition officer, a disease control officer, a health education officer an environmental health officer and a bio statistician. Since filariasis is a health problem in the districts we worked in, and one of our objectives was to implement the findings of the studies in the districts in which they were conducted, the principal investigator worked very closely with the DHMT's of the various districts. The DHMT members were involved in putting together protocols, training activities, assisted in translating interview guides and were sometimes used in data collection and supervision. With such a relationship, even though the studies were conducted in a few communities in each district, it was not a problem implementing the findings of the studies in the whole of the district.

3.4 Study Design and Methods

In this section, the design and methods for each of the objectives outlined in chapter 2 will be described separately.

3.4.1 To determine how people recognise and perceive filariasis, the social and economic impact of such a disease on daily life and the perception of the disease with reference to other diseases (chapters 4, 5)

Sample Size

This study was conducted in the Kassena Nankana district in the North of Ghana. A population of about 3000 individuals above the age of 10 years was studied. Giving that approximately 40% of the population is below the age of 10 years. This indicates a total population of 5000, which required sampling of appropriately 500 compounds. (In this area, people live in family compounds with about 10 people per compound.) We assumed 2% of the population would suffer at least one acute attack (acute phase of the disease characterised by fever, chills, local warmth and tenderness of the affected limb) each year, giving a minimum of 60 acute attacks during the year upon which conclusions can be drawn. An equal number of compounds were selected from two villages (Manyoro and Gomongo) representing the two main ethnic groups in the district (details in chapter 4).

Introduction of Study to Communities, mapping and enumeration

Meetings were organised with chiefs, elders and all resident compound members in the two villages to explain the rationale for the study and solicit their co-operation. All compounds and important landmarks were then marked onto a 1 in 5000 map to ensure easy identification and location of the compounds. This is very necessary because during the farming season the compounds become hidden in the tall millet and sorghum plantations. A census was then conducted of the study area, which included basic demographic characteristics of all members of the compounds.

Ethnographic Work.

Ethnographic data was collected throughout the period of the study. It started with informal discussions with community leaders and key informants. Issues addressed included: general health problems of the community and treatment seeking practices; health services available including traditional systems; accessibility, reliability and effectiveness of these systems; general socio-economic activities in the community; terminologies for problems arising from filariasis and the community' perceptions of the disease. Information gathered from these semi-structured interviews formed the basis for drawing up guidelines for focus group discussions on separate occasions involving community leaders and key informants, traditional healers and soothsayers, modern health care workers, women's groups, men's groups, youth groups and people with chronic disease. After acquiring a general overview of the health problems and socio-economic status of the community, specific attention was then paid to their knowledge on the cause, course and transmission of the filarial illnesses. The community's attitude towards people with chronic disease and the family's role in the management of the patients was also investigated.

Methods employed included informal discussions, focus groups and semi-structured interviews involving the same groups as mentioned above. Participant observation of the community’s attitude towards people with disease (particularly chronic disease), their involvement in the care of the patients and the assessment of the degree of impairment of patients was done throughout the study period by the author. Network analysis was also done to obtain information about impairment from and burden of illness both to sufferers and help providers, in terms of resources and time devoted to affected individuals. Lastly, case studies were conducted to obtain detailed information on all the social and economic related objectives listed above. All the information gathered from the ethnographic work was collated to help design a questionnaire to assess the social and economic impact of lymphatic filariasis. This questionnaire was administered to a cross-section of the population. (see appendix I a-c)

Morbidity and Economic Surveillance.

All residents of the community were followed up every two weeks for one year by a team of four field workers supported by two supervisors. Both field workers and supervisors received adequate training to identify signs and symptoms of acute attacks and of chronic filariasis. The field workers carried out bi-weekly visits to all compounds and collected information on any illness that occurred during the preceding two weeks. All visits to health facilities including traditional healers were also noted. Anybody reported to have or have had symptoms of acute illness was served with a more detailed questionnaire on the course of the illness and the effects of the illness on their activities. Enquiries were also made about treatments sought and the cost involved. All field supervisors carried out regular scheduled visits to the fieldworker to help sort out their problems in the field. The supervisors also reported to the field office on a daily basis, noting acute illnesses on the day of their visit. This was to enable the clinician visit affected persons to confirm the diagnosis. Individuals with confirmed acute attacks were advised to go to the health centre where standard treatment for filariasis was made available. For all confirmed acute cases, one control each was selected after matching for age, sex, occupation and locality from a database of the total population of the district. These controls were served with the same questionnaire to compare how much they spent on health care during the period under review. Fifty chronic cases identified at baseline were visited every three months and interviewed using a questionnaire to assess how much had been spent on their illness episodes and to monitor any deterioration in function and the degree of impairment particularly as it affected farming activities and household chores. These assessments were reformed to controls matched for locality, age, sex and occupation.

Chapter 4 from which this piece of work is written reports only on the ethnographic phase of the study.

3.4.2 To investigate the role of traditional health care providers in the control of lymphatic Filariasis (chapter 5)

The study was exploratory and combinations of qualitative and quantitative data collection techniques were used.

Study Sample and Data Collection Techniques:

A parasitological survey conducted in the Winneba area in Southern Ghana in 1995 indicated that, among the 718 people examined, 6.9% had hydrocele and elephantiasis (Gyapong 1998). All affected individuals (with chronic disease) in the study area were studied with a semi-structured questionnaire. This was to find out from them details of how long they have had the disease where they have gone for health care over the period, naming the provider and where he/she can be located, what was done, reasons for changing the particular provider (if any) and why.

All places mentioned by the patients were catalogued. Each of the healers identified in each of the communities and those available and willing to talk were interviewed with an adapted version of the Explanatory Model Illness catalogue, (EMIC) developed by Weiss (1997). In this method, care providers were interviewed by showing them a picture of a person with either a hydrocele or elephantiasis and then a vignette explaining the condition of the person in the picture was read to the provider. After this was done, the interview then began using a semi-structured questionnaire. (See Appendix II a&b)

3.4.3 To develop IEC techniques on the cause, transmission, and treatment of lymphatic filariasis (based on previous ethnographic work) with the help of community members to facilitate an effective control program (chapter 7)

An exploratory intervention study addressed these aims using qualitative methods. It was conducted in the Winneba district and was carried out in three phases.

Phase one: This involved the training of health and other health related personnel on several issues related to filariasis, working and communicating with people and developing IEC techniques. The training used a wide range of methods, which included lectures, discussions, role-plays, group exercises and field trips.

Phase two: This involved the training of selected group leaders on issues related to filariasis and on developing IEC techniques. Chiefs and elders from all six villages mentioned above were contacted and briefed on the project and their consent was sought. Leaders from three main groups were identified in each of the meetings with the chiefs. They included men’s groups, women’s groups and youth groups. During this phase of the study, the people from these villages actually designed their own IEC techniques with the help of the facilitators trained in phase one and the various group leaders identified in the field. All group leaders received information in sessions on the disease filariasis, its cause, transmission, signs and symptoms prevention and treatment. They were also given guidelines on how to come up with various IEC techniques that would help them spread the message about filariasis. Training of the identified group leaders was done in the communities by the facilitators who had been trained previously and under the supervision of the research team. Each group leader then went to his or her own group, and spent time working with them to develop several IEC methods.

Phase three: The methods developed by the communities, and the impact of the exercise on the lives of people in the study villages was evaluated. This was done through observation and conducting of focus group discussions with men, women and children. Key informant interviews were also conducted with elders in the community, with some members of the DHMT and the doctor in charge of the district hospital. (see appendix II)

3.4.4 To develop, implement and assess the process and effectiveness of a system of community directed treatment of filariasis, which incorporates the health services at the level of implementation (chapter 8)

The study compared two different methods of mass-treatment of lymphatic filariasis with a single-dose of Ivermectin:

1. Health **S**ystem **T**reatment (HST). With this approach, the Public Health System was asked to treat the endemic communities with Ivermectin in the way they would normally carry out a mass-treatment program.

2. Community **D**irected **T**reatment through the **H**ealth **S**ystem (ComDT). The term community-Directed Treatment (ComDT) was taken from the onchocerciasis control programs in which the community itself designs and implements a method for drug delivery that is most suitable to its needs. There is limited involvement of the Health System in this approach. In the present study, the ComDT approach was different in that it was introduced to the community by the Public Health System.

The study comprised two phases: phase I during which basic data was collected about the socio-economic situation in the study area, the presence and performance of health services and other information that was required for the design of the ComDT/HS intervention in the second phase. Phase II was the intervention phase during which both HST and ComDT/HS were executed, one round of treatment was undertaken, and the results evaluated and compared.

Study Units and Sampling

The study unit in this case was determined by the implementation level of the health services, which is the health district. Four study units were selected to be included in the study. Two were randomly allocated to the HS delivery arm and the other to the ComDT/HS arm. Within each study unit, at least two clusters of communities, each served by a health center, were selected for the study.

A total of 10 communities were selected per study unit, giving a total of 40 study communities. Two northern sector districts (KND and BUL) were paired with two southern sector districts (AHA and WIN) and randomly allocated to the HST and ComDT/HS arms. For the actual execution of the study,

- The ComDT concept was introduced by the regular health service (HS) after they have been sensitized by the Research Team. In each of the four study units, at least two clusters of five communities, each served by a health center/dispensary was selected for the intervention. Thus 40 communities were covered per site.
- In addition, within one study unit in the ComDT/HS arm in each study site, 4 more communities served by a health center were selected where both the HS and the Research Team introduced the ComDT concept. These four communities served as a “reference standard” during the evaluation period since it was not certain that the HS would have properly introduced the ComDT concept to all the communities properly.

Evaluation

The evaluation considered a final treatment coverage survey. The methodology for the process of evaluation was mainly qualitative and consisted of in-depth interviews with community leaders, distributors and health workers, and a few focus group discussions (FgDs) with community members. The qualitative evaluation was done in 12 randomly selected villages (see appendix). The evaluation addressed in particular (i) training of health workers (content and method of training), (ii) sensitization of the community (approaches and forum), (iii) selection of the distributors in the ComDT arm (how people were informed, inclusion of subgroups in decision making, criteria for selecting the distributors), (iv) operationalization of treatment (how and where drug was delivered, availability, storage and delays, distribution, rationale for the mode of distribution, compliance, constraints, any payment made), and (v) awareness & experience of community with the other community based programs.

The evaluation of the effectiveness of the different approaches was done through a survey of treatment coverage in all study communities. The survey was carried out some 2-3 months after distribution started. In each village 20 households were randomly selected. All members of the sampled households were interviewed to determine whether they received and swallowed the drugs. Adults above age 15 answered for themselves; mothers or other caretakers answered for younger children and for anyone who was not present at the time of the survey.

The head of the household was also interviewed with respect to awareness of the drug delivery program and its purpose. The research team conducted the survey (see appendix III a & b)

3.5 Selection and Training of Interviewers and pre-testing of Instruments used.

In all the study districts, the principal investigator conducted the group discussions and in-depth interviews with the help of a translated version of the different interview guides used in the studies. In the North, two translators were needed to conduct the interviews. One who was the main moderator and the second who translated the interview to me (the principal investigator). This approach had to be used because of the language barrier mentioned earlier in this chapter. The principal investigator speaks Fanti the local language spoken in the south. There was therefore no need for a translator. All interview guides were developed by the principal author, translated into the various local languages with the assistance of experienced interviewers from the various study districts. These interviewers have been trained and used for several studies in the various study areas.

For the sample surveys, all interviewers were brought together for a period of two weeks and trained on how to administer the various questionnaires. These structured questionnaires were translated into the local language. These questionnaires were also pretested and revisions were made before they were sent to the field.

3.6 Data analysis

For all the studies described above, all qualitative data were transcribed and typed onto a computer using Microsoft word for windows. The interviews done for objective one were analysed using textbase Alpha whilst the interviews done for the subsequent objectives were done using Text Base Beta. All structured questionnaires were entered using EpiInfo and the data analysed using SPSS. To ensure good quality data, all questionnaires were manually checked in the field and all discrepancies sorted out before being submitted for data entry. The author listened to all tapes and manually checked all transcripts of qualitative data before they were entered onto the computer.

SOCIO-CULTURAL ASPECTS OF FILARIASIS IN GHANA

CHAPTER 4

Filariasis in Northern Ghana: Some Cultural Beliefs and Practices And their Implications for Disease Control

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4.1 Abstract

This article reports on how some endemic rural communities in northern Ghana perceive and manage lymphatic filariasis. The disease was mainly attributed to supernatural and spiritual factors. Except for a few instances of neglect, the community was generally caring towards people with the disease. Issues related to marriage, stigma, concealment, and leadership are discussed. On the whole, the importance of social and cultural perceptions of a disease and its relevance to control cannot be over emphasized.

4.2 Introduction

Recent epidemiological investigations in the Kassena Nankana district of the Upper East Region of Northern Ghana showed that 41% of the population above ten years of age was positive for *Wuchereria bancrofti* indicated by microfilaraemia infection and about 3% had chronic disease (Gyapong et al 1993, Gyapong et al 1994). Although not fatal, lymphatic filariasis causes tremendous suffering to its victims. Clinically, the disease is characterized by a wide range of clinical manifestations and the signs and symptoms may differ slightly from one endemic area to another. People in endemic communities may be exposed to the parasite but may show no signs of clinical manifestation or filarial infection. Some may have the parasites but may have no clinical manifestation, others may only have acute manifestations which are characterized by episodic attacks of adenolymphangitis (ADL) associated with fever and malaise and finally, some may show chronic manifestation of the disease which include hydrocele, elephantiasis and chyluria. There is another group of manifestations usually referred to as "occult filariasis" or "cryptic infections". This is because the victims do not show any clinical signs of disease or infection. These include infections of the lungs presenting as tropical pulmonary eosinopilia (TPE) and renal infections sometimes presenting as acute glomerulonephritis (AGN) (WHO 1992b). It can cause serious social and economic consequences because it affects economically active people of all ages. The direct costs of treatment and the indirect costs from inactivity could also be very high but this has not been systematically documented (Evans et al 1993). Advanced chronic manifestations such as elephantiasis of the extremities, genitalia, and breast can have important psychological implications and can inflict grave social wounds (Remme et al 1993, WHO 1987).

In a study conducted in Tanzania, the disease was considered to be socially unacceptable and shameful. People with hydrocele were embarrassed and led a restricted life (Muhondwa 1983). In the Philippines, the story is slightly different. Studies conducted there suggest that the degree of stigma appeared to be associated with the severity and visibility of the disease and that filariasis sufferers were not excluded from social activities. Males with hydrocele could therefore go to school, work, marry and live with their families. Generally, a mildly to moderately enlarged scrotum was not viewed as a disadvantage but rather as characterizing people who were hard working and devoted to family (Lu et al 1989).

Disease control programs in developing countries are often unsuccessful or unsustainable because strategies pursued are inappropriate for the community or incompatible with traditional perceptions of aetiology, prevention and control. Feasible interventions to treat and prevent filariasis will require a broad understanding of traditional perceptions of the disease, its cause and consequences, and means of prevention. Since perceptions of disease vary from place to place, there is the need to carry out in depth-studies of the social, cultural and economic aspects of the disease before embarking on control measures.

This study, which is part of a multi-disciplinary and multi-country study to assess the social and economic impact of lymphatic filariasis, employed both qualitative and quantitative (questionnaires) social science methods to investigate community perceptions of the disease in Northern Ghana. The findings of the qualitative study are presented here.

4.3 Methodology

4.3.1 Study Area

The study was carried out in the Kassena-Nankana district of the Upper East Region of Ghana in the guinea savanna woodland area, with an annual rainfall of approximately 100 cm, most of which falls between May and September. Temperatures range between 16^{o}C and 41^{o}C. The area is contiguous with the border of Burkina Faso and has a typically Sahelian ecological setting. It is mainly rural with dispersed settlements of extended family compounds surrounded by their farmlands. Less than 20% of the community has had any formal education and they are materially very poor (Ghana VAST Study Team 1993). There are numerous small dams in the area, and consequently, many favorable breeding sites for mosquitoes exist. There are two main ethnic groups in the district, the Kassenas and Nankanis with a minority Builsas. Despite these ethnic distinctions, decades of co-habitation and in-migration have produced an intermingling of cultures. The society is male dominant and patrilineal based upon hierarchies of clans and lineages that control access to land and exercise authority in marriages, funerals and religious and social ceremonies (Hunter 1967). The people are mainly traditionalists who revere their ancestral gods. Sacrifices are made at all ceremonies, not only at births, marriages, funerals and festivals but also to determine the cause of a disease. Soothsayers, traditional healers and community elders who usually conduct these ceremonies also play an important role in the social organization, problem resolution, and conflict mediation in the community. Perceptions of disease and its management are usually linked with culture, social organization and religion.

For this study, one community each from the two main ethnic groups was selected. These were Manyoro, a Kassim speaking area, and Gomongo, a Nankani speaking area. The total population of these two communities was 5097. After the areas were selected, community meetings were organized with the chiefs and people of the area to explain the rationale for the study and to solicit their co-operation. At this meeting women were conspicuously absent because of the traditional place of the women in the area. Information from the meeting was however, relayed to them afterwards and they were invited to participate in later informal discussions.

4.3.2 Study Design

The study was multi-disciplinary comprising clinical, epidemiological, social and economic components. A baseline socio-economic survey of compounds, where people live in joint families and a clinical survey were conducted to identify people with filarial disease and assess socio-economic status. A two-weekly morbidity surveillance was also conducted for one full calendar year to identify people with acute stages of the disease (ADL), and to assess the social and economic impact of these acute attacks over time. Qualitative information consisting of key informant interviews, focus group discussions, participant observation, case studies and network analysis, were used to obtain information on a range of community characteristics, and an in-depth understanding of perceptions, prevailing norms and attitudes. For the quantitative aspect, information from the qualitative phase of the study was used to design a questionnaire, which was administered to both affected and unaffected individuals in the community.

The Navrongo Health Research Center, the institutional base for this study has developed a system of community key informants who report on vital events such as new births, deaths and obvious pregnancies. They are mainly community leaders, sectional heads and local teachers who are respected in the community. These key informants together with traditional healers, soothsayers and field supervisors in the Navrongo Health Research Center were interviewed to enquire about the general health problems in the community and treatment-seeking practices, accessibility to these facilities and the reliability and effectiveness of these facilities. A total of 13 key informants were interviewed. The specific issues discussed included terms used to describe filariasis, perceptions of the cause and transmission of filariasis, community’s perception of the disease and attitude towards filariasis sufferers. We also studied the family's role in the management of the patients, the relative importance of filariasis to the community compared with other diseases such as malaria and schistosomiasis, and the main social activities that go on in the community.

Information gathered from the key informants was used as a basis for drawing up guidelines for focus group discussions. A total of twelve focus group discussions were held. These were made up of discussions with groups of men, women, community leaders, traditional healers, and people with chronic filarial disease such as elephantiasis and hydrocele (scrotal swelling). The meetings were well attended and lively, and lasted on the average about one hour.

The researchers continuously observed the attitude of the community towards people with the disease (particularly chronic disease) and their involvement in the care of these patients, and assessed the degree of impairment of filariasis sufferers in performing normal functions.

Field-based staff lived permanently in one compound in the study area for the whole period of the study (18 months) during which they conducted a two weekly morbidity surveillance of all compounds for cases of ADL. They kept a notebook in which events of interest were recorded. These notebooks were inspected weekly by the study's social scientist to extract all data for processing.

For the case studies, 20 people with ADL and chronic diseases were randomly selected and studied to obtain detailed information on all aspects of the social and economic impact of the disease. Some of the issues studied included their perceived cause of the disease, all the various treatments they have sought since the beginning of their illness and their preferences if any. We also studied in detail some social issues related to marriage, stigma and leadership roles in the community and the effect of the disease on their work output especially during the Acute ADL episode. Network analysis was employed to obtain information about impairment from and burden of illness both to sufferers and those who supported or helped them, in terms of resources and time devoted to affected individuals. In this, all persons closely associated with or involved in some way in the patient's routine life were interviewed and observed to obtain further information on the disease and their attitude towards the patient. The people interviewed and observed included parents, siblings, spouses, other relatives and neighbors.

4.3.3 Data Processing and Analysis

Data were recorded by note taking and audio-cassette recording. At the end of each interview or discussion, the tapes were played back and transcribed together with the notes to prepare a report. These scripts were entered into a microcomputer using the Word Perfect word-processing program and analyzed with Text-Base Alpha (Tesch 1989). The program enabled us to identify themes emerging in responses to queries about various aspects of filarial illness and social life in the community.

4.3.4 Quality Control

Field staff were trained in anthropological data collection techniques. All the interviews were conducted by the study's social scientist with the help of the field supervisors as interpreters and note-takers and were recorded onto audiocassettes. All recordings were independently transcribed by two people, and the results compared and corrected to ensure reliability. Where there was disagreement the interpretation was resolved by the two transcribers and a third person who were native speakers of the language used in the interview.

4.4 Findings

4.4.1 Terminology for disease states:

There was no one term for Filariasis. However there are well recognized words in both Kassim and Nankani for the various forms of the disease. The word for *elephantiasis* of the leg is *Natintim* (Kassim) and *Napimpim* (Nankani), *Na* meaning leg and *tintim/pimpim* meaning heavy or large. The *tintim/pimpim* actually describes the movement and the sound made when the person is walking. Similarly elephantiasis of the arm is called *Jitintim* or *Jipimpim* where *Ji* refers to the arm, elephantiasis of the breast is known as *Yilpimpim* (Kassim) or *Bitintin* (Nankani). The word for the acute *ADL* of the leg is *Nasaana* (Kassim) and *Nasaare* (Nankani). *Saana* or *Saare* are specific terms for hot, swollen and painful.

The part of the body affected was described as an "untouchable" and "immovable". Similarly acute attack of the arm is *Jisana* (Kassim) and *Nusaare* (Nankani), and the acute attack of the breast is known as *Yile Saana* (Kassim) or *Bisaare* (Nankani). *Hydrocele* (scrotal enlargement filled with fluid) is called *Manchale* (Kassim) or *Lani* (Nankani) and an acute ADL of the scrotum is called *Paamanchale* (Kassim) or *Pulani* (Nankani). *Paa* or *Pua* is the word for fever, in other words, "fever scrotum". These terminologies literally translate as fever of the scrotum because of the perceived cause of the acute attack.

4.4.2 Perceived causes of filariasis

Spiritual and supernatural causes

Almost all respondents attributed supernatural causes to filariasis. Among the conditions mentioned, elephantiasis of the leg is usually attributed to spiritual causes. It is believed that during "war dances" which are normally performed at funerals, *juju* men from different clans display their spiritual powers by throwing "spiritual medicines" on the ground. Any unsuspecting person, who steps on these, could get elephantiasis of the leg. One old man emphasized the importance of spiritual fortification before embarking on a war dance. He said,

> "you don't see what happens but the medicine is very strong so only a person who has made himself strong will go and challenge a *juju* man in a war dance. As for me, I won't even go and dance whether I have protection or not".

The *juju* men also carry the tails of various animals such as horses, donkeys or cows which are believed to be the source of their power. They are said to be so powerful that a person who picks up the tail by mistake, could get elephantiasis of the arm.

Others also think it is possible to get elephantiasis of the leg by walking on herbs that have been poured on the ground by herbalists who are also thought to be powerful people. It is also believed that dwarfs inhabit certain places in the forest which are usually very soft. If someone walks on such ground and feels the prick of a thorn, he should stand still for a few minutes to allow the dwarfs to remove the thorn. If he walks away immediately and removes the thorn himself, he could get the disease. Others believe that some men use charms to inflict the disease on their wives in order that they do not become attractive to other men. They do this by smearing some herbs on their wife's leg while she is asleep and invoking the spirits to bring the disease upon her. In a focus group discussion, one young man said,

> "I have been married to two very beautiful women but because I did not have enough money they left me. If I had gone to see a *juju* man and put some medicine on their leg, no man would like them and I would still have my wives".

Hereditary

Some respondents believed elephantiasis could be hereditary because the disease was found across generations in particular households. They told us that their parents had it, and they have had it, so it is natural that their children too should get it. It is also believed that hydrocele runs in the family because it is transferred from father to son through the semen during sexual intercourse. One woman whose husband has a hydrocele said

> "my son also has the disease because when I slept with my husband, some of the water from his '*Manchale*' went into me and also into the boy. Women do not have '*Manchale*'. If the child was a girl, she will grow up to have '*Bisaare*'"(acute attack of the breast).

Fever

Hydrocele is believed to be caused by fever. It is believed that whenever a man gets a fever, it usually settles in his scrotum if not properly treated, so by the time he is a teenager, he could have had several episodes, which would cause the scrotum to swell and thus cause a hydrocele. The same is true for the female breast, which is believed to be the equivalent of the male scrotum. Recurrent fevers therefore lead to elephantiasis of the breast.

Diet

Some men with hydrocele attributed it to the increased use of Monosodium Glutamate (MSG) in cooking. Even though it is a recent condiment used in cooking and the disease has prevailed in the area for a long time, it is believed to account for the increased number of young men with hydrocele. One man said

> "in the past, the women used to cook with *dawadawa* (a local spice) and other local traditional spices but these days most of them cook with artificial spices and as a result we are getting many diseases including hydrocele.

It is also believed that eating of very sweet things like mangoes and sweet potatoes can make them get fevers which will then lead to a "*Paa Manchale*".

4.4.3 Treatment

Traditional

Interviews and observations in the community revealed that most filariasis sufferers, have become very resigned to their chronic disease and as a result, they no longer spend their meagre resources in attempts to fight the disease. This attitude towards the disease can be explained by the fact that it has been with people for several decades and they remain unsatisfied with the treatment options available. One woman said

> "the more we send the illness to soothsayers and herbalists for treatment, the worse it becomes".

Another woman with elephantiasis said

> "we have sent all our fowls to the soothsayers and spent a lot of money meeting the demands of the healers".

The degree of fatalism is summed up in the statement made in a focus group discussion by a man with elephantiasis of the leg ;

> "We will leave God to decide on what will happen to us because we do not know what to do any more".

Others, however, have not given up and hope for a cure especially people who developed elephantiasis recently. They continue to patronize traditional healers and soothsayers hoping that they will be cured. For those who are experiencing the problem for the first time, their first source of care is usually the soothsayer who tells them whether the disease is of natural or supernatural causes and advises them on what to do. They are typically advised to perform some rites if it is deemed to be spiritually related, or told to consult a herbalist if the condition is naturally caused. If the soothsayer is also a herbalist, both treatments are administered.

The herbalist will typically give people with elephantiasis of the leg or arm some herbs, which they are told to smear on the affected part of the body. Herbs are put in a broken pot with glowing coals, and the affected body part, which the healer has scarified, is held over the fire. It is believed that the medicine is carried by the smoke into the affected part. Some people smear fresh cow dung on the affected leg, and this is believed to squeeze and drain fluid out of the leg as it dries up. It is also held that because 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 a herbal preparation or ground 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 practice prolonged breast feeding (sometimes up to 4 years) and cow dung could be harmful to children.

Modern medicine

Apart from hydrocele where it is well known that successful treatment is possible through an operation, people with the filariasis hardly ever made use of modern health facilities primarily because of the perceived supernatural cause of the disease and the lack of awareness that drugs to reduce morbidity are available. Most of the people who had used the health facilities reported a reduction in the frequency of acute ADL attacks, but because of distance and the difficult terrain, these facilities are rarely used. Travelling on bicycles, the main available means of transport, for ten kilometres by a patient with acute ADL, which is very painful, is not very common. Most patients wait until the pain has subsided significantly or the episode is almost over before they go to the health facility. Even for hydrocele, there are a number of obstacles to the use of this facility. The major one is that the cost of the service is beyond the means of most of the peasant farmers, secondly there is considerable fear of surgery. Surgical operations, irrespective of how minor they may be, are considered a matter of life and death, and for this reason surgery is not very popular. As one man put it,

> "If I die, because of this operation, who will look after my family".

Self-medication

Most people with ADL tend to treat themselves. They would normally 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.

4.4.4 Attitude of the community and family towards people with the dise ase

Focus group discussions, interviews and observations revealed that the community "accepted" people who have the chronic disease. This we observed to be true especially of those whose legs are not grossly enlarged. You find the affected in the market buying and selling, at the bore hole fetching water and at funerals and other gatherings. When the elephantiasis or hydrocele becomes very big, people suffering from the disease do not feel comfortable when they move around. Sometimes victims of the disease discussed their extreme discomfort, embarrassment and sense of ostracism at the advanced disease stage. For example, some stated that they would rather be at home because they feel shy when the elephantoid leg has pus oozing out of it from infection and they are being chased by flies. We observed that, at this stage of the disease, the patient is confined to a small room and stays there till the pus ceases to ooze out of the leg and the resulting sores have healed substantially. The immediate family will be available to meet their needs but few friends will visit because of the stench. Nonetheless, ostracism is the exception rather than the rule, and most people with elephantiasis and hydrocele move around freely in the community.

Elders in the community who have hydrocele continue to perform sacrifices and attend all functions in the community.

People who have the disease are accepted in the community because it is believed that no one brings it upon oneself. Also, if a person laughs at someone who has the disease or does not treat the patient well, the gods may decide to let that person get the disease too and he or she will be treated in a similar way. Men who have large hydrocele are teased behind their backs. For example, they are said to be carrying their babies in their scrotum because it is believed that when the scrotum becomes very large, it affects their sexual performance and as a result they become impotent. Potential children they would have had if they were potent are therefore believed to be "stuck" in the scrotum. It came out clearly that the only disease that is shunned is leprosy, which is believed to be very contagious and debilitating. People who have leprosy are not therefore fit to live among other people.

4.4.5 Effects on Social and Economic life

Leadership potential

One of the criteria for selecting a chief in the area is that he should be without blemish. It is therefore not possible for anyone with the chronic disease to be installed as a chief. If, on the other hand, he became a chief before he developed the disease, he will continue to remain so because a chief is installed for life. It is believed that it is only God who knows why he has been allowed to develop the disease.

Marriageability

Generally, unmarried people have a problem getting married when they have filariasis. In a focus group discussion with men, they all mentioned that they will never allow their daughters to marry men who have hydrocele; " What about if they are not able to have children?" one person asked. Women are married mainly to help their husbands in every aspect of their lives, especially farming. If a man therefore marries a woman with the disease, he will have to pay for her treatment and caring for her while not receiving any significant help from her. Acute ADL attacks are believed to occur more frequently in the rainy season when she is needed most to help on the farms. She therefore becomes a burden rather than a helper. One man whose wife has elephantiasis of the breast said:

> "I have regretted marrying her because she gets her acute attacks after every delivery. When this happens it affects her breast for a long time and the child becomes very weak. My first child died as a result of this and it has happened again after her second delivery. I have already spent so much money on both mother and child and therefore I will never 'touch her' again. I am going to get married to another woman who does not have the disease and have children with her in peace".

Another person also exclaimed "Who will see death and go for it?". In other words, if a man is aware that a woman has the disease, he will never marry her. The women had similar sentiments about marrying men with filariasis but complained that in such a traditional setting where marriages are arranged by parents, women have little choice about whom they marry. When they protest, they tend to incur the displeasure of their parents and family at large and this is a serious problem since they want to enter marriage with the blessing of the whole family.

Consequently, they accept their parent's choice in good faith and hope for the best. Another person observed that

> "if you are rich and you have the disease you can get a woman to marry because people are interested in money".

There were a few couples, however, who married after one of them developed the disease. They said, "You marry for love and nothing else, so it does not really matter whether your spouse has the disease or not".

Impact on work

Advanced chronic filarial disease hinders manual work, and this constitutes a worry to affected people in the community. There is only one farming season in the year and during this period, it is crucial to maximize effort and productivity. People who have filariasis are at a great disadvantage because they tire easily, especially those who have elephantiasis of the leg. They work for fewer hours at a stretch and have to rest because of severe discomfort. When they have acute attacks, it is worse because then they cannot work at all. Women who have the disease of the breast reported that they have problems mainly after delivery but otherwise, they are able to work; nonetheless, working hours are limited by the disease.

4.5 Discussion

Until recently, lymphatic filariasis had not been on the priority list of the Ministry of Health in Ghana. This is because the magnitude of the problem had not been systematically documented. Feedback of the findings of this study and others (Gyapong et al 1993, Gyapong et al 1994, Gyapong et al 1995) to policy makers of the Ministry of Health suggest that in the very near future a national filariasis control program could be embarked upon. Collection of baseline data in the form of a national epidemiological survey for lymphatic filariasis has already provided the first step (Gyapong 1995). At a recent consultative meeting on filariasis held in Malaysia (WHO 1994a), global strategies were outlined for the control of filariasis, including:

1. Controlling of the disease (morbidity) by use of antibiotics and rigorous local hygiene with or without local antibiotic and anti-fungal agents to prevent ADL.
2. Treatment of the human population using either Diethylcarbamazine(DEC) fortified salt (0.2 - 0.4% w/w) or treating the population with a single annual or semi-annual mass administration of Diethylcarbamazine (DEC mg/kg body weight). DEC is the standard treatment for the disease
3. Reducing the vector population using biocides, polystyrene beads, insecticide impregnated bednets, indoor spraying and community participation in integrated vector management.

In order to achieve any success with any of these strategies in our study population there will be the need for a substantial amount of appropriate health education. This is because local perceived cause of the disease are very different from the scientific interpretation and suggested control strategies do not appear to be compatible with current health seeking practices. Since the community is a very important unit for disease control (Paul 1987, MacCormack 1983) especially if the participatory approach is desired, the factors identified in this study could form the basis for formulating potential health education messages. Bermejo and Bekui (1993) identified four factors relevant to the design a good framework for community participation in disease control. These include the political background, community characteristics, managerial capacity of the provider, and the epidemiology of the disease.

In their case studies of the Guinea Worm Eradication Program in Ghana and the Nicaraguan Tuberculosis Control program, they concluded that, political support and availability of resources do not necessarily guarantee community participation and success of the program. They emphasized the importance of other determinants such as commitment to primary health care, intersectoral collaboration and the understanding of the basic epidemiology of the disease by the population at risk. The findings of this study provide an understanding of these factors and their relationship to disease control in the area. Hunter (1992) also identified four areas of coordinated efforts to achieve success in control in this study area. These include mass chemotherapy, vector control, community participation and adequate financial commitment.

In view of the perceived cause of the disease, a substantial health education component will be required for these suggestions to be fruitful and sustainable. Hunter also identifies the irrigation company in the region as a major contributory factor to the upsurge of the disease and suggests substantial financial input from the company towards amongst other things, (1) basic entomological research, (2) vector control, (3) epidemiological investigation and modeling interventions, and (4) clinical support. There is, however, evidence to suggest that the disease was present before the inception of the irrigation companies in 1984 (Gold Coast Medical Reports 1936/37).

Since elders and key informants are highly regarded in the community, they could be given special training on the cause, transmission process and prevention of filariasis. They could then become educators in the communities. In view of the community's strong belief in traditional practices, there will be the need to plan a special training package for the traditional healers. In this way, some of their practices which tend to worsen the condition such us scarification and the use of cow dung on the legs, could be stopped. Studies from Brazil indicate that regular thorough cleaning of the elephantoid leg with antiseptic solutions and topical antibiotics could reduce the size of the leg, and possibly the occurrence of ADL (WHO 1994b).

During the discussions, men with hydrocele expressed their concern about the fact that their wives were using artificial spices to cook for them. If DEC medicated salt is to be introduced, there will be the need for extensive education on its value if compliance is to be high. Secondly, in an area like the Upper East Region of Ghana where onchocerciasis until recently was highly endemic, the use of DEC could be potentially dangerous because of the possibility of severe adverse reactions in individuals still harbouring *Onchocerca volvulus* microfilariae since it causes severe unpleasant side-effects. The documented side effects, which have been the main drawback include weakness, dizziness, lethargy, nausea, and vomiting. In microfilaria positive patients there could be systemic reactions such as headache, malaise, urticaria, and pain in the joints. There could also be local reactions such as lymphadenitis, lymphangitis, abscesses, ulceration and transient lymphoedema (WHO 1992b). Though not fatal, such reaction would be an impediment to patient compliance. There will be the need for close monitoring and prompt management of side-effects if the program is not to be jeopardized. Research on the possibility of using Ivermectin in these communities should be given top priority. If high doses of ivermectin were found at the community level to be safe and better than, or comparable to the effect of DEC, this could provide alternate chemotherapuetic agent in the management of lymphatic filariasis in areas where the use of DEC is potentially dangerous due to concomitant infection with other parasites like *Onchocerca volvulus*.

This is because adverse reactions to ivermectin are generally mild and of shorter duration compared to the reactions seen with single dose of DEC. Ivermectin at high dosages (200-400 Fg/kg) given annually or semiannually seem to present a good alternative to single 6 mg/kg DEC doses in the same regimen (Addiss 1993)

To relieve themselves of pain, many of the affected individuals in the community bought drugs from peddlers who gave medications that included antibiotics and analgesics. Because of the distance and the pain incurred during ADL episodes, patients find it difficult to go to the health facilities and it is likely that even after educating them about the disease, they will continue to use the services of these drug peddlers. It is therefore important that in a control program where the use of drugs is essential, drug peddlers who are already administering the drugs be identified and trained on the appropriate use of basic drugs. This could be done by identifying and involving local assistants such as village health workers in the process. Community leaders could also help identify some drug peddlers who could be trained. The greatest problem we envisage is that of vector control. Even though the nuisance of mosquitoes is a major problem, the community did not associate filariasis with the mosquito at all. In their opinion, people get hydrocele from many fevers but not from mosquitoes. Intensive health education messages need to be developed to explain to the community the role of the mosquitoes in transmitting filariasis. It is only after this link has been made that other vector control measures can be effective.

Finally we found that most personnel at government health facilities in the district lacked sufficient knowledge and clinical expertise to manage filariasis. In fact, one of the focus group discussions with health personnel ended with a lecture on the epidemiology of the disease because the health workers knew very little about it. If the community is to be encouraged to use modern health facilities, intensive education targeted at health personnel and the provision of a management protocol at all the available facilities. This is important because it is expected that, once the community has gained increased awareness of the disease, there will be increased attendance at these health facilities for treatment and it will be counter productive if competent care is unavailable.

4.6 Conclusions

Despite medical advances leading to improved understanding of the etiology of disease, community understanding of the cause of filariasis in rural areas of northern Ghana as in many other developing countries continues to be linked with cultural and traditional beliefs emphasizing spiritual or supernatural concepts. These perceptions affect every aspect of treatment. As a result of this situation, some intervention programs may not be successful because communities do not perceive them as capable of solving their health problems. We have therefore suggested that in order for intervention programs to be successful it is important to alert both the community and health providers about issues related to filariasis, help them make choices in seeking and providing health care while maintaining positive traditional health care practices. It is also important to encourage the use and enhance the quality of government health facilities, to try new health care practices and to inform them of the most straightforward and effective behavioral alternatives for health promotion and finally, promote simple behavioral changes that reduce risk and enhance health. The role of the development of appropriate IEC on the cause transmission and management of Filariasis is paramount for a successful filariasis control program in this country.

Chapter 5

The Burden of Hydrocele on Men in Northern Ghana.

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5.1 Abstract:

The social and economic impact of lymphatic filariasis was studied in Northern Ghana. Qualitative methods of gathering information revealed that even though the disease was a problem to both men and women, men with hydrocele suffered a greater psychosocial burden. Particular attention was paid to them, distinguishing men with small hydroceles and men with large ones. Out of frustration men with small hydroceles sought health care from a wider range of places than men with larger ones. The pain associated with adenolymphangitis (ADL) renders them inactive for up to five days. Complications of lymph scrotum and ridicule from community members were a problem. Unmarried men in particular found it difficult to find a spouse with their condition, and various degrees of sexual dysfunction were reported amongst married men. The clinical significance and the value of time and attention for counseling to mitigate the effects of the disease on damaged male identity and the need for gender studies to address male issues and the need for including psychosocial issues in the calculating of DALY’s is also discussed.

5.2 Introduction:

The 1993 World Bank Development Report uses Disability Adjusted Life Years (DALYs) as a standard measure for comparing the public health impact of different diseases. In this report, the global burden for lymphatic filariasis was estimated at 850,000 DALYs lost, which represents only 0.23% of the global burden of parasitic and infectious diseases (World Bank 1993). Even though the disease does not kill, it is ranked as the second leading known cause of disability worldwide (Ottesen et al 1997). In Africa alone, it is estimated that there are some 4.6 million cases of lymphoedema and over 10 million cases of hydrocele (Michael et al, 1996). These figures represent about 40% of the global burden of the disease. These estimates were largely based on extrapolations from only gross chronic clinical manifestations due to lack of data on the acute phase and other stages of the disease. Based on more recent knowledge of the epidemiology of the disease, the figure of the DALYs lost is seen as a gross underestimate, especially in the light of new findings relating to incidence, duration, and severity of acute adenolymphangitis (Gyapong et al 1996a). Such a definition ignoring ADL significantly underestimates the burden of disease not only because the acute disease occurs more frequently, but also because it occurs among younger age groups, which are positively weighted in the calculation of DALYs. The younger age groups also constitute the majority of the population in endemic areas. More importantly, since the psychosocial burden of the disease is difficult to quantify and has not been taken into much consideration in these calculations, one can still say that the DALY figures are underestimates.

In recent years, efforts have been made to document the burden of the disease on affected individuals (Amuyunzu 1997, Ramu et al 1996, Bandyopadhyay 1996, Gyapong et al., 1996d) but, little attention has focused on the important but hidden disability associated with genital manifestations of the disease. In women, chronic manifestations affecting the genitals are rare. When they occur, the effect is hidden. Women also experience manifestations of the breast but this is also very rare. Hydrocele, which is the accumulation of fluid in the tunica vaginalis in the scrotum, has been reported in several countries to be a very common manifestation of the disease (Amuyunzu 1997, Lu et al 1989, Muhondwa et al 1983). In Ghana, Gyapong et al (1998) used it as a rapid diagnostic index for lymphatic filariasis. Whether in a man or woman, a genital manifestation would go a long way to affect the roles each of sexes play in society.

Gender refers to women's and men's roles and responsibilities that are socially determined. It is related to how both men and women are perceived and expected to think and act as male or female because of their biological differences (WHO 1998). Gender roles according to Tanner and Vlassoff (1998) change over time and over an individuals life stages but in practically all cultures, women have a lower status than men. They are for example denied the right to manage their own property, and have little control over their own sexuality. This is shown in the variables of the gender framework for tropical disease research proposed by Rathgeber and Vlassoff (1993). The three tiered gender variables which link to disease prevention and treatment include issues related to economic/productive activities, social /reproductive activities and personal factors. Over the years, studies of gender and tropical diseases have focused almost exclusively on women (Wijeyaratne 1992). This is due to the fact that up to the late 1980's the male model was used as the standard for most health measures, development of therapy and so on. It is in the light of the above problems of women that the WHO proposes the adoption of the gender approach to policy and planning.

This paper is written from a study whose aim was to look at the social and economic impact of filariasis. It attempts to address the important but neglected aspect of the effects of having a hydrocele on men in Ghana. It also highlights the fact that, when a disease impairs male sexuality, its significance may be socially amplified, inasmuch as sexual functioning may be culturally defined as the essential feature that defines an acceptable male self-image. It shows how gender stereotyping may damage men. We also look at the whole issue of disability and the need to include psychosocial aspects in the calculation of DALYs.

5.3 Materials and Methods

The study was conducted in the Kassena-Nankana District of Northern Ghana and was part of a multi centre study coordinated by WHO. The objectives were to document the community's definition of filariasis and their knowledge on the cause and transmission of the disease. The attitude of the community towards individuals with the disease, treatment seeking practices and the role of the community in the management of the disease. We were also interested in the effect of the disease on social and economic activities. Ethnographic data was collected throughout the period of the study. The study begun with informal discussions with community leaders and key informants. Issues addressed included general health seeking practices, terminologies for filariasis and the community' perception of filariasis. Information gathered from these semi-structured interviews formed a basis for drawing up guidelines for focus group discussions and in depth interviews involving affected and unaffected individuals in the community. Specific attention was paid to the objectives listed above. The principal author lived in the study communities and observed the community`s attitude towards people with disease (particularly chronic disease), their involvement in the care of the patients and the assessment of the degree of impairment of patients. All the information gathered from the ethnographic work was collated and used to design a questionnaire administered to a cross section of the community in a bid to assess the social and economic impact of lymphatic filariasis.

Every individual in the community was given a full clinical examination by clinicians and medical assistants at easily accessible locations, to define disease rates at baseline, particularly chronic filarial disease. At baseline out of a population of about 5097, 404 individuals with various degrees of chronic filarial diseases were identified in the community. They were categorised into those with infections of the Upper limb (UL) Lower Limb at early stage (LL12), advanced lower limb infection (LL3) Hydrocele of tennis ball size (HT) and large hydrocele (HL). For the crossectional survey, 20 affected individuals in each of the categories mentioned above were randomly selected to be administered with a questionnaire designed from information gathered during the ethnographic phase. A similar number of unaffected individuals were interviewed using a similar questionnaire but with the aid of vignettes depicting the various categories mentioned above. The results of questionnaires from men with hydroceles are presented in this paper. The information generated from the ethnographic phase was recorded on cassette, transcribed and analyzed using Textbase Alpha, a database management system for qualitative textual data Tesch (1989).

5.4 Results

5.4.1 Living with a hydrocele

After the survey we had HL=19, and HT=22. The youngest patient was a 15-year old school boy and the oldest a 95-year-old man. They have had the condition for between 6 months and 32 years. Of the 41 cases of patients with hydrocele interviewed, 11 experienced at least one episode of ADL. Headache, fever, swelling, pain and tenderness of the scrotum are characteristic of this condition. In addition, the scrotal area becomes very hot. This ADL episode could have been as a result of bacterial etiology of the scrotal wall. During focus group discussions and key informant interviews, another experience was mentioned, which had not been reported in the sample survey, namely, leakage of lymphatic fluid through the scrotal skin and cellulitis. One elderly man discussed his illness experience in a focus group discussion, as follows:

> I don't get acute attacks, however from time to time slimy water passes out of my scrotum, and my waist becomes stiff for about 2-4 days. This happens at least twice a year.

What the man described above could have been Lymph scrotum, which is one of the complications of hydrocele repair. However lymph scrotum could occur without hydrocele repair. It is also not uncommon for patients with lymphedema of the scrotal wall and lymph scrotum to also have a hydrocele creating an even greater burden for men than just pure hydrocele. It must be noted that these are possible explanations since the pathophysiology of lymph scrotum is not yet well understood.

5.4.2 Care Seeking

TABLE 5.1: Treatment seeking practice for hydroceles in northern Ghana

SOURCE OF HELP	Small hydroceles N=22 (%)	Large hydroceles N=19 (%)
Soothsayer	5(22.7)	0
Trad. Healer	2(9.1)	0
Self Medication	8(36.4)	2(10.5)
Relatives/Friends	1(4.5)	0
Drug Peddlar	8(36.4)	2(10.5)
Health Center/Hospital	5(22.7)	3(15.8)
Other	5(22.7)	9(47.4)

During the study period, 54% of men with hydrocele of tennis ball size (HT) and 26% of men with a larger hydrocele (HL) had sought relief of some sort for their condition. Table 1 indicates that 15% of men with HL and 23% of men with HT had visited the hospital. Ten percent of men with HL and 36% of men with HT had gone to the drug peddler for analgesics to relieve the pain during acute attacks. The same number (10% of HL and 39% of HT) resorted to self-medication in the form of a mentholated balm, which was massaged on the swollen scrotum to relieve the pain of acute attacks. Almost 50% of people with HL said they sought no help and did nothing; they said they would just wait and see what would happen to them. This could be explained as the result of their having experienced the condition for a longer period of time, and disappointment in the past with all the treatment options the HT patients were currently trying, which had not given the HL men much relief. The greatest desire of both groups of patients was to have surgery.

Their fear of "temporary death" while under anesthesia and the cost of the surgery prevented them from going to the hospital. A fifty-year-old man who has 2 wives and 6 children offered this account of his fear:

> I know I have to go in for an operation but what if I die? Who will take care of my children and my family? Since the disease has not killed me, I will stay like that till you people do something about it.

One man who had undergone a successful surgery had to borrow money to pay for it, and his brother in the city had to come and help to help pay the cost. The man with the hydrocele explained:

> I paid it myself and I had a brother in Kumasi who also helped in paying for the debt. I paid 35,000 cedis.

(about 35 US dollars in 1995). For a man who cannot earn a regular income because of his incapacitation, this is a considerable sum of money, not readily available if at all.

5.4.3 On Being a "Man" and having a Hydrocele:

The concept of manliness combines sexual functioning and social responsibilities. In the study area, a real man "Baro" (Kassim) "Boda" (Nankani) is someone who can satisfy a woman sexually, has many wives and children, large farms, and the ability to provide for the total needs of the family. One who does not fulfill such criteria for manliness is said to be a woman "Oyi kaamo"(Kassim) or "Adela Poka" (Nankani). Men whose hydrocele interfered with this concept of male identity were deeply frustrated. An elderly man who had to retire from regular employment prematurely expressed his frustration in the following way:

> Who wants a disease, if I wanted it or if I felt it was something good, would I have been wanting to remove it and throw it away. I wish I did not have this disease, so that I could also do my normal work to my satisfaction. I worked with Ghana Railways for seven good years and later joined the survey department; but for the disease which brought me home, I think I would have been better by now.

In addition they feel like a burden to their family because they have less income and cannot work as they could before they had the disease. One man said:

> A hydrocele patient is a problem during the farming season. After 2 to 3 hours of weeding it becomes difficult to walk. You have to take a rest for a brief period. You cannot even bend down and get up at once. You can only employ labor to weed if you can afford the capital. When you are a peasant farmer and cannot afford the labor costs, then you must die on the field with your hoe. When you even ask for help, you need money to buy them drink and food. Otherwise, they will not work. Unless you have children to work for you, or your in-laws/daughter or sisters husband may sympathize with you and work for you.

In addition to their economic physical handicap, the issue of marriage for young unmarried men and sexual problems for men with large hydroceles was raised. In a group discussion with unaffected men, the following discussion arose.

Q. What are the marriage prospects of a man who has a hydrocele

> R1: “They find it difficult to get married because in our area we consider such people as sick people. Nobody who is normal would like to marry a sick boy or girl. They often find it difficult to marry, but in a case where you get married before the disease occurs, you are forced to keep your spouse. This is because you can not sack your wife because she has "naa pimpim"(elephantiasis) neither would your wife leave you because you have now developed "paa manchale" (hydrocele).
>
> R2: “If you marry my daughter and develop a hydrocele afterwards, I can't take her back. But if I get to know you have it, and you come in for my daughter, I will drive you away.
>
> R3: “if I get to know my daughters fiancé has such a load in the scrotum, I will never endorse any proposal of marriage, even if she is in dying need.”

This statement proved to be controversial, however, and a young man argued:

> R4: " No that will be crude, you will have to allow them to get married."
> R3: "No I will not (dismissing the idea)."
> R4: "After the marriage he can contact a doctor to help him remove it."
> R3: "Ay, but what if he cannot produce children again?"

This discussion between the more elderly man and the young man indicates the loathing men in the community have for the disease and the dilemma it presents to unmarried men. Once married, a hydrocele is less likely to end a marriage than it is to obstruct one but, it continues to exert its effects; 10.5% of HT told us it affected their sex life, and 35% of men of HL reported a wide range of adverse effects, including pain during acute attacks and reduced desire for sex. As a matter of great concern, 29% of HL men reported that their penis was too far embedded in the scrotum to achieve an erection for a satisfying sexual relationship.

Men with the condition reported they were sad and had all kinds of negative feelings about the condition, but they did not say they avoided social functions, hid their condition or had been teased. Perhaps minimizing the social liability helped to cope with their self-stigma and stigmatization from others as a result of their condition. Unaffected people, on the other hand, readily explained what they understood to be the social impact of the disease, especially for men with large hydroceles. Among patients with hydroceles, 7.2% admitted they avoided social functions, compared with 25.4% of unaffected individuals who said such men avoided social functions. Only 7.5% of affected men admitted to concealing their condition, but 66.1% of unaffected persons said men with hydroceles tried to conceal their condition by wearing especially large pants. About 50 % of men with HL admitted that they were teased whilst 80.5% of the unaffected population said such men were teased.

5.5 Discussion.

The peak incidence of noticeable hydrocele seems to occur in early adulthood between the ages of 19-34 when men are physically robust and actively formulating social and sexual identities. This is also a time when they are pursuing career and family goals. The disease not only interrupts these pursuits but, its very location threatens the integrity of the body and an organ that is associated with self esteem, sexuality, fertility and masculinity issues of importance to ill and healthy men alike. In this study, younger men who have seen what elderly men have gone through because of their condition are extremely concerned and therefore spend time and money seeking care for their condition because of what they know it could progress to. The results also indicate that the qualities that make a man are hampered when he has a hydrocele. He gets regular acute attacks and therefore cannot farm. He has to hire labor, which has financial implications. If he has a large hydrocele, the penis is embedded in the scrotum and so he cannot have a proper erection for sexual intercourse.

Although our study considered only hydrocele arising from lymphatic filariasis, other tropical diseases may also have specific effects on men but this is not known since (as mentioned in the introduction,) the male model has been used over the years as a standard for most health measures. Vlassoff (1997) expressed this concern when the Gender Task Force of WHO/TDR came to the final year of its three-year work-plan. It had achieved most of its goals but a particular area which had not been addressed was gender difference in the impact of filariasis including the social stigma attached to hydrocele in men and gender sensitive interventions for female and male patients. This concern about mens health has also been shown in political circles. Speaking at a conference on young men's health at Aston University in Birmingham, the British Minister for public health Yvette Cooper is quoted by Yamey (2000) of the British Medical Journal as saying "promoting men's health has failed so far". Because it may be painful to disclose and discuss the kind of problems reported from this study, such research as we conducted requires a substantial commitment to time spent with the people involved. According to Vlassoff (1992), information of a sensitive nature including the fear and suffering experienced from stigmatizing diseases may be difficult to capture by survey techniques and qualitative methods are essential to unveil the complex dimensions of a problem. This was not the case in our study since the first author spent two years in the community observing, listening, interacting, and employing a variety of qualitative methods, which put these men sufficiently at ease to discuss personal aspects of this sensitive, stigmatizing condition. Dreyer (1997) reported a similar experience in a clinical setting in Brazil.

The greatest desire for a man with a hydrocele in the study area was to have surgery on the other hand, the fear of death and cost of the operation was a problem to the men studied. We therefore raise a number of issues. Is it possible to provide hydrocelectomies in a setting where the fear of temporary death will not be felt? Can something be done about the cost of this surgery such that more people can benefit? If treated as day cases, can patients handle their post operative wounds properly ?

In the Ahanta West district in Ghana, the district Medical officer with assistance from World vision has started a program where men with hydroceles are operated on free of charge at a health center as day cases with local anesthesia (In this regard, it is important to note that, Hydrocelectomies depending on the size and extent of damage can be performed under local anesthesia). Taking this course of action even without support from a Non Governmental Organization (NGO) like World Vision could reduce the cost involved in having this kind of operation and take away the fear of temporary death under general anesthesia.

A few weeks before the day of the operation, people in the surrounding communities are informed by health workers of the date on which the operations will be performed. All men with hydroceles are encouraged to register. Any one who did not register during the one week given period would have to pay for the operation. Two weeks before the operation the men are brought together for pre and post operation counseling. These men are taught how to wash and keep the scrotal area clean before the surgery and how to take care of the postoperative wound. After the operation, all patients are observed for a day and allowed to go home.

The approach described above begun during the latter part of 1999 and has not been evaluated but, since surgical intervention for men with hydrocele is one of the concerns of the Global Program for the Elimination of Lymphatic Filariasis as a public health problem, we think that in addition to disseminating as broadly as possible the most practical surgical techniques appropriate for the care of patients with hydrocele, it would be worth looking into the feasibility of adopting the Ahanta West approach.

The results have also shown that apart from issues related to inability to work when experiencing acute attacks, and the cost of surgery, the emotional and psychosocial burden on patients with the hydrocele in rural communities is enormous. Murray (1994) mentions four key social preferences or values that must be incorporated into an indicator of the burden of disease. These are: the duration of time lost due to a death at each age, the value of time lived at different ages, non- fatal health outcomes and time preference. The fact is that, psychological resilience and personal values, the stresses perceived by the patient and those close to him, and his available strategies for coping with the physiological challenges imposed on him by the disease form the core of the problem. These psychological consequences of disease for both men and women have been under researched and under valued in the DALYs calculation and needs to be considered.

In conclusion, this paper has attempted to address the critically important but frequently overlooked topic of male urogenital disease in lymphatic filariasis. It has also given some insight into the psychological or social burden of hydrocele in filariasis endemic areas particularly in Africa. Addressing the burden of persons already suffering from chronic filarial disease is an important component of the current global program to eliminate filariasis and we have raised issues with regards to some barriers to and more widespread availability of hydrocele surgery.

Chapter 6

Lymphatic Filariasis: concepts of causation and treatment practices among traditional healers in Southern Ghana.

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6.1 Abstract

From 1992 to date several studies have been conducted on lymphatic filariasis in Ghana. Even though there is some information on treatment seeking behavior of people with the disease, there however still remain an information gap in the health care providers' perspective and practices. Using an adapted version of the Explanatory Model Illness Catalogue, this study looked at perceptions of traditional healers on cause, transmission, cure, treatment practices and referral procedures. Healers in this district see the various manifestations of Filariasis as linked to each other. Even though they see very few cases, they refer men with hydrocele to the district hospital and would make scarifications, apply herbs and tie the legs of people with elephantiasis. They would refer elephantiasis cases they cannot handle to another healer or refer to the hospital as a last resort. Issues related to the need for incorporating traditional healers in formal training sessions for health workers on filariasis are discussed.

6.2 Introduction

The World Health Organization defines traditional healers as a group of persons recognized by the community in which they live as being competent to provide health by using vegetable, animal and mineral substances. The treatment methods used by these groups of people are based on the social, cultural and religious backgrounds as well as on the knowledge attitudes and beliefs that are prevalent in the community regarding physical, mental and social well being and the causation of disease and disability (WHO 1976). In Africa, it is estimated that traditional health providers deliver 60-80% of all births and provide up to 80% of all health care services to poor rural families (Hoff 1997).

According to Twumasi (1997), traditional medicine plays a very vital role in health care seeking in many countries. Over the years, much research has been done in this area in terms of the types of diseases the healers deal with and the social structure of their clients. Research has also looked into therapy management and the specialty of the healers. The practice adopted by many national systems in general and Ghana in particular, is to embark on systematic research into various aspects of traditional medicine before policy statements can be made about them.

6.2.1 History of traditional medicine in Ghana.

Before the advent of colonial contact in Ghana, traditional healers were the sole practitioners of medicine in the country and their practice was legitimate. They treated ills, had consultations with a wider public and gave protective charms to people who asked for their services. With the advent of colonial rule, a new medical system was established in the country. The justification was that the explorers and colonial administration found the country beset with many ills, including preventable and communicable diseases. Under colonial rule, European medical practitioners were posted to Ghana (known previously as Gold Coast) to cure and treat these ills. Twumasi (1975) notes that upon contact with the traditional healing practices, there was a conflict of interest between the government and the healers in terms of operational style, theoretical organization and organizational methods. The colonial government encouraged the institutionalization of the new system of modern medicine by providing it with a legislative instrument in 1878. The aim was to liquidate the native practice of traditional medicine completely mainly because the healers were thought to be quacks who lived on the neuroses of their illiterate people

It was not until Ghana’s independence in March 1957 that indigenous cultural practices were revitalized. The late Dr. Kwame Nkrumah (the first president of Ghana) was constantly seeking for an African way of doing things. In 1963, the Ghana Psychic and Traditional Healing Association was formed. This fell to pieces after the overthrow of Nkrumah in 1966 but was revived by the opening of a center for scientific research into plant medicine in 1975. Dr. Oku Ampofo was appointed the head and his mandate was to find out appropriate ways and means to organize traditional healers and encourage them to bring their herbs to the center for scientific analysis and testing. The center received a lot of cooperation from the healers. The center still exists today and furthermore, there have been a series of discussions and practical steps taken to incorporate traditional health care into the Ministry of Health. This has resulted in the development of a strategic plan for traditional health care in Ghana (2000-2004) MOH (1999).

The document outlines two broad objectives. The first is to make available to the people of Ghana the practice of traditional health care as a well-defined and recognized system, complementary to other systems using all available bodies of knowledge for the benefit of Ghanaians. The second is to protect and ensure sustainable use of medicinal plants, animals minerals and other elements of nature (eg sound, light, etc) and develop their use in a form that is effective and safe for human use. In the area of filariasis control we are interested in using all available means of reaching people with information and developing control measures.

6.3 Methodology

6.3.1 Study area

The work was done in selected communities in the Winneba district of the South of Ghana where filariasis is a problem and where a lot of work has been done and is still going on in relation to the disease. The district is in a coastal area but, the main occupation is farming. Fishing is actually reserved for migrants to the community. The women in the community mainly catch small fish and shrimps in the river close by, but are also traders and fishmongers.

Migration and inter marriage has contributed greatly to the downfall of the local tradition. Today large numbers of the people in the village who have migrated to other places come together only annually to celebrate their festival *(Akwambo)* which is held at the end of August. The main road to the village is untarred but there is a good transport system where taxis go in regularly from Winneba the capital town in the district.

Even though people in Winneba are Christians, they believe in ancestral worship. Libation is poured regularly to the ancestors in praise and in supplication and their blessing is sought for the community at all times. In times of trouble, they are called upon to heal the land. Their priest and priestess healers are highly respected and they deal with "spiritual" problems in the community. " Both physical and spiritual protection is sought from them in the form of talisman powders and so on". The main source of formal health care is the Winneba hospital, which is about 4 km from the study villages. There are several traditional healers in the community who also deal with many health problems.

6.4 Study Design

The study was exploratory and employed a combination of qualitative and quantitative data collection techniques. The objectives were to find out the perception of the healers on the disease, what the healers did for the affected individuals, what referral mechanisms they had in place and their potential contribution to the Global effort to eliminate filariasis.

Healers who had treated filariasis were identified using information from people affected with filariasis who had been identified in an earlier survey. All places mentioned by these affected individuals were catalogued. Key informants in the villages where these healers were present, were interviewed, and an additional list of all traditional healers in their communities was also collated and added to the list of care providers mentioned by the patients.32 traditional healers, 3 private practitioners the hospital and the DHMT (two institutions we have been working with in the district were mentioned). This paper presents findings from the traditional healers only.

Of the 32 traditional healers listed, 26 were identified in six communities with the help of an elder in one of the communities where the author has worked since 1995. (The others were either too old to talk or were not present in the district during the study period). This elder went personally with the author who speaks the local language and explained the purpose for being in the community and encouraged each of the identified healers to participate. They were told that failure to do so would not go against them. They were each assured of confidentiality of the information to be collected.

Each of the healers was then interviewed based on the Explanatory Model Illness catalogue, (EMIC) developed by Weiss (1997). The EMIC was designed to elicit illness-related perceptions, beliefs and practices in a cultural study of leprosy, and mental health in Bombay, India. Since the tool was developed for healers and patients in 1992 a number of studies have adapted various forms of the instruments for studies of mental health, leprosy, diarrhoeal diseases Filariasis and Onchocerciasis. More recently, it has been used to study tuberculosis.

Once the interview instrument was designed, four interviewers were trained on how to administer it. The instrument was pre-tested and a few changes made. For the actual interview, we had two pictures (hydrocele and elephantiasis) of affected people from a different district as a starting point for conducting the interview. The healer was first shown a picture of a hydrocele, then a vignette about the picture was read and then the questions were asked. After that the picture of elephantiasis was shown, another vignette was read and then the interview followed. Each healer was therefore interviewed twice. The pictures helped the healers capture what we were describing properly. Since the respondents were few, each of the interviews was recorded on a cassette recorder so that the interviewer would concentrate on circling appropriate categories on the data sheet.

A week after all the interviews had been completed, a discussion was held with the healers and members of the DHMT together on the role the two parties could play in the control of the disease in the district.

6.5 Results

6.5.1 Categories of healers Identified

Three main categories of healers were identified in the study area. They were *Akomfuo* (priest healers/spiritualists) *Nnunsifuo* (herbalists) and *Maame a ogye awo* (Traditional Birth Attendant TBA). These same categories of healers were identified by Twumasi (1975) and Ventvogel (1996) who were also studying traditional healers in Ghana. A number of the healers combined professions. Of the 26 healers we spoke to in the four communities, six were categorized as Herbalists / TBA another six as priest healers/ herbalist and two were priest healers/TBA. Four practiced solely as TBA only and two practiced solely as priest healers. Each of these healers had a story about how they came into that kind of profession. Four of them had been taught by their spouse or by a parent. Another four said it was a gift from God or that it was inherent. All the spiritualists/fetish priests/priestesses said they had been called into the bush by dwarfs where they spent between 2-7 years studying the art of healing. These reasons for becoming healers were also identified by Appiah Kubi (1981) and Tsey (1997) who worked in other parts of Ghana. According to them, people became healers either through common knowledge of remedies used by many people, family secrets where knowledge concerning certain illnesses are passed on from generation to generation or professional knowledge obtained by priest healers.

6.5.2 Concepts of disease causation

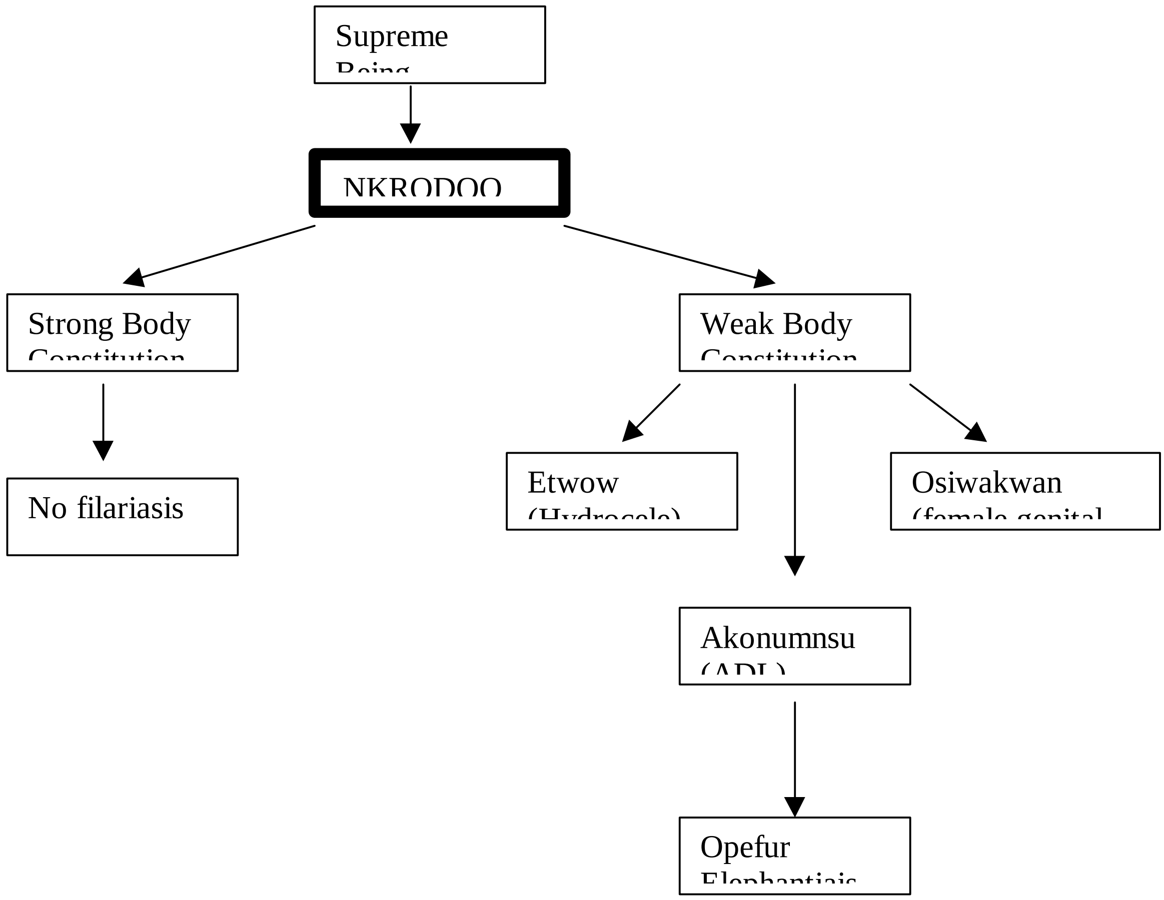
The Akan word for disease is *yade? derived* from *?yaw* (pain) and *ade* (a thing) in other words, disease is a painful thing. The pain is in two forms. The physical pain, which affects the body, and the pitiful situation in which the sick person, and the people on whom he/she depend find themselves in which is also described as painful. Akans conceptualize that all diseases that attack the physical body originate from the belly since it is the center of the body. They believe that an accumulation of dirt in the body can cause ill health hence the regular cleansing of the body through enemas with all kinds of herbs and spices is very important to them The idea of prevention and protection of the human body is also an important issue. Prevention by keeping the body clean and protection from disease with the use of charms and amulets acquired from a fetish priest or a healer, is a very common practice. The belief is that there are five main kinds of diseases that can affect a person. They are

1. *Hunhun mu yadee* (spiritual sickness). These can be caused by witchcraft and destructive powers that can be bought or acquired from a spiritualist.
2. *Efie Yadee* (homesickness) this is caused by bad feelings that arise within a family.
3. *Honam mu yadee* (diseases of the body) these are the ones that emanate from the belly. Dua bo (curse from the gods) an enemy goes to consult a deity to bring ill health upon someone who has offended him.
4. *Mogya mu yadee* (sickness of the blood)

Two different pictures were shown to each of the healers. The first was a large hydrocele, the second a large leg. With the exception of one very old lady, each of healers was able to identify the pictures easily. The TBA in particular could distinguish elephantiasis from the edema that a woman may develop during pregnancy.

The framework in figure 6.1 shows how the healers conceptualized filariasis.

Figure 6.1 Framework for explaining Filariasis



In the study area as in Northern Ghana, there is no one term for Filariasis, but there were four main conditions *Etwow, Osiwakwan, Akonumnsu* and *Opefur* which describe aspects of the disease. They are all linked to the abdomen and they are all *Honam mu yadee* and *Mogya mu yadee*. This finding is different from what has been found in India (Ramiah et al 1996b), Haiti (Eberhard et al 1996) in the North of Ghana(Gyapong et al 1996d) and in two other ethnic groups in the South of Ghana (Ahorlu 1999) where the different manifestations of the disease are seen as separate and are not linked. According to the Winneba healers, everyone is born with *Nkrodoo*: a condition in the abdomen. A person born with a strong body constitution stays healthy. However, a woman with a weak body constitution who is promiscuous is likely to get *Osiwakwan*. Only one healer mentioned that he had seen this condition before but that was long ago. (Even in clinical settings, female genital manifestation of filariasis is rare.) If she is not promiscuous but stands for a long time in water, gets a sore on her leg or takes in a lot of alcohol, she can get *Akonumnsu* which progresses to *Opefur.* If the person with a weak body constitution is a man who likes sweet things, works extra hard and does not eat well, he can get *Etwow* or *Akonumnsu*, which would also lead to *Opefur*. Only one healer mentioned the biomedical explanation that the pictures shown were a result of filariasis. He said.

> This is elephantiasis (using the English word) it can affect the hands and the breast too. Men can also get Etwow (hydrocele) from it.

There were others who had different opinions. Another healer said

> It is a dangerous disease and some people even say that what causes elephantiasis is also the cause of hydrocele, but that is not true. It is the way your body is built. No one knows whether he will get it or not.

With regard to cure of the conditions, all healers mentioned that men with hydrocele could get rid of their condition if only they went to the hospital. In their opinion, nothing can be done about elephantiasis since people had tried several places and the size of their leg was still the same or in some cases getting worse. They recognized however that that if herbs were tied to the leg that was not that big, the size could reduce but not completely to normal.

6.5.1 Activities of healers and their experience with treating filariasis patients

Generally, the herbalists /fetish priests and priestesses healed all manner of diseases that were brought to them. The TBAs dealt with only deliveries and pregnancy related problems. TBAs who had other gifts could also cure a wide range of ailments. The conditions brought to them included bodily pains, all kinds of swellings of the body, fever, madness, stomach problems, stroke, fibroids, infertility and other pregnancy related problems. The spiritualists in particular could reverse curses that had been put on people. Non of the healers advertised themselves. According to one of them,

> *“ I never do that. Those who come here and get cured go and tell others about what has happened to them.”*

When asked if people with elephantiasis came to them for health care, 24 of the healers said no when the picture of hydrocele was shown and 20 of them said no when the picture for elephantiasis was shown. This information was consistent with what patients in the district had reported.(Over 60% of the patients who helped identify the healers had gone outside the district to seek health care.)

Two of the healers had treated men with hydrocele and six of the healers had treated people with elephantiasis. To treat the hydrocele, one of them had smeared a paste of herbs on the swollen scrotum to relieve the man of pains from acute attacks. The second person gave first aid with a concoction called *"Kakepi"* It is a tree root which is ground into a smooth powder and mixed with either water or palm wine. (I was shown the powder). The person drank this became drowsy, and slept for a long time. A second preparation was made and given to the patient when he woke up in the form of enema and this, according to the healer helped him pass out all the impurities in his stomach, which were giving him the problem. The preparation normally depends on the type of condition and the severity. For some people, it is a combination of tree roots, barks, ginger and pepper that are boiled and given to the patient to drink. For others, it is a combination of leaves mixed with some water or palm wine. If a man with a small *Etwow* drinks the preparations, he urinates and has diarrhoea; after a few days, the scrotal swelling reduces. This flushing out of impurities from the body is reminiscent of the “plumbing model” that Helman (1993) describes in his book Culture Health and Illness. The fluids, which are contained in the scrotum, prevent the proper functioning of that organ and must therefore be flushed with an enema so by expelling the impurities the patient will be relieved. If on the other hand the scrotum is very large (cupping his hands to show the size he means), there is nothing he can do about it. The person would have to go to the hospital for surgery.

In the healer’s view, it is unwise for patients with a hydrocele to eat okra, sweet things and heavy food. This is because,

> *The okra is very slimy and when you eat it, it means the intestines have become very slimy and then can move into any gap in the body very fast. Sugar is very sweet and, the worms in the body like sweet things so when someone with* Etwow *eats a lot of sugar it attracts the attention of the worms and they come to the surface and then we give them some medicine to kill them.* Fufu *is lumpy and heavy and the weight makes the* Etwow *become worse*

It is worth mentioning that the two healers who mentioned that they had treated a hydrocele before stated that it is only when it is very small that they can do something about it. If it had been left to become very big, it was only the doctors who could do something about it.

The four healers who had treated people with elephantiasis had cooked herbs for them to drink or had made scarifications, smeared a paste of ground leaves and spices on the leg, and tied it with a cloth so that the medicine could seep in properly. Since very few of the healers interviewed had seen people with filariasis, we were interested in finding out what these healers would have done if these patients had come to see them. For Hydrocele, 14 of the healers said they would refer the person to a hospital because that is the only place where something can be done about the condition. Others said they would cook herbs for them to drink or give them an enema to flush out the impurities from their system.

For elephantiasis, 10 would send them to the District Health Management Team, 8 would make scarifications to let out the bad water, spread herbs on it, massage and bandage. The spiritualists would consult the spirits and two people emphatically said they did not think there was any cure for such a disease since people who had it just got worse even though they had been to several places to find a cure. All the healers felt it is only God who can decide if a person could be healed from such a dangerous disease. They were however emphatic that surgery could correct a hydrocele. All healers felt that if a person did not seek any care for their condition, the leg or hydrocele would grow bigger and seriously affect their functioning. If they were not lucky, they could die. One of the healers said

> It has never occurred in my house before but I believe that if you do not seek medication, for it you can die.

6.6 Discussion

Patients with elephantiasis have been interviewed extensively in studies conducted in Ghana however, this study is the first one to interview a wide range of traditional health care providers about filariasis. Results from this study indicate that very few traditional healers saw patients with either elephantiasis or hydrocele. Only 9 out of the 26 healers had treated any cases. The reason as we learned from the patients is that since their condition was very disgraceful, they did not want others to know what was happening and preferred to seek cure from outside the district in the hope that they would be healed before anyone noticed their problem. The other reason could be because the disease was thought of more as physically rather than spiritually caused. We noticed that even though the healers knew little about the biomedical cause and prevention of both elephantiasis and hydrocele, they recognized the signs and symptoms of the disease. They knew that traditional medicine could not help both conditions; all they could do was provide temporary relief. The healers also knew that the best place to take a hydrocele was to the hospital for surgery. With elephantiasis, they would make scars, apply herbs to the affected limb and tie with a cloth.

This they said reduced the size of the leg so long as it was not too big. With findings from this study coupled with the complaints from the healers that they are not involved in health programs, it would be useful to include them in future training sessions on filariasis with health care providers. The most important reason being that despite cultural transformations due to missionary work and changing political systems, people still stick to their traditional methods of health care seeking. As Comaroff (1981) puts it, allopathic medicine is used for relief of disabling physical symptoms, indigenous healing for physical symptoms and signs of interpersonal conflict and Zionist healing for what appears to be spiritual intrusions.

The second reason is that many healers take a holistic approach to health care than regular health care providers. Psychologically, the therapy of healers usually involves talking to patients at length, understanding their hopes and fears. They treat the whole person embedded in society (MacCormack 1981). (This is exactly what a person traumatized from having a hydrocele or elephantiasis needs.) Socially, traditional medicine has important social functions and promotes social cohesion and re-integration, healing the social relations that have led to illness. Culturally, they share the worldview of their patients, speak the same language and are rooted in the indigenous cognitive system of the patient (Bichmann 1979).

Another reason to include them in training sessions would be to encourage some of their useful practices like referral of patients to the hospital and bandaging of the affected limb. Harmful practices like scarification must be discouraged. Even though scarification is a common treatment for elephantiasis in Northern and Southern Ghana (Dunyo, 1997, Gyapong 1996d), Shenoy (1995), Dunyo (1996d) and Dreyer (1999), have noticed that there is a worsening of elephantiasis through ADL induced by this kind of treatment. In recent years, Shenoy (1995) and Dreyer(1999) in clinical settings have found out that persistent local hygiene and prevention of entry lesions with antiseptics and topical antibiotics salves can stop ongoing attacks and prevent their recurrence. This is very useful information, which can be given to both health workers and healers in training sessions. Health staff could then supervise healers just like they do with TBA’s on regular outreach visits. Since over 50% of the healers were illiterate, the training could be done in the local language. Several materials and manuals have been prepared used in Brazil and Haiti for training sessions on the same subject. These could (with permission from the authors) be adapted for use in the training.

Videos and pictures of success stories could be shown to them to help dispel the idea that people with the condition just get worse and nothing can be done for them. It must however be stressed during the training that the prevention of repeated ADL does not reverse the fundamental defect and that attacks recur when local hygiene is slacked. One good practice of the healers, which can be encouraged during the training, is the bandaging of the affected limb.

To date, Traditional healers have been left out of many health programs because their mode of operation is seen as a bane rather than a blessing but sick people go to them anyway. When the traditional Birth Attendant program started many years ago, there was an outcry from health staff about the dangers of using them but with proper training, regular in-service training and supervision, their work has been found to be very useful. Today, training of Traditional Birth Attendants is now part of the health policy of the Ghanaian Government (Eades 1993). The issue about whether the western health care system should or could be linked into non-western types of health care has long been the subject of debate among social scientists, medical practitioners, and health care planners.

The discussion begun in the 1970’s and was boosted by the adoption of the primary health care strategy by the World Health Organization (WHO). Over the past few years however, it seems the general policy of WHO has shifted from the fairly revolutionary primary health care concept and has returned to a more orthodox and technology oriented approach to health problems. This has led to the placing of traditional healers under drug management and policy but, these therapy managers provide more than just drugs. Opinions continue to vary as to whether traditional healers should be linked to the formal health sector or not (Young 1983, Bannerman 1983). Sometimes, it is argued that incorporation may be a paternalistic way of making the clients of traditional healers available to western interventions or that the process of inclusion would be slow but comprehensive colonisation of traditional healing (Freeman and Motsei 1992). Although it cannot be excluded that such developments could happen, it should be possible through mutual respect to minimize mistrust. If this crucial and basic prerequisite is not there on both sides, it is probably better to retain the status quo and leave the two systems to co-exist. This is because each medical system has its own merits and limitations. Incorporation of the merits of each system can help to improve the health delivery system in Ghana in particular and other developing countries in general.

FILARIASIS CONTROL IN GHANA

Chapter 7

Developing Information Education and Communication (IEC) Techniques With Community Members for Filariasis Control in Ghana

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7.1 Abstract

This paper describes the process used to develop Information Education and Communication techniques (IEC) for filariasis control in an endemic district on the coast of Ghana. The study was carried out in three phases: Training of community workers as facilitators; designing, development and pre-testing of messages by each community and evaluation of the program. Within a two-month period, community members developed their own IEC techniques which included songs, role-plays, a poster and poem based on guidelines given to them by the trained facilitators. In addition, they came up with games and the use of talking drums; techniques they were not introduced to but which they felt would be useful in communicating the message about the cause, transmission, prevention and treatment of filariasis properly. An awareness creation Durbar was held at which all communities presented techniques they had developed. The whole process was recorded on video and during the pre-testing stage, each community was given the chance to comment on all the techniques developed. The exercise was found to be beneficial to the communities and the DHMT. Some factors to consider when using this approach in health education are discussed.

7.2 Introduction

Lymphatic filariasis is a major social and economic burden in 120 million people in 73 countries in the tropics and sub tropics of Asia, Africa, Western Pacific and parts of the Americas. The magnitude and worldwide scope of the problem once presented a dismal control prospect. During the past decade however, significant research advances have led to an increased understanding of the severity and impact of the disease, new diagnostic and monitoring tools and especially new treatment and control measures (Ottesen et al 1997).

Ethnographic studies conducted in several parts of the world have shown that endemic communities and even some health workers have some misconceptions about the disease. The various manifestations of the disease are seen as separate disease entities and therefore there is no one term for filariasis. People thought that elephantiasis was caused by sorcery, juju and stepping on spells cast during war dances, stepping on herbs or standing for a long time in rivers and streams and in extreme cases, men give it to their wives so that other men will not be attracted to them. In the case of hydrocele, the belief was that it could be hereditary or caused by eating too many sweet things and drinking sweet drinks like palm wine or even too much cycling. Apart from that, fever that was not treated properly could settle in the scrotum leading to a hydrocele (Evans et al, 1993, Gyapong et al 1996d, Ramaiah et al, 1996b, Amuyunzu 1997, Ahorlu et al 1999).

As a result of the perceived causes, treatment practices include consultations with soothsayers and traditional healers, the use of herbs, scarifications on the affected limb, and painkillers for the acute phase

(Gyapong et al, 1996a&b, Ramaiah et al, 1996b, Dunyo et al 1997). These findings have implications for disease control and hence the decision was made to develop IEC materials and techniques with the active participation of community members, as none existed for filariasis control in Ghana. The aim was to move away from the standard health education practice of developing messages at the national level with little input from the community. Such messages are most of the time difficult for the recipients to understand and do not always meet the needs of the communities for which they are meant.

7.3 Methods

7.3.1 Study Area

The study was conducted in six villages in the Winneba district of the Central Region of Ghana. Each village is a community with its own chief and elders who are the main decision-makers. The term community instead of village will therefore be used to refer to these six villages. The district is the site for some ongoing studies on filariasis by the Ministry of Health (MOH) and a University Research Institute. The villages in this district have been enumerated and mapped. Night blood and clinical examinations have also been done on most residents. Ethnographic studies have been conducted into the beliefs of the people regarding filariasis.

The communities are rural, and have about 64% illiteracy rate and are served by a district hospital, which is between 5-15 km away and easily accessible. Disease control efforts have concentrated mainly on the EPI preventable diseases, guinea worm, the distribution of ivermectin for onchocerciasis control and malaria control activities particularly the promotion of mosquito bednets. The main channels of educating the community are through posters and talks at the hospital by community health nurses.

The overall prevalence of filariasis is 10-20% while elephantiasis is 2% and hydrocele 10-15%. However, since the disease has till very recently not had a control program, it is not seen as priority and therefore it is not included in the list of diseases for which health education is done.

7.3.2 Study Design

The study used mainly qualitative methods like group discussions, key informant interviews and observation. The objectives were to train community workers in IEC techniques for filariasis control and come up with a manual for future training sessions. To draw on information gathered from previous studies to design IEC techniques with active community involvement, and then to develop and field test the messages and raise awareness about the disease in the district. It was carried out in three phases. Phase one involved the selection and training of health and other health related personnel as facilitators on several issues related to filariasis, working and communicating with people and developing IEC techniques. In Phase two, the facilitators in conjunction with chiefs and leaders from various groups in the community developed action plans for their work with the communities and actually developed their messages. These were pre-tested and used in various ways. In the final phase, the impact of the whole program on the lives of the community members was evaluated through non-participant observation and conducting of focus group discussions with men, women and children. Key informant interviews were also conducted with elders in the community and with some members of the DHMT and the Doctor in charge of the district hospital. This paper focuses on the processes involved in developing the messages.

7.4 Results

7.4.1 Training of Trainers

The training was for two weeks and designed for health workers, community development workers and schoolteachers. The aim was to select a core of people sufficiently trained and having the necessary skills to help community members develop their own IEC techniques. The teachers were to target all school going children while the health workers and other community development workers were to target the various categories of people in the community. All the participants (six teachers, three community health nurses, two environmental health workers, one nutrition officer and one community development officer) had lived in the study area for at least five years, had a good working relationship with the community and could speak the local language well. A district school health coordinator and two people from the local FM radio station were observers. The research team and the District Director of Health Services facilitated the whole process. Topics treated included: Meaning and benefits of community participation. Community entry and communication skills. Cause, transmission, signs and symptoms, prevention and treatment of filariasis. Guidelines for Developing and designing IEC techniques. For the session on IEC, Participants were introduced to a wide range of techniques which included group discussion, role-play, puppet show, flannel graph, flip chart, songs, radio, television and posters. For each technique they were given a list of guidelines on how they could be developed. At the end of the training session, participants had the chance of demonstrating their own techniques. Other participants then made suggestions for improvement. It was important that the participants went though this exercise so that they could constructively assist community members to come up with their own IEC methods. Based on this training, a manual has been developed which is to be used in similar training sessions by other districts where filariasis is endemic.

7.4.2 Preparation of Action Plans and Development of the Various Techniques

At the end of the training, a member of the DHMT and the research team introduced all facilitators to the chiefs and elders of their assigned communities. Some community members were present at this session and were given the opportunity to ask questions in relation to the program in general and the disease in particular. Thereafter, each facilitator spent a period of two weeks with their community to identify various groups and individuals they could work with, identify cultural practices and taboos pertaining in each community which would guide them in their work, and develop a work plan for the assignment. All work-plans were brought together discussed with the research team and revised before the facilitators actually started the process of developing the techniques.

Completed plans followed a similar pattern except that the days and times for meetings varied from community to community. Communities were told that all messages would be presented at a durbar for all to see. This was enough incentive for all communities to try and develop the best technique.

During the implementation of the program, two of the six communities did not participate. In one of the communities, the facilitator had to drop out of the program due to other district commitments and it was not feasible to train another facilitator. In the second community, the chief and opinion leaders believed that talking about the disease in the open could increase the number of elephantiasis cases in the community and were therefore uncooperative. The chief said:

> "If you come and do this program here and my people start getting the disease, what will I do?".

The duty of the facilitator during the development process was mainly to guide the community. Facilitators identified the main groups in the communities and worked with their leaders who were brought together for a two-day training session on cause, prevention and treatment of filariasis. In addition, they were given guidelines on how to develop IEC techniques. Equipped with this information, all group leaders met with their various target groups, briefed them on what they had learnt during their training and begun the process of developing their own messages and materials, which took two months.

Nsuekyir produced a choral song, a role play, a poster and the use of talking drums
Atechedo produced a choral song and a role play
Gyangyanadze, a war song and a role play

Gyahaadze, a Nyonkro[1], a role play and a game

Each of the communities once exposed to the various techniques, and details on the disease, chose the techniques they felt suited them most. Two communities added their own techniques (a game and talking drums.) which they had not been exposed to but identified as means through which the information about filariasis could be spread.

Different strategies were used in developing the techniques. The facilitator suggested or was asked to develop the story line for a role-play. People volunteered to develop a particular method and brought a draft and suggestions were made on how to improve it.

Women composed the songs and taught the rest of the community, while men did the drumming. Teachers briefed the head-teacher of the school on the program. Consent was given on condition that lectures would be given during the environmental studies period, which was taught during two one-hour sessions a week. “The mosquito” a topic in the syllabus was used as a starting point and within two weeks, all issues related to the disease and developing IEC techniques were dealt with. The teacher chose the story line for the role-play and selected pupils for specific roles. The pupils composed their own songs, poems and came up with a game. All techniques were developed after school hours. In one community where the facilitator was a chief and the head-teacher of the only school, he just gave lectures to the children on the various issues. No other person was involved till the women’s leader in that community heard about what the other

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[1] Nyonkro is a popular type of music usually sang by Akan women. The words of the song most of the time have several verses and teach a lesson or talk about a particular situation in life.

communities were doing and got the whole community organized to come up with a role-play and a song. In all communities, several rehearsal sessions were held where the techniques were refined and most importantly checked by the facilitators and the research team. The aim was to use the information collected during the ethnographic phase and make sure that positive cultural belief and practices were emphasized and wrong notions replaced with the correct ones. Some positive notions were: Recognition that the disease is a problem. The different manifestations are linked to each other.

Care must be sought as soon as one sees the signs and symptoms. Hydrocele can be treated through surgery. Some of the wrong notions corrected were: All manifestations of filariasis start in the stomach. The herbalist is a good place to go to for health care. Making scarifications on the leg drains out the bad fluid and is useful.

7.4.3 The Role of the DHMT and Research Team

The research team in collaboration with the DHMT developed a couple of ways through which they felt the message on filariasis could reach the communities. These were an awareness creation durbar[2] and an interactive radio program. The awareness creation durbar organized in one of the communities was to be the climax of all the activities for developing the techniques. It was also to get people who had not heard about the messages to see and hear about what was going on. White “T” shirts with an elephantoid leg in front and a mosquito behind designed by the research team and some local experts were printed from the national level and distributed to all those who attended the function. Communities, which took part in the program, shared some of their experiences.

The head of the national disease control unit encouraged community members to use the methods they had developed and the occasion was also used to talk about other disease control initiatives such as the malaria control program. The whole function was video recorded and used as a starting point for discussions during the pre-testing of the messages. The interactive radio programs were organized at the local FM radio station using the local dialect and English. The moderator had a set of prepared question on the cause, signs and symptoms, prevention and treatment of Filariasis, which the District Disease Control Officer who was the resource person answered.

7.4.4 Pre-testing the Messages

Two weeks after the durbar, the video recording was shown to each community on a separate day. Using an interview guide, the research team asked community members in a group discussion to comment on the content and clarity of each of the messages. They were also asked to say which message they liked best and why. Men, women and children in all the communities liked the songs presented by the Gyahaadze and Atechedo communities most. Some of the reasons given were that the song explained the disease very well especially the relationship between elephantiasis and hydrocele. The rhythm of the song was so good, it was easy to learn and one could not help but dance to it. Choral music as presented by Nsuekyir was not very much appreciated mainly because it lacked the qualities listed above. With regards to the play, Nsuekyir received the best vote, because it depicted the fact that the disease affects both adults and children and could affect their education and their jobs. Gyahaadze was praised for depicting that the disease manifests as elephantiasis and hydrocele. The play from Gyangyanadze was rated poor in

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[2] A gathering of chiefs, elders, community members and important dignitaries in the district

all the communities and even in their own community. At Atechedo one woman made this comment about the play from Gyangyanadze.

> "The people of Gyangyanadze did not do well at all. We did not understand their play and they were shouting too much."

People in all the communities were impressed with the fact that a schoolgirl from Nsuekyir was able to come up with a poem. The use of the use of talking drums in their opinion was very innovative. The game from children of Gyahaadze was also impressive.

People from Gyangyanadze in particular mentioned that given another chance, they would do much better. They blamed their facilitator for not giving them enough guidance. The women's leader in the village said this about the facilitator.

> "It is true that he is a sub chief and our headmaster but he is so dull. Look we have a group that plays the flute in this community. They have even been to England before. If we knew, we could have had them involved. Next time, please call me when you have a discussion with the chief about things of this nature"

Community members did not think that the poster from Nsuekyir was necessary. Some comments on the poster were

> "it is a waste of money". "The rain destroys it". "I can't even read the things they have written on it"

7.5 Discussion

Health education is not a new topic and several studies (Lloyd 1994, Brieger 1996, Hewlett 1997, Agyepong1998, Francis 1997 and Vlassoff et al 1995) including the one being discussed have done good formative research to gather information that will guide the process of developing good IEC techniques. This they have done by using a working knowledge of the people and their relevant customs in the area of the particular disease including its mode of transmission and ways to prevent it.

The problem with many other studies is the ability to apply appropriate educational strategies including community organization, communication and selected training techniques. Most of the time, after the background information has been gathered, the research or health team goes back to develop materials and messages, which they think are most appropriate to address the issue at hand. The first time the community sees or hears about this message is when it is being pre-tested on them. As Krogstad et al (1996) have rightly put it, when health or social workers develop health messages on their own, it is difficult to have a good partnership with the people for whom the message is meant. People tend to change their poor health behaviors when they have been involved in exploring the consequences of this behavior (Rifkin 1996).

Having gone through this bottom up approach, we will not hesitate to say that with proper guidance, communities are capable of informing, educating and communicating properly messages about issues which are a problem to them. The communities were involved in the process from planning of the training, selecting of trainees, preparation of action plans and deciding on which technique to use. They only received guidance on how to come up with the messages and were free to choose whichever channel they felt they were comfortable with. Feeling a part of the process, they did not hesitate to add new methods to the ones they had already been introduced to.

Not only were the communities involved in the implementation process, but during the pretest, they were able to evaluate the messages they had come up with themselves and rank the various techniques on the content and its suitability for their purposes. Community members could make such comments only because they had been exposed to and had understood the basics of the disease in question through the various channels used by the community and the research team.

In this study, whilst the community came up with their own messages, the research team and DHMT also came up with their own to reinforce what the community had done. The radio messages did not entirely reach the community but at least people in the main town heard about the discussion and went to the DHMT for more information. The importance of multiple methods was also mentioned by Lloyd et al (1994) and Agyepong et al (1998).

One of the major problems Ministry of Health faces is that, there is only one Health Education Unit and next to nothing in the 110 districts in the country. Apart from that, there are not enough trained health educationists. As a result, many of the messages and materials produced for the existing programs in place are produced at the national level and sent down to the various regions and districts to be used in the communities. More often than not the posters and pamphlets are printed in English, which is unfortunate since over 60% of the people for whom these messages are designed for are illiterate. In addition to the above, the filariasis control program has only just been introduced into the country and there are no materials on the subject.

The problems outlined above are the more reason why community workers in general not only health workers need to be properly trained as facilitators to work with leaders of various groups or religions and even traditional healers. They each have a role to play in the community and invariably have their own way of getting the message over to particular target groups. The teachers who were trained for this program targeted the school children while other community workers targeted the rest of the community. This shows that when other non-health other sectors are involved in control activities, filariasis becomes a general and not a Ministry of Health problem alone. (The district school health coordinator has started having discussions at the regional level about the possibility of incorporating sections of the manual developed into the school curriculum.)

This use of facilitators is important. Brieger (1996) has observed that facilitators in health education help plan the learning activities but must be willing to learn themselves. The person must come to a full understanding of why people communities behave the way they do. Training of facilitators must lead them to come to a full understanding of why people in the communities where they are working behave the way they do. (The facilitators we trained are people who only work in the communities. They are not natives of the communities in which they worked. This is why the research team made the facilitators spend two weeks in their selected communities studying community practices before they came up with action plans. However care must be taken in selecting facilitators. The only headmaster and chief of one of the villages who volunteered himself for the training had all his messages criticized during the pre-testing exercise because he virtually worked alone.

When community members participate enthusiastically in developing and transmitting their own IEC messages, it can be very effective. However, a program relying on voluntary participation must also allow for people to say “no”. This happened in on one of the communities where no one showed overt disease but the parasitological survey showed there were people in those communities who were positive for microfilaria. In other words, where the disease is hyper endemic, communities are likely to perceive it as priority and may be willing to participate in efforts to control it. In communities where the disease is milder, participation may be less enthusiastic.This was problem was also raised by Mutabazi and Duke (1998) as one of the constraints which may affect the Onchocerciasis control program. This problem can be overcome if more time is spent on community awareness.

Chapter 8

Community-Directed Treatment for Lymphatic Filariasis Control in Ghana

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8.3 Abstract

The elimination of lymphatic filariasis as a public-health problem is currently dependent on the delivery of annual drug treatments to at least 80% of the eligible members of endemic populations for at least 5 years. However, for various reasons, this goal may not be achievable by the health systems of most endemic countries in sub-Saharan Africa, particularly if treatment is not community-directed.

In Ghana, community-directed ivermectin treatment involving the regular public-health services at the implementation level (ComDT/HS) has recently been compared with mass-treatment in which only the health services participated (HST). Health staff and the target communities appreciated the ComDT/HS approach more than the HST approach and were more willing to participate in the community-directed scheme. The treatment coverage achieved by ComDT/HS (74.5%) was not only much higher than that of HST (43.5%) but also probably adequate for filariasis elimination. HST coverage was particularly poor in villages located >5 km from a health facility, but distance from such a facility had no significant effect on treatment coverage in the ComDT/HS arm. As virtually all the subjects who received drugs swallowed them, compliance with treatment was not a problem. The ComDT/HS approach is therefore recommended, especially for areas where access to health facilities is poor and the health workers are over-stretched. The implications of these findings for the global program for filariasis elimination are discussed.

8.2 Introduction

The introduction in recent years of single-dose treatment regimens with diethylcarbamazine (DEC) or ivermectin, alone or in combination with albendazole (Cartel *et al.*, 1992; Addiss *et al.*, 1997; Cao *et al.*, 1997; Ottesen *et al.*, 1997; Beach *et al.*, 1999), has been an important breakthrough in filariasis control. The interruption of transmission and eventual elimination of the disease as a public-health problem now seems possible (Anon., 1997). As a result, the global strategy for the control of lymphatic filariasis has been redefined, and is now principally based on annual, single-dose, drug treatment of all the eligible members of endemic communities (Ottesen *et al.*, 1997). The challenges are to achieve adequate treatment coverage's and sustain annual delivery for sufficiently long periods. In most endemic countries, high coverage and sustained drug delivery to all high-risk communities are difficult to achieve by the health services alone. These services are often overburdened with other responsibilities, short of resources, and the target communities often have little involvement in the treatment programs.

For the drug-delivery strategy to work, it must be simple, effective and sustainable, within the context of the socio–economic constraints of the endemic countries. In 1994, the World Health Organization, in collaboration with the Onchocerciasis Control Program (OCP) and a group of scientists working on a multi-country study on community-based treatment with ivermectin, developed the concept of community-directed treatment. With this concept, the community itself has the responsibility for the organization and execution of the treatment of its members. The results of the large, multi-country study have shown that community-directed treatment is feasible and effective in onchocerciasis control (WHO 1996) and such treatment is now the basic control strategy of the African Program for Onchocerciasis Control (Amazigo, 1998). Data from other studies, on drug delivery for the control of onchocerciasis, indicate that the more the target communities are involved in the delivery process the better and more sustainable this process becomes (Katabarwa and Mutabazi, 1998; Mutabazi and Duke, 1998; Schwartz *et al.*, 1998; Katabarwa *et al.*, 2000). The aim of the present study, in Ghana, was to compare the effectiveness of a delivery strategy based on mass-treatment by the regular health-care system with that of a system of community-directed treatment only involving the health services at the level of implementation.

8.3 Methods

The two-phase study compared three different methods of mass-treatment of lymphatic filariasis with a single-dose of ivermectin: mass-treatment through the regular health services (HST); a system of community-directed treatment involving the health service at the implementation level (ComDT/HS); and, as a ‘reference standard’, ComDT/HS in which both the health services and the research team introduced the ComDT/HS concept to the target communities. The communities treated were in the four study districts of Builsa (BUL) and Kassena Nankana (KND) in the north of Ghana, and Ahanta West (AHA) and Winneba (WIN) in the south. The study communities in two of these four districts (selected at random) were treated by HST (BUL and WIN) and those in the other two districts were treated by ComDT/HS (KND and AHA). Two clusters of five communities (all villages) were selected for study in each district, giving 20 communities treated by HST and 20 by ComDT/HS. In addition, within one district (AHA) in the

ComDT/HS arm (again, selected at random, from the two such districts), four more communities were selected for the 'reference-standard' treatment.

In the first phase, basic data on the socio–economic situation in the study areas, the presence and performance of health services, and other information required for the design of the ComDT/HS intervention in the second phase, were collected. During this phase of the study, the District Director of Health Services (DDHS) for each of the four study districts were interviewed, using a semi-structured interview, to identify any relevant training facilities and programs run by the government or by non-governmental organizations. The DDHS also provided information on local points of drug supply and characterized the drug-delivery system with respect to procurement and transfer from the central source of supply through the different levels to the target communities. Group discussions were held with the other members of each district's health-management team (DHMT) and other health personnel, to determine the availability of health-service personnel to assist with community-directed treatment for lymphatic filariasis, and to assess their knowledge of lymphatic filariasis and their attitudes towards the target communities. In-depth interviews were held with key informants in each study community, to help characterize the social structure and organization of the community. These informants were also asked whether they thought filariasis was a problem in their area.

The relevant, regional and district-level health authorities were contacted and then briefed, firstly on the concept and objectives of the ComDT/HS, using the OCP in Africa as an example, and then on the detailed findings from the Phase-1 interviews. The research team then discussed the concept of annual, single treatments for the control of filariasis, other aspects of filariasis control in general, and the possibility of interrupting transmission in a period of 5–7 years if high coverage were achieved. The implementation staff were then trained, by the district-level staff, on the etiology of filariasis, the benefits and side-effects of treatment, the management of the side-effects, the use of the subject's height to gauge adequate dosage (see below), the exclusion criteria, and record keeping. Since there were, at the time, no health-education materials or messages relating to filariasis in Ghana, the implementation staff were also given guidelines on how to develop information, education and communication (IEC) messages. The same information was collected and the same steps were taken to train and sensitize the health system for both of the main treatment arms (ComDT/HS and HST).

Phase 2 was the intervention phase during which both HST and ComDT/HS were executed (see Table 8.1). Activities 1–6 carried out by health workers involved sensitization and planning for the mass distribution exercise, training of implementation staff and community distributors, developing of IEC messages and execution of the campaign. Activities 7–14 comprised the actual drug distribution and so differed between treatment arms.

Table 8.1: The activities carried out in the two arms of the study

	Activities	**Activity executed by:** **HST**	 **ComDT/HS**
1	Sensitization and planning for mass drug administration	Senior health officials	Senior health officials
2	Training of key trainers	Senior health officials	Senior Health officials
3	Training of implementation staff	Key Trainers	Key Trainers
4	Development of health education messages and IEC materials	DHMT	DHMT
5	Execute IEC campaign	DHMT / health worker	DHMT, health worker
6	a. Sensitization of community on Drug Delivery	Health worker	
	b. Sensitization of community on ComDT		Health Worker
7	Selection of community distributors		Community
8	Training of community distributors		DHMT, health worker
9	Selection of drug delivery method	DHMT	Community
10	Decision on time table for drug delivery	DHMT	Community
11	Drug procurement	Health worker	Community from agreed place
12	**Drug distribution**	**Health worker** (+/-community assistant)	**Community Distributors**
13	Monitoring of drug delivery	Health worker	Community
14	Record keeping	Health worker	Community Distributors

In the HST arm, after the sensitization, the health service was requested to distribute the ivermectin as they would normally do any mass drug distribution for their district. The strategy for implementation was therefore left solely to the discretion of the DHMT. The disease-control officer, who was given the task of organizing the drug distribution, met and informed the chiefs and elders of the target communities about the drug to be distributed and. its purpose. The officer told the chiefs and elders that they would be informed of the day on which the drug would be distributed.

In the ComDT/HS arm, the concept of community-directed treatment, defined as ‘decision, planning and distribution of drugs by the community for the elimination of filariasis’, was introduced to the target communities by members of the regular health service (HS), after these health workers had been sensitized by the research team. A health worker visited each target village and met the chief and opinion leaders. Details of the problem of filariasis and of the necessity and benefits of control were discussed. The elders then facilitated a meeting of the whole community. At this meeting, details of the treatment process (drugs, dosage, benefits and likely side-effects) were given by the health worker. Issues related to assessing the quantity of drugs required at village level, evolving mechanisms for drug distribution by the community (e.g. the month, time and duration of treatment and the selection of community-based distributors), and the supportive role of the health service (with regards to supply of drugs, treatment of side-effects, training of any distributors, record keeping and transportation of drugs from district to villages) were also discussed. In four additional communities in AHA, the research team introduced the concept of ComDT and they served as the “gold standard” communities.

One round of treatment was then undertaken. A measuring stick marked in four bands, representing heights of 90–119, 120–140, 141–158 and >158 cm, was used to determine an adequate dosage for each eligible subject (one, two, three or four, 3-mg tablets of ivermectin, respectively). Finally, three months after the distribution, all 44 study villages, from the HST, ComDT/HS and ‘reference-standard’ arms, were selected for evaluation soon after the treatment round had been completed. In each village approximately 20 households (chosen using four, randomly selected clusters, each of five households) were visited for a questionnaire-based survey by the research team, to assess coverage and other variables. An adult (almost always the head of the household) was the interviewee in each selected household. Twelve of the study communities (three from each arm) were selected for qualitative data collection, to compare the implementation of the HST and ComDT/HS strategies.

8.3 Results

8.3.1 The Sensitization Process

The qualitative assessment indicated that much consultation and many discussions had taken place between the health workers and community leaders before the introduction of the ComDT/HS concept. Videos on filariasis had been shown to all the target communities and the health workers had supplemented these with talks during the community durbars they had organized to explain the whole program. An elder in one of the ComDT/HS communities explained the processes they went through:

> ‘First your people came and explained everything, then, we went to every corner of the town, and told them about the program. After that we assembled the people again, saying that if the drug came we will distribute it and we also told them many things about the drug because they had taught us about it at the health office. When the drug came we assembled the people again and then begun to distribute the drugs for about 2–3 days before everybody received theirs.’

An elder in one of the HST communities explained how he had heard about the program:

> ‘An announcement was made that they've brought some drugs, so everybody should meet at the chief’s palace for it.’

8.3.2 Selection and Training of Distributors

The community-based distributors selected by the communities in the ComDT/HS arm were from various backgrounds and included teachers, retired civil servants and ex-service men as well as the much commoner farmers. Community members had their own criteria for selecting distributors. One elder said:

> 'We looked for people who had a good character. The elders in the community are very busy so we selected young people who could read and write to go and learn about the drug and come and distribute it for us.'

Another group of people said:

> 'We had a meeting and after explaining the nature of the work, we asked people who thought they could do the work to come forward. Some people volunteered themselves and we all accepted them.'

One of the ComDT/HS communities was particularly democratic, holding elections and casting votes to select its distributors. All of the ComDT/HS distributors selected in the south of the country attended a 2-day course on drug distribution at the offices of their local DHMT. The implementation health staff trained all distributors, and the topics were the same as those of health-worker training but with particular emphasis on the fact that each community needed to decide on its own time and mode of drug distribution. In the HST arm, health workers did the distribution. In some HST communities, however, the health workers sought the assistance of some community members (with whom they had worked previously on various health programs) for the drug distribution. These volunteers were not given any formal training.

8.3.3 Drug Procurement, Storage and Distribution

There were no problems in the procurement or storage of the ivermectin tablets, in any arm. The tablets were sent from the national level to the respective DHMT and kept at the DHMT offices until the time of the distribution. In the ComDT/HS, each distributor informed a health worker of the day the distribution was to be done. On the agreed upon day, the tablets were brought to the community the local health worker. (Although the original aim was to leave the ComDT/HS communities to decide by themselves when they wanted the distribution done and to collect the tablets from the DHMT offices drugs themselves, the local health workers ended up carrying the tablets to the communities, because of the numerous health-worker–community interactions that had already occurred.) The distribution process took between 2 and 14 days, depending on the size of the community and the method used. Under no circumstance were tablets given to one resident for the treatment of another.

In the ComDT/HS arm, the method of tablet distribution varied from community to community. Some Ghanaian villages are divided into sections for easier governance, each section having its own leader. In any ComDT/HS villages split into such sections, the updating of community registers, the taking of heights of each resident for the drug distribution, and the distribution of tablets (from a point central to each section) was done by section. If you were registered in a particular section, you had to take some of the tablets intended for that section (the drug distributors for the sections were community leaders and could easily identify people who did not belong to their section). Distribution from a central point was sometimes supplemented with house-to-house deliveries (to complete the treatment of all eligible residents). Some ComDT/HS villages only used house-to-house distribution. Residents who were absent during central-point or house-to-house distributions were asked to visit the house of the distributor, to collect the drug. Most farming communities chose to limit the distribution to the early morning (05.00–08.00 hours) or evening (after 17.00 hours), to limit disturbance of the work in the fields.

In the HST arm, health workers were assigned to the communities they covered as part of their normal work. There was no census or updating of registers. Tablets were distributed from one central point in each community, very early in the morning on a single day. In some instances, where the health worker had a community member assisting, the tablets remaining after the mass distribution were left with the volunteer, who could then carry on distributing in the absence of the health worker. In some very small communities, such volunteers completed the exercise by going from house to house. Because of misinformation, only residents with overt disease, such as elephantiasis, were treated in one of the HST communities. An elder from this community had this to say during the evaluation:

> ‘If the distributor had explained to us as, you've done, we would all have taken it. He did not do that, he only served those who had the elephantiasis. I am sure the left over is with him.’

In some of the other HST communities, the chiefs had received the tablets but no distribution had been done because the health workers had never returned to explain how the ivermectin was to be distributed.

8.3.4 Record Keeping

Records for the drug distribution were kept differently in each of the four study districts. In the ComDT/HS communities, the community registers were updated and ruled to cover a 5-year period. On each day of the distribution, the number of tablets given to each person was recorded against his or her name. In the HST arm, none of the registers was updated but the disease-control officer collected summary information, at the community level, on the number of tablets sent, the number of residents treated and the number of tablets left over.

8.3.5 Coverage

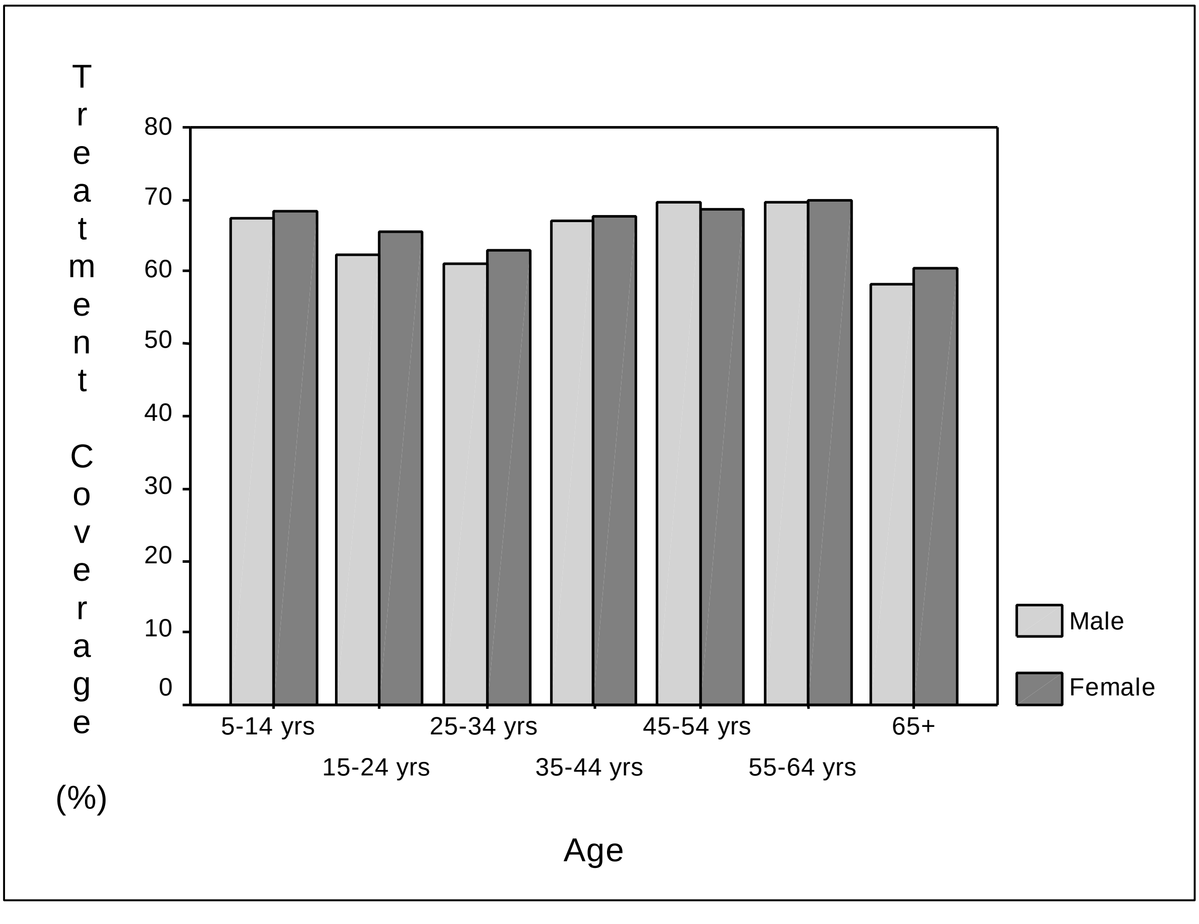
During the survey of selected households, 810 respondents (mostly heads of households) were interviewed. Of these, 388 (47.9%) were male and 422 (52.1%) female, with similar mean ages for the two sexes. These respondents reported, in total, 3278 members of their households, of whom 2797 were present and eligible for ivermectin treatment. The respondents were asked if they had received ivermectin tablets during the preceding 2–3 months and, if so, whether they had swallowed the tablets. Overall, 63.8% of all the respondents had received tablets. Only 15 (0.5%) of the respondents claimed not to have swallowed the tablets given to them (Table 2), even though a quarter of the respondents in the HST arm and one third of those in the ComDT/HS arm did not know the exact purpose of treatment. Based on these results, treatment coverage was defined as the percentage of respondents who reported to have received and swallowed the tablets. Hence, overall treatment coverage was 63.3%. (Since the definition of coverage used here is based on the information obtained from those present at the time of the household survey, it may over-estimate the actual treatment coverage if, as seems likely, those who were absent were more likely to have been left untreated than those who were present.)

TABLE 8.2: Coverage and compliance in the various treatment arms

Study arm	No. and (%) of respondents in arm who reported that they had: Received and swallowed the tablets		Received but not swallowed the tablets		Not received the tablets	
HST	694	(49.2)	1	(0.1)	715	(50.7)
ComDT/HS	1103	(73.8)	14	(0.9)	378	(25.3)
Research-standard	279	(74.8)	0	(0.0)	94	(25.2)
All	2076	(63.3)	15	(0.5)	1187	(36.2)

Coverage appeared to be the same for males and females, and not to vary very much with age-group (Fig 8.1).

Figure 8.1: Treatment Coverage by age and sex.



Coverage among those aged 15–34 years (the most active age-group economically and the most mobile) was slightly lower than among most other age-groups, although treatment coverage was lowest in the elderly (>64 years). The method used to distribute the drugs had a very marked effect on coverage, the treatment coverage obtained with HST (49.2%) being much lower than that obtained with ComDT/HS (73.8%) and far below that probably necessary to interrupt transmission and eliminate filariasis (Table 8.2). However, within treatment arms there was considerable between-village variation in coverage (Fig. 8.2). The local health services appeared effective at introducing the ComDT/HS approach, since additional introductions by the research team (in the 'reference-standard' approach) had no significant benefit (Table 8.2). The lack of a health facility in an HST community appeared to reduce coverage (Table 8.3), as the health worker distributing the tablets then had to had travel long distances. However, coverage in ComDT/HS communities appeared unaffected by the absence of a local health facility (Table 8.3).

Figure 8.2: Box plot of coverage range within the two main study arms

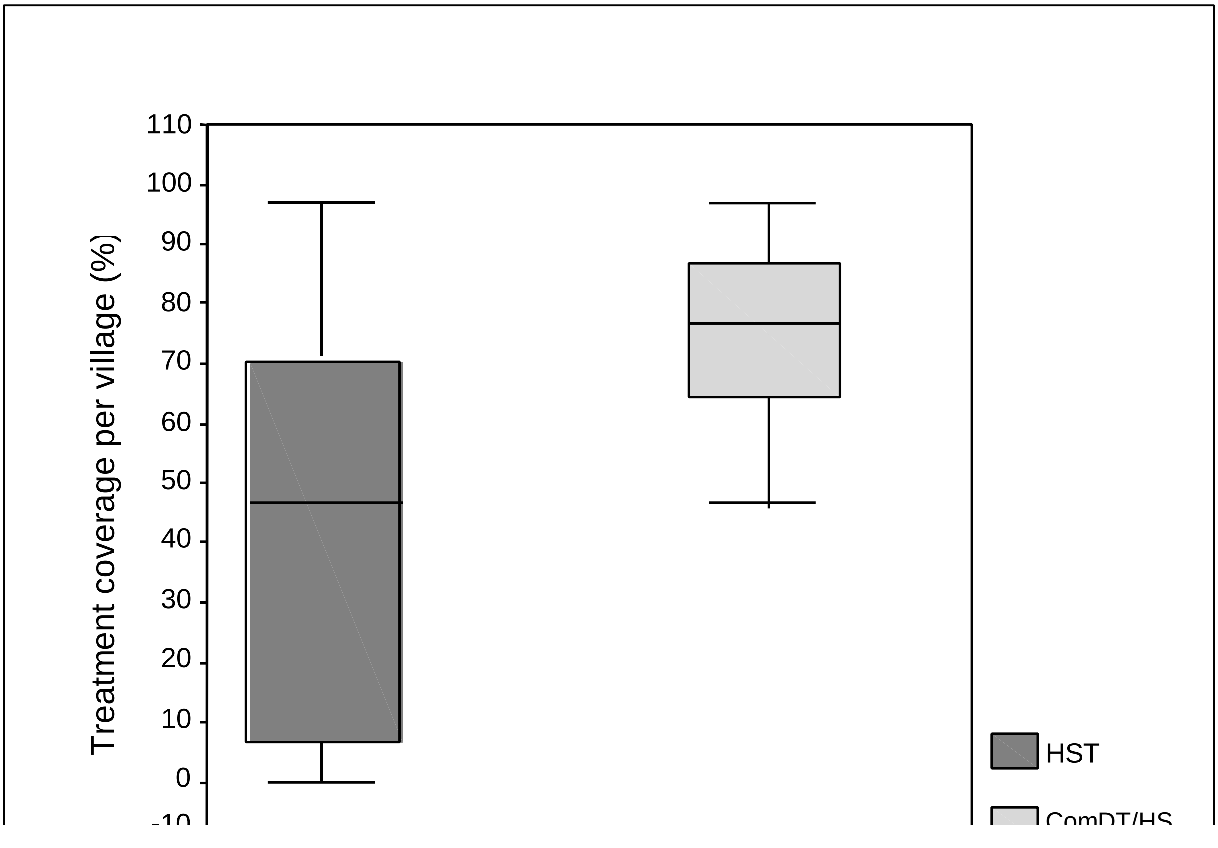


Table 8.3 Coverage in the study arms with or without health facility

Study Arm	Health Facility Present		No Health Facility	
	Received Treatment	Did no receive Treatment	Received Treatment	Did not receive Treatment
HST	632 (53.9%)	546(46.1%)	64(27.9%)	169(72.1%)
ComDT/HS	537(72.5%)	209(27.5%)	580(77.4%)	169(22.6%)

8.4 Discussion

The present results indicate that community-directed treatment with ivermectin can be effectively implemented through the regular public-health services. In general, the target communities and local health staff appreciated the ComDT/HS approach and were willing to take part in it. Although is not yet known what level of treatment coverage is required to achieve elimination, data from some preliminary computer simulations indicate that coverage of about 80% may be sufficient to interrupt transmission over a 5-year period (Plaisier *et al.,* 1998). Based on this criterion, it appears that ComDT/HS can achieve the treatment coverage required for the elimination of lymphatic filariasis. The treatment coverage achieved with HST was, in contrast, poor and insufficient for filariasis elimination. HST coverage was particularly poor in villages located >5 km from a health facility, but distance to the nearest health facility had no significant effect on treatment coverage in the ComDT/HS arm.

Virtually all those who received ivermectin tablets then swallowed them, and compliance with treatment was not a problem. In the ComDT/HS approach, the community-based distributors were able to perform credibly, with little supervision. The perceived benefits and minimal side effects of ivermectin treatment should help promote future distribution programs. One important issue with regards to sustainability is that of maintaining awareness about the disease and the importance of taking the drug yearly and over a long period of time. There are no relevant IEC messages or materials in Ghana apart from those produced by a few affected communities during a small-scale research project (unpublished observation). Perhaps this project can be scaled up to improve filariasis-related health education in other endemic districts and to cover other diseases.

In the ComDT/HS approach, the issue of incentives for the drug distributors came up over and over again (data not shown) and has often arisen in programs where community participation is needed. Some of the distributors requested certificates, to show that they had been involved in a health program. Some wanted T-shirts with elephantiasis logos, as a sign of appreciation of their contribution. Another group suggested radios or bicycles. There were also health workers involved in the HST who also felt they should be given something since, for them, the ivermectin distribution represented extra work. It might be worth considering certificates as incentives, as they are relatively cheap and less controversial than cash. There were a few distributors who mentioned that a desire to help was really what motivated them to do the job, and this is an attitude that must be encouraged.

Askew and Khan (1990), in a study of the community-based delivery of family planning, suggested that it was important that women not only participated in the program but were selected as distributors, to enhance the uptake of the program. In the present study, however, only three of the many distributors chosen, by their communities, for ComDT/HS arm were women. Two of these female distributors dropped out after the first day of distribution because the work was too time-consuming; they had babies and could not leave their homes early in the morning to take part in the exercises because of the roles they had to perform as mothers and wives. The one remaining female distributor was an elderly woman who was assisted by her son in house-to-house delivery. It seems important to allow communities to select their own distributors (irrespective of gender), since the communities know what role particular community members can perform best.

The generally good records that were kept by the ComDT/HS communities went a long way in enhancing their drug distribution. The updating and/or creation of the records represented a considerable effort but one with long-term benefits. The record books have been ruled for 5 years and, if kept properly, should help in the monitoring of subsequent annual treatments and of the continuity of treatment of an individual over time. Although Schwartz *et al.* (1998) thought identity cards would help in monitoring treatments, such cards would be very expensive to use within a nationwide control program.

Although the ComDT/HS system has proved its worth in a research setting in Ghana, it is important that the present results be translated into a much larger program. In the present study, many of the ivermectin distributors were very useful ‘agents of change’, especially in telling people about the program. Nationwide application of the ComDT/HS approach should lead to the elimination of lymphatic filariasis as a public-health problem, at least in Ghana and probably in the rest of Africa where access to health facilities is poor and health workers are over-stretched. Sustainability of the ComDT/HS concept should be studied in the light of the requests for incentives. This is said despite the fact that encouraging communities to participate actively in, and run their own distribution programs, and maintaining the enthusiasm of communities to persevere, over the several years that such programs must continue, constitute the essential nub of a good community-based program (Mutabazi and Duke 1998). The extent to which the element of implementation through the health services can strengthen community-based drug distribution for onchocerciasis control, and how relevant the ComDT/HS approach might be to the distribution of drugs for the control of other endemic diseases need to be explored.

DISCUSSION AND CONCLUSIONS

CHAPTER 9

9. Discussion and Conclusions.

In the preceding chapters, we have tried to look at lymphatic filariasis from the way people with the condition see it and the perception and treatment practices of traditional healers for the disease. We have also carefully considered the important issue of gender and filariasis from a broader perspective beyond women's health paying particular attention to men with hydrocele. Concerned with implementation as well as research, we conducted two studies. In the first one, information gathered from the studies on lay perspectives of filariasis was used to examine ways in which community members could contribute to the design of effective IEC methods. In the second one, two different methods of mass-treatment of lymphatic filariasis with a single-dose of ivermectin were implemented and evaluated. The thesis therefore presents an example of how a topic of research interest has moved several steps in a period of six years from a couple of exploratory studies to the actual implementation of some of the recommendations resulting from the initial work.

We found that there are marked differences in perception and health care seeking behavior between people in the areas studied. Whilst patients from Northern Ghana tended to visit more soothsayers and traditional healers because of their uncertainty about the cause of their condition, more people in the South went to health facilities. If they visited a traditional healer, it was outside their own district in the hope that they would be cured by the time they returned to their own community. Traditional healers applied some harmful health care practices to affected limbs (scarifications) which worsened the state of the already destroyed leg. In addition, some of their interventions were useful like massaging and bandaging the affected limbs and referring cases they could not handle to health facilities. These useful practices could be capitalized upon in the effort to eliminate filariasis as a public health problem. In chapter 5 we addressed gender issues related to filariasis paying particular attention to men mainly because most studies on filariasis have not addressed the role of gender in the burden of hydrocele on the men it affects. We also raise questions about the need to pay more attention to psychosocial issues in the calculation of the DALY's.

The two intervention studies showed that with guidance, people in the different villages we worked in are capable of designing IEC messages, which are suited to their needs. With regards to drug distribution, once members of study communities are informed and involved in planning and implementation of interventions from inception to evaluation, they are able to achieve higher coverage rates than when health workers took charge.

The main topics in chapters 4 through 8 have been discussed in the individual chapters. In this section, we would like to look at some methodological issues that arise in conducting the type of studies described above. We also attempt to discuss the overall contribution of the framework of cultural epidemiology to a practical understanding of filariasis. We consider issues like ethnicity, lay concepts of ill health, lymphatic filariasis as a disabling condition and how the international classification of disability fits into the cultural context of the disease. We address gender issues and some of the problems associated with health care seeking. Based on the experience of the first author, we also look at the place of an anthropologist working the Ministry of health and how this facilitated the implementation studies that are described in chapter 7 and 8. we finally make some recommendations for action.

9.1 Methodological Issues in Tropical Disease Research: An anthropological perspective.

Anthropologists have become increasingly interested in infectious and tropical disease control in recent years (Manderson 1998, Inhorn and Brown 1997). This results partly from anthropological curiosity about the natural biological and cultural worlds and their intersections. It has also been due to the interest of workers in public health in anthropological methods and theories and the resulting involvement of anthropologists in international health programs of multilateral organizations and bilateral aid programs (Gove and Pelto 1994, Vlassoff and Manderson 1994). However, Good (1994a) expressing concern about the role of medical Anthropology in public health, notes that in most intervention driven, medical and public health programs, scientific medical knowledge is positioned as super ordinate to folk beliefs.

Typically, anthropologists conduct extensive field research to contextualise human behavior and specific beliefs and values. They employ ethnographic techniques, which yield qualitative data. These methods include open-ended interviews, semi or un-structured, combined with intensive systematic observations and the usually long-term participation of the researcher in the society under study (Koss Chioino 1997).

Accompanying these techniques are those aimed at acquiring specific types of information from selected key respondents and groups, such as life histories and ethnographic mapping of concepts. Many of the traditional anthropological studies are conducted for academic purposes but we think that where a disfiguring and disabling condition such as filariasis is concerned, one needs to go beyond academic research and to apply findings in interventions that benefit the sufferers.

Moving from the basic to the applied field of anthropology in areas such as policy and program development, monitoring and evaluation, health communications and so on the situation is slightly different. It demands that anthropologists take short cuts in their research methodologically while maintaining the methodological mix that has characterized conventional ethnography. This led to the development of Rapid Assessment Procedures (RAP), which have been used for projects in nutrition, acute respiratory infections and malaria (Scrimshaw and Hurtado 1987, Manderson and Aaby 1992, Agyepong 1995). These approaches represent an effort to obtain information in the all too common situations that require quick low-cost information, particularly in cases where behavioral interventions are the only means of disease control through preventing transmission. Manderson (1998) who critically examined her own work in this area, notes that this approach forces anthropologists to clarify and adapt the methods and techniques of anthropology to allow relevant data to be collected which might then inform policy, programs and specific interventions. Rapid approaches may sacrifice contextual information and probably oversimplify behavior due to the brevity of fieldwork. They lack participant observation, which enhances the validity of data and serves to ensure this.

The studies from which this thesis is written included both ethnographic and RAP. Objective 1 and 2 dealt with sufferers, unaffected individuals and traditional healers and examined the experience and meanings of filariasis, health care seeking practices of patients and activities of practitioners; it examined the burden of the disease on those who were affected. This was one of the first studies carried out in the area of filariasis when the World Health Organization through its Tropical Disease Research Program (TDR) began to support field based studies on a number of priority diseases. These field studies included specific agendas for behavioral research by anthropologists, economists and human geographers. Through such studies on filariasis, we tackled the multidisciplinary nature of our questions with an interdisciplinary approach in order to reach results and conclusions of a trans-disciplinary nature (Tanner 1994).

The study team was made up of an anthropologist (the first author), who spent a year doing ethnographic studies using participant observation. This was combined with focus group discussions, in-depth interviews, and case histories to understand the complexities of the disease throughout the study period. The team also included a clinician who did all the clinical examinations and morbidity surveys, and trained field workers who used a version of the EMIC to collect information during the sample surveys. Overall, the EMIC has the capability of getting a lot of information, although the scope of inquiry must be adjusted to consider the interest of the research and the attention span of the study sample. This is especially true for people with a chronic condition like filariasis who expect something tangible after giving their time again and again and who have previously been frustrated in their efforts to find relief. Although researchers can adapt the EMIC to address particular study aims, care must also be taken not to dilute the information by cutting too much from the instrument and thereby eliminating important contextual information needed to make sense of findings and formulate policy.

Similar to what other researchers have done (Brieger 1996, Lloyd et al 1994, Francis 1997), the third objective was to use information from the extensive ethnographic studies in collaboration with members of the affected communities to develop their own IEC messages (chapter 7). This process encouraged community residents to assess and improve IEC messages. For the fourth objective, (the study on Community Directed Treatment described in chapter 8) one year was spent before the intervention to understand the social structure and organization of the communities, and the decision-making processes. As with objective one, standard ethnographic methods were used, and the information from phase one (results not presented) was used as a basis for planning and implementation of the mass drug distribution exercise.

9.2 Doing Research in the Ghanaian Ministry of Health.

These extensive research activities over such a long period of time with minor problems was possible only because the anthropologist and principal author was employed by the Ministry of Health. Involvement of the Ministry of Health (Ghana) in research in more recent times dates to 1990 when the Health Research Unit was formed. Though its interests cover both biomedical and applied research, its activities have focused on applied or operational research. Over the past ten years or so, it has developed capacity within the ministry of health at all levels. It has established three field research stations for more complex studies and has established linkages with other stakeholders in research including universities, research institutions and NGOs. Such linkages and networks are proving to be a useful basis for the overall development of research in the country. Because of the different views about research agendas, the Ministry of Health in Ghana has recognized that a research agenda is not just a list of topics but a framework of related issues that concern different stakeholders. The agenda must support the health system with data collection and analysis. It is not static but has to take into account continual changes. Agenda setting is not a one-time research activity that takes place before establishing a research program, but it is a process that has to be built into that program. Consensus meetings and a participatory approach play an important role in this. (MOH 1998)

The priority of the Ministry of health in Ghana is to conduct research to identify health problems in the community. Such research should lead to practical solutions for identified problems. To succeed, such research requires a partnership between health sector units that implement services, researchers investigating ways in which services can be improved and the community, which is the ultimate beneficiary of research findings. Priority is consigned to interdisciplinary research efforts, recognizing the complexity of health systems and the need for social research on appropriate health service strategies. Priority is also given to research that relates directly to policy or to strategic planning as well as program development. Selection of specific topics is based on the relevance and scientific merit of the topic, district based research topics, topics selected by the district teams and the level and complexity of the research.

Before the late eighties, conducting research in the Ministry of Health in Ghana was not institutionalized. The main arguments were that research should be left to the Universities and policy implementation should be left to the Ministry of Health. The problem with this was that the universities carried out research that was of no interest to the Ministry and even if it was, the findings were published in journals that politicians and policy makers do not have time to read. The creation of the Operations Research Unit, now the National Health Research Unit (HRU), with social scientists trained in operational research methods seemed to help bridge the gap between research and policy. Operations research in this case is defined as a process of identifying and solving problems. This process involves 5 basic steps. Problem identification and diagnosis, strategy selection, strategy experimentation and evaluation, information dissemination and information utilization.

Each of the three research stations mentioned earlier is in a unique ecological setting where work proceeds in close cooperation with local authorities. Each of the three centers also has their own area of interest but go through the operations research process. The Navrongo Health Research Center (NHRC) situated in the North of the country started off with studies of Vitamin A supplementation (Ghana VAST study team 1993), and then conducted studies of risk factors for childhood morbidity (Binka 1995), the bednet trials

(Binka 1997), studies of filariasis (Gyapong 1996, 1998, 1999,2000) and a family planning project, all of these had a major social science input.

Today the results of all the studies are being implemented at the National level. Vitamin A is being given on a regular basis at maternal and child health units in the country and in schools. Bednets are being promoted nationwide and the number of children under 5 sleeping under a bednet has become a health indicator. Based on results from the family planning study, the ministry has a policy to implement community-based health planning and services (CHPS). After 5 years of research on filariasis, the country now has a national control program going on.

The Kintampo Health Research Center in the middle belt of the country has been working on Vitamin A and more recently on issues related to maternal mortality. At the Dangme West Health Research Center most of the studies have been on malaria (Agyepong 1995, 1998) and have been conducted by the DHMT. This team comprises a public health physician, a public health nurse, a disease control officer, a nutrition technical officer, a health educator, the district accountant and the author of this thesis who is a social scientist. Problems to be researched into are identified at regular DHMT meetings and from annual reports. Each of the team members then develops a strategy, which is put together in a proposal form and implemented in the district. (Some of the studies are funded through the district, in addition the center also puts in applications to international agencies for funding). Filariasis is not a problem in the Dangme West District, however, all the studies for this thesis were conducted in collaboration with the DHMTs in the various other districts we worked in. The DHMT’s currently have filariasis control activities on their annual action plans and with the DHMT members as focal persons, even when the research team is not in the district, the work on filariasis goes on.

At the national level (HRU) research questions are generated in three ways. In the first instance researchers in the unit respond to a call for letters of intent advertised by international organizations on research topics, which may have a potential impact on the health of the people in the country. In the second scenario, research questions come up from a weekly meeting of directors in the ministry of health. The director of the research unit is usually present at these meetings and when there is a problem that requires research the unit is asked to develop a proposal. Thirdly, the unit receives requests from all levels of health administration in the country, including the National level, the regional level and even the district level where health activities are implemented. Fourthly, the research scientists in the unit write proposals which reflect their various backgrounds and interests and submit them for funding to the Ministry of Health or other funding agencies in or out of the country. The questions that have been addressed in the last couple of years are of a wide range. They include disease related problems, quality of care, access to health care, polypharmacy, inequalities in health, STD’s, tobacco. More recently the unit has looked at an evaluation of the exemptions policy in the country and is also trying to address issues related to applying research to policy. Once the studies are completed, the results are disseminated at all the levels of health administration (National, Regional, District, Community). Articles are also published in peer reviewed journals. At national level, research findings are disseminated to policy makers who take decisions on how to move forward with these results. Moving from research to actual implementation is an arduous task and for most academic studies the problem has been the dissemination of the results of very good work. Within the Ministry of health in Ghana, dissemination is done at various levels.

First of all at the district (the level of implementation of health services) in order to have a feedback on what had been found and what needs to be done about it. This type of dissemination is usually in very simple language and sometimes in a selected community with members of the DHMT present. At the Navrongo Research center, community durbars for dissemination of results are a regular feature. In other instances the dissemination is at the DHMT level and people from the community level are invited. Dissemination at the district level may involve other sectors of government that have a role to play in the implementation of the results (Ministry of education, agriculture, etc).

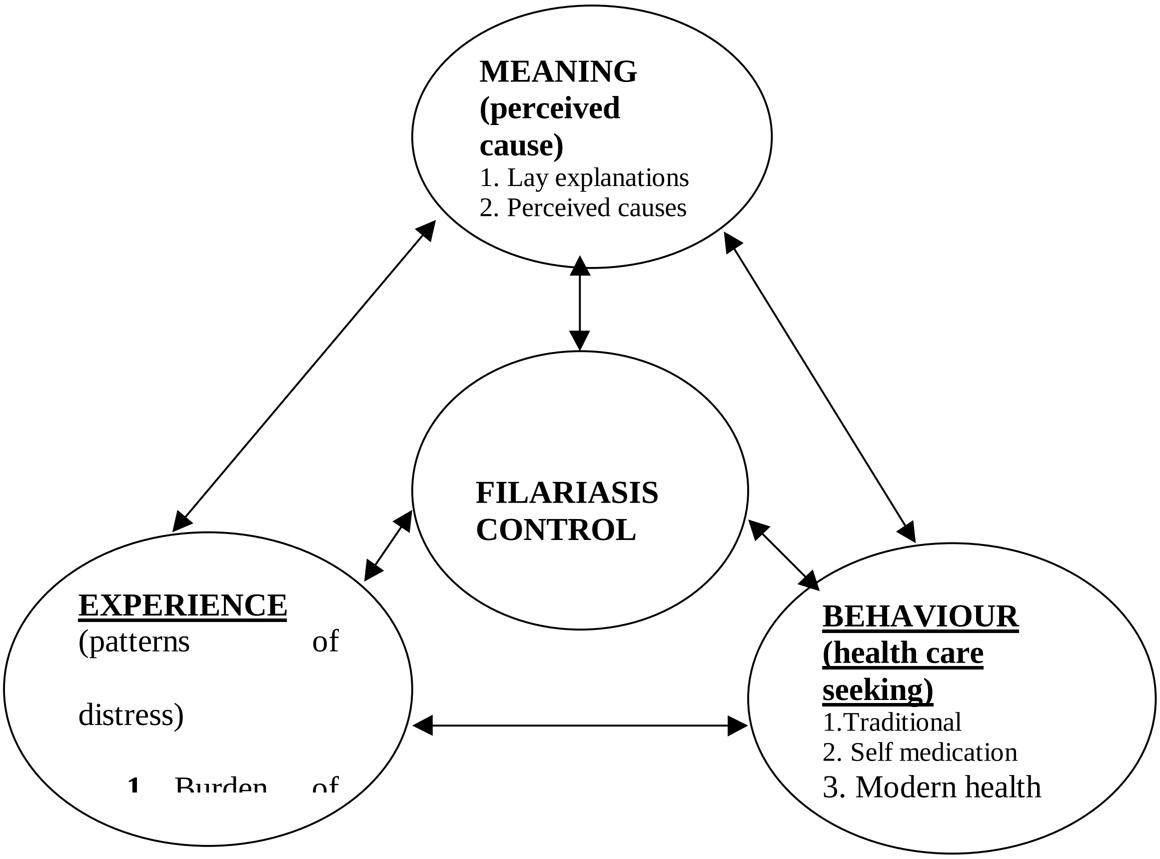
Dissemination of research information at the national level may involve a group of policy makers in one day meeting where findings are considered and policy recommendations are made. The press, directors of health, the university community, donors and political leaders are usually invited which highlights the results of the studies and also commits the political leaders and all stakeholders present into making a pledge to ensure the implementation of the program and to support further studies. Various people are then tasked to move the policy recommendations forward and depending on how much pressure is applied and who is in charge, a policy document is produced and distributed for use at the various levels of health care in the country.

This approach in the various research units of combining qualitative research with quantitative research, and combining social science with Epidemiology falls within the cultural Epidemiology framework, which is the framework guiding the development of this thesis. In the next section we will examine contributions of this framework to the control of lymphatic filariasis in Ghana.

9.3 Contribution of Cultural Epidemiology to the study of filariasis in Ghana

From chapters 4 through 8, we have used the cultural epidemiology framework to examine the impact of culture on illness experience and the cultural determinants of occurrence, course and outcome of filariasis. As shown in figure 9.1 below, we were able to elicit lay concepts of ill health, concepts of filariasis as a disability and the burden of the disease. We also discuss gender health care seeking and filariasis control. Each of these issues, which relate to the broad topics of the framework: experience (patterns of distress) meaning (perceived cause) and behavior (health-care seeking).

Figure 9.1 Contribution of anthropology to the understanding of LF



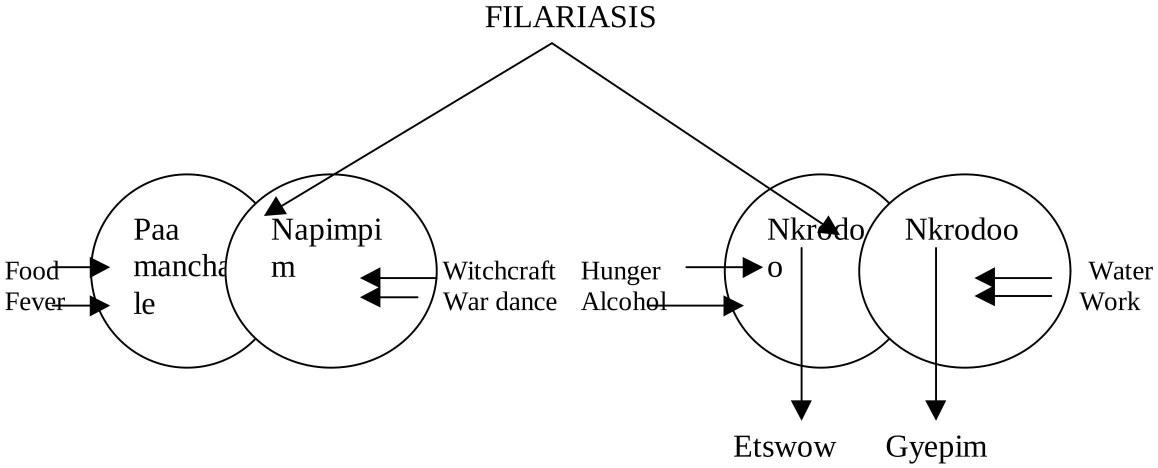
9.3.1 Meaning of filariasis

In figure 9.1 above, issues related to lay explanations for ill health and perceived causes, falls under the broad category meaning of filariasis. In other words, what does it mean to have elephantiasis or a hydrocele in the districts studied. How do people in the various districts who are from different ethnic backgrounds perceive and conceptualize the condition and how different are their experiences with the condition.

In a recent survey of the literature Nations (1986) revealed that, ethno medical studies of lay recognition, etiology and treatment of infectious diseases are even rarer than behavioral studies. This is because of the entrenched belief in the biomedical community that indigenous beliefs and practices are irrelevant to the problem at hand. Yet information of this sort is of the utmost importance in ensuring the success of public health efforts especially with regards to a disabling condition such as LF.

Our study showed that, between two different ethnic groups, concepts of causation are completely different. The Kassena and Nankani people of Northern Ghana see the various manifestations of filariasis as completely separate entities and externalize the disease by attributing hydrocele to fever and elephantiasis to witchcraft and the evil eye. The Ewutu Efutu people along the coast of Ghana on the other hand, internalize the disease and link each of the various conditions to the stomach in which every human being has an Nkrodoo. Both elephantiasis and hydrocele are manifest if the person has a weak body constitution, drinks a lot of alcohol, or works too hard (shown by the broken lines in figure 9.2 below). The explanations given for the cause of the disease went a long way to influence their help seeking behavior.

Figure 9.2 Ethnicity and lay explanations for Filariasis



In chapter two, we indicated that studies of lay perceptions have been useful for planning and implementing of programs. Other studies have also indicated problems without such data to inform studies. Overall, the signs and symptoms experienced and the social organization and context within which different individuals experience a particular condition influence the way the cause and other aspects of the condition are explained. As Hahn (1999) has rightly noted, taking into account the context of an experience is not just a matter of using knowledge of the local setting to achieve public health objectives. It is a matter of understanding, addressing and responding to local perspectives, concerns and values.

9.3.2 Experience with filariasis.

In figure 9.1 we have indicated that one of the issues dealt with in the cultural Epidemiology framework relates to patterns of distress experienced by people with the disease. In our study, the signs and symptoms and the social context within which a person lives influences the kind of burden placed on an affected person. In chapters 4, 5 and 6, we raised issues related to functional impairment and disability as a result of having any of the manifestations of filariasis. We also raise issues about the calculations of DALY's and the fact that more attention needs to be paid in terms of the psychosocial burden of the disease especially with regards to men. In this section, we look at the international classification of disability vis a vis the socio-cultural context of the disease as experienced by sufferers.

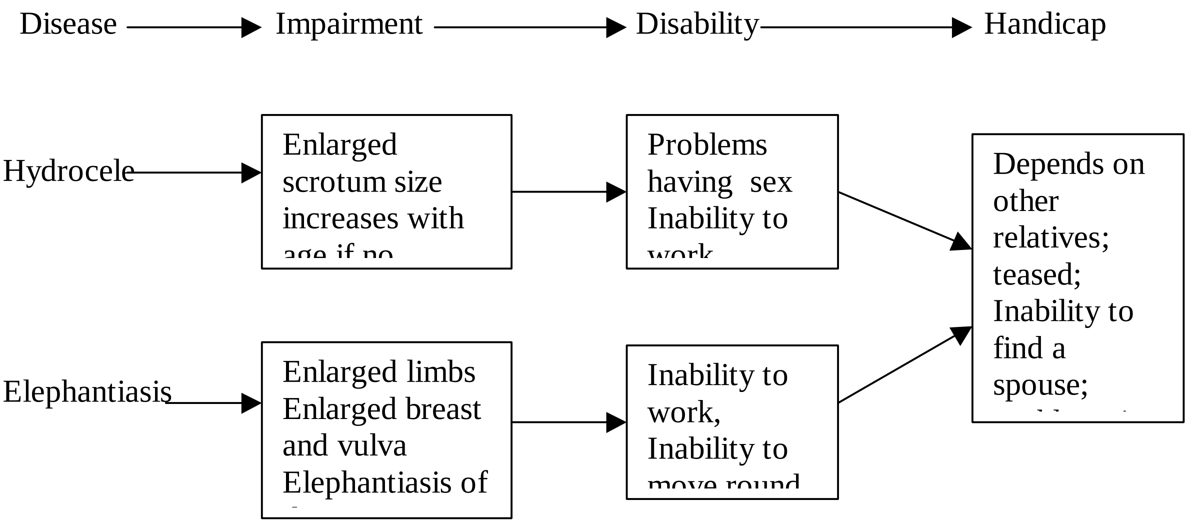
9.3.2.1 Disability: International classification versus cultural relativity

In chapter 6 we indicated that even though burden of disease is measured in Disability Adjusted Life Years (DALY's). Not only is it difficult to calculate but also, useful information to guide services comes from qualitative and narrative accounts of experiences and suffering caused by disease. The psychosocial aspect of disease burden needs more attention in the calculation of the DALY's. It helps us appreciate the nature of suffering and implications for treatment and control. In this section we will take the WHO classification of disability and see how it fits within the cultural context of lymphatic filariasis.

The international classification of impairments, disabilities and handicaps (ICIDH) developed in the 1970s was issued by the WHO as a tool for the classification of the consequences of disease (as well as of injuries and other disorders) and their implications for the lives of individuals (WHO 1980). The manual explains that a disease leads to an impairment ; representing a disturbance at the organ level, which leads to a disability; a disturbance at the personal level, which in turn leads to a handicap; the disadvantages experienced by the individual as a result of impairments and disabilities (WHO 1980).

Using the information in the preceding chapters, a diagrammatic representation of this WHO concept for filariasis in the Ghanaian context is presented in the figure below.

Figure 9.3 Diagrammatic representation of filariasis as a disability.



The manual also gives examples for each of the categories. For impairment, some examples given are language, hearing, vision and skeletal. A person can then have a disability in speaking, listening seeing, dressing, feeding and walking. The examples for handicap include orientation, physical independence, mobility and social integration (WHO 1980; 33). Going strictly according to the manual and looking critically at the information presented in the diagram for filariasis based on findings in the earlier chapters, we notice that a man with a small size hydrocele or someone with minimal lymphedema who rarely gets acute attacks would be classified as normal. The person who has a large hydrocele or elephantoid leg but is able to go about his duties without assistance may also be classified as normal by the WHO classification but clearly would not regard himself or herself as normal and this person would not be considered normal by the community.

In the same way, Halantine and Berge (1990) note that among the Kel Tamasheq there are precise terms for a variety of faults which include freckles, protruding navel and flabby buttocks. These are not on the WHO list of impairments.

A search through the literature indicates that much ground work for classification of disability was done in North America (Ablon 1981, Murphy 1988, Estroff 1981, Sacks 1985). However, the concept of disability itself must not be taken for granted. In many cultures in low-income countries, one cannot be disabled for the simple reason that disability is not a recognized concept. Among the Akans in Ghana however, one can identify words for a blind *anifrani* or a lame person *Obubuafuo*. Perhaps the closest word to disability is *Oyarefuo* a sick person. But, it would be totally unacceptable to use that word for a person with any of the manifestations of filariasis, since this has stigmatizing connotations and means the person is incapacitated and cannot move. This term can only be used if the person is going through an acute phase of the disease, characterized by fever, chills, pain and swelling of the affected limbs.

The point in the life cycle at which disablement occurs may well be crucial for the meaning and implications of disability (Ingstad and Reynolds white 1995). One may expect that having elephantiasis or a hydrocele later in life after one’s social and economic position is well established and when the debilities of age are more or less expected, has a different significance from the same problem experienced as a young adult. The unfortunate thing about this disease is that in a majority of people, it starts at an age when they are most active economically and at the time when they are forming social and economic identities. The implications of the disease for life in general and for gender identity in particular are very crucial especially in male dominated societies like the ones in which these studies on filariasis were conducted.

Ingstad and Reynolds Whyte (1995) have observed that American middle class culture, disability is treated as unspeakable and invisible, and exists within and is created by a framework of state legal economic and biomedical institutions. Concepts of personhood, identity and value while not reducible to institutions, are nevertheless shaped by them. Notions of citizenship compensation, and value lost through impairment and added through rehabilitation, are institutionally reinforced constituents of disability as a cultural construct. In countries of the south, where this kind of institutional infrastructure exists only to a limited degree, disability as a concept and identity is not an explicit cultural construct. The meaning of impairment must be understood in terms of cosmology and values and purposes of social life.

One of the recurring themes in the American and European conceptualization is that of autonomy and dependence. In fact, Murphy asserts that they are universal aspects of all social relations and that dependency is a problem that all disabled people must often confront (Murphy 1987: 156) The same is true for filariasis as reported by Amuyunzu et al (1997), Ramiah et al (1996) and Gyapong et al (1996). People with elephantiasis need to depend on their families for support especially when experiencing acute attacks. Women suffering attacks are secluded in a small room and attended to by their children if they have any at all (chapter 4) Men with hydrocele who cannot work on their farms have to depend on hired labor, which has cost implications or on the extended family

Philips (1990) using oral narratives to interpret the experience of disability in the American culture points out that in the American culture, the disabled experience is simply the experience of being a social minority. To be able to cope with this situation, many disabled people have been involved at one time or the other in disability centered activism and all tend to network with other disabled persons. This kind of networking and disability-centered activism is a thing yet to be experienced in places like Ghana, India, Tanzania and Kenya. Where most of the early studies on filariasis were conducted. The only place where networking and self help groups have been tried for filariasis is in Brazil where Dreyer and her team have formed filariasis clubs where women come together to talk about their condition and help each other wash and keep their feet clean. Recent discussions with a team working on the disease in Haiti indicate that women have been put in self help groups to enable them engage in proper morbidity control and to get involved in other income generating activities to earn more income for themselves and have a better quality of life.

Like disease, a disability is defined primarily by those qualified to judge physical and mental functioning according to generally accepted standards (WHO 1980: 27). It is on the basis of the biomedical definition of impairment that the classification is proposed as a universal tool.

However, having studied filariasis using the methods described in the beginning of this discussion, we think like Ingstad and Reynolds White (1995) that a cultural relativist position, rather than the universalizing approach would be a more useful approach to looking at the concept of disability. This is because, cultural relativism, looks at a phenomenon within the relevant cultural context. Studies on disability therefore require us to move away from the clinic towards the community, where individuals and families live with deficits.

9.3.3 Gender and help seeking for filariasis.

Gender is not represented directly under experience meaning and behavior because it is a factor that influences the three issues and is an especially important factor in shaping illness experience. The framework provides a way to study these factors of gender and its role in filariasis and other diseases. The question from a gender perspective is what are the effects and how they operate with respect to the views of gender and the disease in a cultural context.

In chapter 5, we addressed some gender issues paying particular attention to men and raising pertinent issues related to gender and tropical diseases. According to the WHO, being male or female has a major effect on an individual's health and well-being. From our cultural epidemiological perspective, gender shapes both the experience and meaning of illness. Gender also affects exposure and risk of disease. The natural cause of disease may be different in men and in women and they may respond differently to ill health while the wider society may respond differently to sick males and females as indicated by research presented in chapter 4 and 5. The two groups may respond differently to treatment and also have different access to health care and may even be treated differently by different health care providers (WHO 1998). Gender stereotyping damages men in certain ways. They are expected to be the bread winners; as a result, they work longer hours, damage their mental and physical health and the expectation of what it means to be a real man may make it difficult for men who are ill to admit weakness and seek medical help (Sabo and Gordon 1993). Women on the other hand may find it difficult to use health services for completely different reasons.

Studies have also shown that the social interpretation of particular diseases may also be important especially with disfiguring diseases where people are reluctant to expose their bodies (Hawson 1996). In chapter 6 we reported that some men with hydrocele refuse to go to government hospitals because female nurses will attend to them. They would rather see a private medical practitioner or a male medical assistant to drain the hydrocele on a regular basis. People may want to move far away to seek treatment rather than using services in the community which are more likely to expose them to scrutiny of their neighbors. With stigmatizing conditions such as filariasis, leprosy, onchocerciasis, schistosomiasis and the like, unless asked, a patient may not talk about a problem especially if it is concealable as in a genital deformity unless sufficient confidence facilitates disclosure. Other studies have documented the failure to communicate information, lack of cultural sensitivity and dehumanizing treatment which itself has affected women’s and possibly men’s willingness to use services (Fried 1990, Jacobson 1991, Garmain and Chen 1994).

Tanner and Vlassoff (1997) have noted that health services play an important role in influencing gender-related aspects of malaria. They mention as one of their concerns the fact that in issues related to quality of care health workers are not gender-sensitive enough. In a study of gender and quality of care using the health workers for change manual, healthworkers admitted that unconsciously, they treated women with a good standing in society much better that regular women. They also mentioned that since men are very busy, when they bring their children for Maternal and Child Health services, they are attended to much earlier than women. The other issue is that since health services focus almost exclusively on women’s reproductive function, opportunities are lost for the detection of multiple conditions and for detecting sensitive genital manifestations.

The training of health workers in Ghana requires that in addition to handling complaints brought to them, they are expected to pay attention to any obvious physical problems that a patient has and to deal with them to the best of their ability. Unfortunately, over the years, this has not been the practice. Patients presenting to a health facility or to an outreach service who have other physical problems are treated for the problem they presented to the health worker with, and without a comment or attention to the additional problems. It would be important in the light of tropical diseases in general and filariasis in particular to make health workers especially at the district level more sensitive to the health needs of people who visit their facilities particularly people who report with an acute manifestation of a chronic disease. In the case of filariasis, health workers in endemic districts need to be sensitized to look out for various manifestations of the disease and to discuss them with the patient. The patient client relationship and the quality of care provided at health facilities need to be addressed properly if health workers can talk to patients in such a way that they do not feel embarrassed. This is important because for people with filariasis and leprosy if someone is teased, laughed at and seen as an outcast in the community, but treated nicely by health workers, they are likely to visit health facilities more regularly and receive health education and treatment for their conditions. It is even likely that with better patient-client relationships, many of the hidden genital manifestations are more likely to receive clinical attention. Health services for men should ensure that patients as much as possible are seen by male health workers, so that it is easier for men with embarrassing conditions to speak about them and have the appropriate education and care.

9.3.4 Role of communities in the effort to control filariasis

Since the mid 1970's community-based approaches to health promotion and disease prevention have become increasingly common because they are thought to provide an effective strategy for addressing health problems in a cost effective way (Guldan 1996). In a critique of these views, Tanner and Vlassoff argue that the term community participation is vague and inasmuch as communities are composed of men and women who relate to each other in ways that affect their understanding of health, their health-related behavior and ultimately their health (Tanner and Vlassoff 1998). In their typology for treatment seeking for malaria based on endemicity and gender, they mention that the community appears to be a less important influence than personal or household factors in the selection of malaria control strategies, however for diseases where vectors are a key part of the transmission cycle, the community is an extremely important target for intervention.

In 1997, the World Health Assembly passed a resolution calling for the elimination of lymphatic Filariasis as a public health problem. Since then, a lot of effort has been invested by the WHO and other donor organizations to see to it that the aims of the Global Program for the Elimination of Lymphatic Filariasis (GPELF) become a successful reality.

These aims are to reduce and eliminate the transmission of lymphatic filariasis, reduce and prevent morbidity (suffering and disease) in affected individuals and provide strengthening benefits to the health services (WHO 1999). These aims are clearly community targeted and with the principal challenge of the program being effective delivery of drugs to all endemic communities and the positive results from the studies on community-directed treatment (ComDT) (chapter 8) it is clear that a lot of community interaction is needed. This is especially important for disseminating information about the disease. In ComDT, health workers may be responsible for sensitizing community members about the disease but that is not enough. Members of the community must be willing to take it upon themselves to make sure that everyone is convinced to take the drugs for as long as needed as was the case in one community where it was suggested that anyone who does not take the drug should be sanctioned because they could be causing the disease to spread (chapter 8) Secondly, to avoid a situation where drug distributors receive drugs but do not distribute, but sell the drugs instead, everyone must be involved in the process as a check on the distributor. With regards to morbidity control an even greater community effort is needed in the mobilization of people with all stages of the disease and for them to know the importance of regular washing of feet to prevent bacterial infections.

In addition to re-emerging tropical diseases like malaria and tuberculosis, there is the need to pay special attention to filariasis. This is so because infectious diseases once thought to be under control are re-emerging at even higher rates. Cassel (1999) has indicated that this is due to global interdependence, modern hospitalization, trade and social and cultural patterns. This has led to diseases that were previously restricted geographically now spreading to regions once thought safe. Filariasis in Ghana in the early 1990's was thought endemic only in the Northern parts of the country and in some coastal areas, but initial results from an ongoing geographical mapping of the country indicates that there are some cases in the forest belt too, and there are even some isolated cases in urban areas.

The WHO has stated that the inability for whatever cause to complete a course of treatment is a major reason why TB is poorly controlled and the WHO has strongly advocated Directly Observed Treatment Schedule where every dose of drug is taken with the supervision of a reliable person (WHO 1997). In the ComDT process, community members are selected to do this in the hope that everyone will get the drug. Health workers only play a supervisory role. The issue of elimination and the need to take the drug over a long period of time needs to be stressed to avoid a situation where individuals get tired of taking the drug. Combining the taking of drugs with local hygiene may help but then after spending years of trying to find a cure without success, mere washing with soap and water may sound too simplistic and that is where the ambassadors come in. The drugs will be provided but it is up to people to take the drug.

If individual heads of households ensure that they and their family members take the drugs, are convinced enough to wash and keep feet clean and would be advocates for the prevention of the disease it will go a long way to improve the program and to facilitate its control in Ghana and the whole elimination process.

9.4 Operational issues and recommendations for action.

In our earlier discussion on medical anthropology in the Ghanaian ministry of health, we mention that one of the key roles of the research unit in the ministry of health is to disseminate research results and implement the recommendations at the district level (level of health implementation in the country).

After completing these studies we make these recommendations.

1. The two most important problems for men with hydrocele was the cost of care and the frustration after a hydrocele recurred after surgery. We therefore recommend the need for surgical intervention for men with hydrocele which would either be free of charge or at a reduced rate and the use of the most appropriate surgical techniques to prevent the hydrocele from getting re filled. It would also be useful if these surgical interventions are done at health centers

rather than in hospitals. This cuts down on a lot of cost and would hopefully take away the fear of temporary death in a large operating theater.

2. In chapters 4,5 and 6 we reported that people with filariasis are shunned in their community, teased and laughed at. We also made note of the fact that because of the stigmatizing nature of their conditions, they find it difficult to report to health facilities. Apart from that, there have been complaints about the quality of care patients with filariasis receive at health facilities. We recommend that as part of regular in-service training, health workers be made more sensitive to the needs of people with filariasis particularly as this concerns their clinical relationship; they need to explain the nature and treatment of the condition to affected individuals. In line with this we recommend that it would be useful to having male workers see men with hydrocele. With all these factors put together, both men and women would be able to report at health facilities rather that hide their conditions because of the stigma leading to social isolation in the community.
3. In working with community members to develop their own IEC messages, a manual was prepared to help health workers in that effort. We recommend that this manual be tested, revised as needed and adopted for use in other districts in the country.
4. Traditional healers have been criticized for the medications they prescribe and some of their health care practices. In chapter 6 we found out that some of their practices would be beneficial in the efforts at morbidity control. Due to the fact that over 80% of people with elephantiasis had visited a traditional healer at least once over the course of their illness, we recommend the inclusion of traditional

healers in health worker trainings for morbidity control for filariasis. In such trainings, they can learn about the adverse effects of some of their practices and effective interventions consistent with their ability and style of practice.

5. One of the goals of the GPEL is to interrupt transmission and this can be achieved through chemotherapy. In chapter 8 we described an example of how drugs can be distributed and report that the community achieves higher coverage when they deliver drugs than when the health system does the delivery. We recommend that Control programs use the ComDT approach for drug distribution. It would be useful to see how practical it would be to use this approach on a large scale and to document how district health systems cope with the implementation.

All the above recommendations need to be considered in the wider context of the national filariasis control program. We therefore have outlined some specific issues that need consideration at the national level, the district and community level and for medical anthropologist working on tropical diseases

National level:

The aim of the Global Program for filariasis is to eliminate the disease, and this calls for a massive concerted effort on the part of national governments. In our earlier chapters, we highlighted the need for cultural and ethnographic studies that will inform national program in their drive to control and/ or eliminate tropical diseases. This has been done in chapters 4-6. In chapters 7 and 8 we described efforts to use IEC techniques and a community approach for the control of filariasis. At the end of the chapters, we have made recommendations .The onus now lies on the public health and disease control units of the Ministry of Health to come up with a policy for filariasis control in the country. Once this is done the disease will receive the necessary attention like any other disease on the national health agenda. It may be useful to organize a day to raise awareness about the disease.

It would also be worth including elephantiasis on the list of diseases for surveillance that are reported on a monthly basis at various health facilities. Urban filariasis requires attention as well as efforts to get health personnel in urban areas involved in the national effort to eliminate the disease. The Mectizan donation program and Merck and Co are donating drugs free for the elimination of the disease. Once the drugs arrive in the country, efforts must be made to ensure that they reach the districts that need the drugs.

District and community level

Once mechanisms have been put in place at the national level, the policy documents and other suggestions need to be disseminated to the district and sub-district level. The district health systems also need to sensitize people at community level so they can take the initiative to carry out programs. In May 2000, an international training of trainers workshop for filariasis control managers on management of lymphedema in Brazil included participation from Ghana. Chapters 4 and 5 clearly indicate that ADL is the most common source of concern for affected individuals. It is also the commonest cause for loss of productivity in endemic countries. We think that various group leaders or individuals in various communities should organize affected individuals to manage lymphedema properly. Community-directed treatment has been clearly recommended as a strategy for mass drug administration in Ghana. Ivermectin has been donated to the GPELF to treat endemic populations for as long at it takes. Once the drugs reach the communities, they would have to be taken and dedicated community members need to ensure that this is done. The district Health Management Teams together with other health related sectors like education and agriculture could be brought together to ensure that this idea becomes a reality.

Implications for Medical Anthropology

In going out to study this aspect of anthropology, one of the most glaring findings was the overwhelming gap between anthropological theory (the framework underlying the construction of anthropology itself) and the practical needs for knowledge to guide implementation of solutions to problems identified at the district level. The question then was how useful will these "abstract theories" be in my work in the Ministry of Health in general and in lymphatic filariasis research in particular. After studying various theories and looking at them within the context of this work in filariasis, I realize that that they informed the work in a useful way. Like Hahn (1999) notes in his book Anthropology and Public Health, anthropological theories are important in two ways. Firstly they help explain the particular circumstances in other words, problems for a community for which a program is being planned. Secondly, theories about behavior and community change may also suggest effective or ineffective project design. Using the example of filariasis, one can say that the theories and other concepts in anthropology can have substantial consequences for public health if the following points are taken into consideration.

1. The results of the studies are presented not only in project reports, at international meetings and in scientific journals but are presented at one day meetings in simple and easy to understand form to policy makers and followed up to be sure that action is taken on the recommendations made.

2. Anthropologists doing ethnographic work in particular villages should not only isolate themselves in the village but get involved in the overall district process. They should participate in activities of the District Health Management teams. In this way, they can make useful contributions to the understanding and elimination of disabling diseases such as lymphatic filariasis.

3. Since anthropologists traditionally spend long periods of time in communities, they can be linked to district health systems where information from their methods of information gathering (cognitive and behavioral in nature) can be fed back into the district plan and used in intervention programs. Recommendations made from this collaboration can be channeled through the health system and implemented in control programs.

9.5 Areas for further Research

The chapters in this thesis have clearly looked at LF from various perspectives. Attempts have also been made to incorporate the findings from the cognitive and behavioral studies into action. There remain however a number of research issues that need to be addressed.

1. Information from patients, healers and even health workers indicates that there is still the need to increase awareness about various aspects of the disease. In chapter 6, we attempted to develop IEC messages with the help of community members. These messages did not have aspects of morbidity control and lymphedema management. With our example as a background, and the fact that there are no educational materials on the disease, it would be useful to study, compare and find the best advocacy strategies for the different stakeholders at the national district and community level in the global effort to eliminate filariasis.

2. The studies also looked into LF as a disabling condition, but there is also the need to conduct research to address issues relating to stigma and the burden of filariasis, especially in urban areas where LF is increasingly becoming a problem.

3. Chapter 8 showed that ComDT is capable of reaching coverage levels of over 70% which are sufficient for the elimination of LF as a public health problem. We have recommended that the ComDT approach be implemented on a large scale but there is the need to address issues on how cost effective will this kind of intervention be.

9.6 General Conclusion

After studying various aspects of lymphatic filariasis over such a long period ranging from lay perspectives to interventions for control, we conclude that

1. Anthropological contributions to the control of tropical diseases in general and filariasis in particular are important and should not be underestimated.
2. The burden of the disease on men is much more than previously thought and therefore needs more attention in terms of the psychosocial burden and surgical intervention for hydrocele and other factors related to it.
3. There appears to be a dearth of information regarding contributions of the psychosocial burden of disease in the calculation of DALY’s and this needs to be considered.

4. Traditional healers may perform some harmful practices which contribute to the progression of lymphedema. They may also be helpful, however with traditional treatment that includes of some useful practices like bandaging and massaging, they can be a useful resource in efforts at morbidity control since they are used by over 80% of populations in Ghana and widely used in many other developing countries.A community approach to the elimination of filariasis as a public health problem is very crucial especially in the design and implementation of Information Education and Communication messages, in the mass distribution of drugs and in the potential management of lymphoedema for the reduction of morbidity in people with elephantiasis.

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SOCIAL ASPECTS OF LYMPHATIC FILARIASIS

Semi-Structured Interview For Affected Persons

Census Serial Number: #_______________ Date Of Interview: __________

Pathology Group ________________

LL12=Lower Limb Stage 1 and 2 LL3=Lower Limb Stage 3 ADL=Acute Attack

HT=Hydrocele Tennis Ball Size HL=Hydrocele Large

Time Interview Begins: ________________________

Interviewer: ___________

1. We would like to talk to you today about your (....local term....)".If more than one condition ask which of them concerns you most

2. What is it about your condition that concerns you most?

Concern	Spontaneous			Prompted		
2.1 Fever	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.2 Chills	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.3 Pain	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.4 Swelling	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.5 Functional Impairment	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.6 Appearance	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.7 Physical discomfort	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.8 No problem	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.9 Other specify						

3. For how long have you had this condition [ ] yrs [ ] mths

4. Have you done anything to seek relief for your condition? 2. Yes 0. No

5. People seek help from many different sources. We are interested in all the different kinds of help that you might have sought for your condition

Place				
5.1 Relative/friends	2. Yes	0. No	8. NA	9. NK
5.2 Health worker	2. Yes	0. No	8. NA	9. NK
5.3 Traditional Healer	2. Yes	0. No	8. NA	9. NK
5.4 Drug store/chemist	2. Yes	0. No	8. NA	9. NK
5.5 Health center	2. Yes	0. No	8. NA	9. NK
5.6 Hospital	2. Yes	0. No	8. NA	9. NK
5.7 Private practitioner	2. Yes	0. No	8. NA	9. NK
5.8 Cannot say	2. Yes	0. No	8. NA	9. NK
5.9 Other specify				

6. Which of these places did you go to first?

Place				
6.1 Relative/friends	2. Yes	0. No	8. NA	9. NK
6.2 Health worker	2. Yes	0. No	8. NA	9. NK
6.3 Traditional Healer	2. Yes	0. No	8. NA	9. NK
6.4 Drug store/chemist	2. Yes	0. No	8. NA	9. NK
6.5 Health centre	2. Yes	0. No	8. NA	9. NK
6.6 Hospital	2. Yes	0. No	8. NA	9. NK
6.7 Private practitioner	2. Yes	0. No	8. NA	9. NK
6.8 Cannot say	2. Yes	0. No	8. NA	9. NK
6.9 Other specify				

7. What were your reasons for choosing this kind of help?

Reason				
7.1 Convenience	2. Yes	0. No	8. NA	9. NK
7.2 Affordability	2. Yes	0. No	8. NA	9. NK
7.3 Family's choice	2. Yes	0. No	8. NA	9. NK
7.4 Healers reputation	2. Yes	0. No	8. NA	9. NK
7.5 Other specify				

8. What kind of treatment did you receive?

Treatment received				
8.1 Home based	2. Yes	0. No	8. NA	9. NK
8.2 Traditional	2. Yes	0. No	8. NA	9. NK
8.3 Modern	2. Yes	0. No	8. NA	9. NK
8.5 Other specify				

9. Who paid for this treatment? 1. Self 2. Family/relative 3. Other specify…….

10. Now lets talk about the last time you sought help for this kind of condition. What kind of help have you sought recently for your condition?

Place				
10.1 Relative/friends	2. Yes	0. No	8. NA	9. NK
10.2 Health worker	2. Yes	0. No	8. NA	9. NK
10.3 Traditional Healer	2. Yes	0. No	8. NA	9. NK
10.4 Drug store/chemist	2. Yes	0. No	8. NA	9. NK
10.5 Health centre	2. Yes	0. No	8. NA	9. NK
10.6 Hospital	2. Yes	0. No	8. NA	9. NK
10.7 Private practitioner	2. Yes	0. No	8. NA	9. NK
10.8 Cannot say	2. Yes	0. No	8. NA	9. NK
10.9 Other specify				

11. What were your reasons for choosing this kind of help?

Reason				
11.1 Convenience	2. Yes	0. No	8. NA	9. NK
11.2 Affordability	2. Yes	0. No	8. NA	9. NK
11.3 Family’s choice	2. Yes	0. No	8. NA	9. NK
11.4 Healers reputation	2. Yes	0. No	8. NA	9. NK
11.5 Other specify				

12. What kind of treatment did you receive?

Treatment received				
12.1 Home based	2. Yes	0. No	8. NA	9. NK
12.2 Traditional	2. Yes	0. No	8. NA	9. NK
12.3 Modern	2. Yes	0. No	8. NA	9. NK
12.5 Other specify				

13. Who paid for this treatment? 1. Self 2. Family/relative 3. Other specify…….

14. Did you also make use of any home remedies while you were seeking help from these sources? 2. Yes 0. No 3. Other specify………………………..

15. Among the different kinds of help that you received, which did you like best [ ]

16. Why did you like it best?

Reason				
16.1 Convenience	2. Yes	0. No	8. NA	9. NK
16.2 Affordability	2. Yes	0. No	8. NA	9. NK
16.3 Family’s choice	2. Yes	0. No	8. NA	9. NK
16.4 Healers reputation	2. Yes	0. No	8. NA	9. NK
16.5 Other specify				

17. If there was anything you could do, what would you do for your condition?

____

____

18. Do you think this condition can be helped? 1. Possibly 2. Yes 0. No 99. Uncertain 8 NA

19. Do you think this condition can be cured completely? 1. Possibly 2. Yes 0. No
99. Uncertain 8. NA

20. People have many different ideas about what causes a condition like this. What do you think has caused your condition?

Perceived cause	Spontaneous			Prompted		
20.1 Working in the sun	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
20.2 Walking long hours	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
20.3 Sexual activity	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
20.4 Spiritual	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
20.5 Food related	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
20.6 Poor personal hygiene	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
20.7 Fever	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
20.8 Mosquitoes	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
20.9 Other specify						

21. Do you think this condition can be passed from you to another person?
1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

22. How can this condition be passed from you to another person?

____

23. Do you know of any ways to prevent this condition?
1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

24. How can you prevent this condition?

____

25. Do you know of any other people in this community with this condition? 2. Yes 0. No

26. Do they ever help or advise you? 2. Yes 0. No

27. Does this condition keep you from going out and about? 2. Yes 1. Sometimes 0. No

28. Has this condition affected your daily work?

1. Sometimes 2. Yes 0. No 99. Uncertain 8.N/A

29. How has this condition affected your daily work?

Effect on daily life				
29.1 Stopped work	2. Yes	0. No	8. NA	9. NK
29.2 Changed jobs	2. Yes	0. No	8. NA	9. NK
29.3 Altered activity	2. Yes	0. No	8. NA	9. NK
29.4 Work fewer hours	2. Yes	0. No	8. NA	9. NK
29.5 No change	2. Yes	0. No	8. NA	9. NK
29.9 Other specify				

30. Has this condition affected your schooling or educational opportunities?

1. Possibly 2. Yes 0. No 99. Uncertain 8. N/A

31. How has this condition affected your schooling?

Place				
31.1 Stopped school	2. Yes	0. No	8. NA	9. NK
31.2 Frequent absence from school	2. Yes	0. No	8. NA	9. NK
31.3 Failure in school	2. Yes	0. No	8. NA	9. NK
31.4 Impaired performance	2. Yes	0. No	8. NA	9. NK
31.5 Admission refused	2. Yes	0. No	8. NA	9. NK
31.6 Forced to leave school	2. Yes	0. No	8. NA	9. NK
31.7 Changed schools	2. Yes	0. No	8. NA	9. NK
31.8 Cannot say	2. Yes	0. No	8. NA	9. NK
31.9 Other specify				

32. Does this condition keep you from taking proper care of yourself; eating, washing, toilet, etc.?

1. Possibly 2. Yes 0. No 99. Uncertain….8. NA

33. How will this keep you from taking proper care of yourself?

Effect on daily care?				
33.1 Eating	2. Yes	0. No	8. NA	9. NK
33.2 Washing	2. Yes	0. No	8. NA	9. NK
33.3 Toilet	2. Yes	0. No	8. NA	9. NK
33.4 Other specify				

34. Some people feel okay about this condition and others are concerned. How do you feel about your condition?

Feelings about condition				
34.1 Feel good	2. Yes	0. No	8. NA	9. NK
34.2 Feel bad	2. Yes	0. No	8. NA	9. NK
34.3 Mixed feelings	2. Yes	0. No	8. NA	9. NK
34.4 Cannot say				

35. Are there any particular feelings that describe your reaction to this condition?

Description about feelings				
35.1 Pride	2. Yes	0. No	8. NA	9. NK
35.2 Worry	2. Yes	0. No	8. NA	9. NK
35.3 Sadness	2. Yes	0. No	8. NA	9. NK
35.4 Fear	2. Yes	0. No	8. NA	9. NK
35.5 Diminished self worth	2. Yes	0. No	8. NA	9. NK
35.6 Other specify				

36. Some people feel like a burden to others because of this condition. Do you feel that way too?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

37. What kind of burden do you mean?

Type of burden				
37.1 Lowers family income	2 Yes	0. No	8. NA	9. NK
37.2 Cost of health care	2. Yes	0. No	8. NA	9. NK
37.3 Domestic chores	2. Yes	0. No	8. NA	9. NK
37.4 Other specify				

38. Do you stay away from social functions, such as weddings, festivals, and so forth?

1. Sometimes 2. Yes 0. No 99.Uncertain 8. NA

39. Why would you stay away from social functions?

Reason for staying away				
39.1 Personally uncomfortable	2. Yes	0. No	8. NA	9. NK
39.2 Others Uncomfortable	2. Yes	0. No	8. NA	9. NK
39.3 Family decision	2. Yes	0. No	8. NA	9. NK
39.4 Unrelated to filariasis	2. Yes	0. No	8. NA	9. NK
39.4 Other specify				

40. Do you try to conceal his/her condition by the way he/she dresses or in some other way?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

41. Do people make fun of you because of this condition?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

42. Will they make fun of you in your or behind your back?

42.1 In your presence: 1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

42.2 Behind your back: 1. Possibly 2.Yes 0. No 99. Uncertain 8. NA

43. Is there anything in particular that you do for yourself that helps you forget about your problem?

____

If "married", go to 44. If "unmarried", skip to 48

44. Do you think this condition has affected your marriage?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

45. How has it affected your marriage?

Effect on marriage				
45.1 Quarrels	2. Yes	0. No	8. NA	9. NK
45.2 Infidelity	2. Yes	0. No	8. NA	9. NK
45.3 Spouse desertion	2. Yes	0. No	8. NA	9. NK
45.4 Divorce	2. Yes	0. No	8. NA	9. NK
45.4 Other specify				

46. Has this condition affected sexual relations with your spouse, or any other aspects of your sexual life?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

47. How has it affected your relations with your spouse?

____

48. Do you think this condition would make it hard for you to find a spouse?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

49. Do you think that this condition could make it difficult for others in your family to find a spouse?

    1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

Social Aspects Of Lymphatic Filariasis

Semi-Structured Interview For Unaffected Persons

Census Serial Number: #________________ Date Of Interview: ___________

Vignette Type: _________________

LL12=Lower Limb Stage 1 and 2 LL3=Lower Limb Stage 3 Large ADL=Acute
HT=Hydrocele Tennis Ball Size HL=Hydrocele

Time Interview Begins: _________________________

Interviewer: ___________

1. We would like to talk to you today about a condition that affects some people. "He calls it (....local term....)".

3. What do you think concerns him/her most about this condition?

Concern	Spontaneous			Prompted		
2.1 Fever	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.2 Chills	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.3 Pain	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.4 Swelling	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.5 Functional Impairment	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.6 Appearance	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.7 Physical discomfort	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.8 No problem	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
2.9 Other specify						

3. Where would he/she go for treatment?

Place				
3.1 Relative/friends	2. Yes	0. No	8. NA	9. NK
3.2 Health worker	2. Yes	0. No	8. NA	9. NK
3.3 Traditional Healer	2. Yes	0. No	8. NA	9. NK
3.4 Drug store/chemist	2. Yes	0. No	8. NA	9. NK
3.5 Health center	2. Yes	0. No	8. NA	9. NK
3.6 Hospital	2. Yes	0. No	8. NA	9. NK
3.7 Private practitioner	2. Yes	0. No	8. NA	9. NK
3.8 Cannot say	2. Yes	0. No	8. NA	9. NK
3.9 Other specify				

4. Which of these places do you think is most effective?

Place				
4.1 Relative/friends	2. Yes	0. No	8. NA	9. NK
4.2 Health worker	2. Yes	0. No	8. NA	9. NK
4.3 Traditional Healer	2. Yes	0. No	8. NA	9. NK
4.4 Drug store/chemist	2. Yes	0. No	8. NA	9. NK
4.5 Health center	2. Yes	0. No	8. NA	9. NK
4.6 Hospital	2. Yes	0. No	8. NA	9. NK
4.7 Private practitioner	2. Yes	0. No	8. NA	9. NK
4.8 Cannot say	2. Yes	0. No	8. NA	9. NK
4.9 Other specify				

5. Do you think this condition can be helped?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

6. Do you think this condition can be cured completely?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

7. People have many different ideas about what causes a condition like this. What do you think has caused his/her condition?

Perceived cause	Spontaneous			Prompted		
7.1 Working in the sun	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
7.2 Walking long hours	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
7.3 Sexual activity	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
7.4 Spiritual	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
7.5 Food related	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
7.6 Poor personal hygiene	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
7.7 Fever	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
7.8 Mosquitoes	2. Yes	0. No	8. NA	2. Yes	0. No	8. NA
7.9 Other specify						

8. Do you think this condition can be passed from him/her to another person?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

9. How can this condition be passed from one person to another

____

10. Do you know of any ways to prevent this condition?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

11. How can you prevent this condition?

____

12. Do you think this condition will affect his/her daily work?

1. Sometimes 2. Yes 0. No 99. Uncertain 8.N/A

13. How can this affect his/her daily work?

Effect on daily life				
13.1 Stopped work	2. Yes	0. No	8. NA	9. NK
13.2 Changed jobs	2. Yes	0. No	8. NA	9. NK
13.3 Altered activity	2. Yes	0. No	8. NA	9. NK
13.4 Work fewer hours	2. Yes	0. No	8. NA	9. NK
13.5 No change	2. Yes	0. No	8. NA	9. NK
13.9 Other specify				

14. Do you think this condition will affect his/her schooling or educational opportunities?

1. Possibly 2. Yes 0. No 99. Uncertain 8. N/A

15. How will this affect his/her schooling?

Place				
15.1 Stopped school	2. Yes	0. No	8. NA	9. NK
15.2 Frequent absence from school	2. Yes	0. No	8. NA	9. NK
15.3 Failure in school	2. Yes	0. No	8. NA	9. NK
15.4 Impaired performance	2. Yes	0. No	8. NA	9. NK
15.5 Admission refused	2. Yes	0. No	8. NA	9. NK
15.6 Forced to leave school	2. Yes	0. No	8. NA	9. NK
15.7 Changed schools	2. Yes	0. No	8. NA	9. NK
15.8 Cannot say	2. Yes	0. No	8. NA	9. NK
15.9 Other specify				

16. Do you think this condition will keep him/her from taking proper care of himself/herself, eating, washing, toilet, etc.?

1. Possibly 2. Yes 0. No 99. Uncertain….8. NA

17. How will this keep him/her from taking proper care of him/her self?

Effect on daily care?				
17.1 Eating	2. Yes	0. No	8. NA	9. NK
17.2 Washing	2. Yes	0. No	8. NA	9. NK
17.3 Toilet	2. Yes	0. No	8. NA	9. NK
17.9 Other specify				

18. Do you think this condition will ever keep <u>him/her</u> from going out and about?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

19. Do you think he/she thinks less of himself/herself because of his/her condition?

1. Possibly 2. Yes 0. No 99. Uncertain…..8. NA

20. Do you think he/she feels like a burden to others because of this condition.

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

21. What kind of burden do you mean?

Type of burden				
21.1 Lowers family income	2 Yes	0. No	8. NA	9. NK
21.2 Cost of health care	2. Yes	0. No	8. NA	9. NK
21.3 Domestic chores	2. Yes	0. No	8. NA	9. NK
21.4 Other specify				

22. Do you think he/she would stay away from social functions, such as weddings, festivals, and so forth?

1. Sometimes 2. Yes 0. No 99.Uncertain 8. NA

23. Why would he/she stay away from social functions?

Reason for staying away				
23.1 Personally uncomfortable	2. Yes	0. No	8. NA	9. NK
23.2 Others Uncomfortable	2. Yes	0. No	8. NA	9. NK
23.3 Family decision	2. Yes	0. No	8. NA	9. NK
23.4 Unrelated to filariasis	2. Yes	0. No	8. NA	9. NK
23.4 Other specify				

24. Do you think he/she will try to conceal his/her condition by the way he/she dresses or in some other way?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

25. Do you think people make fun of him/her because of this condition?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

26. Will they make fun of him/her that in his/her presence or behind his/her back?

26.1 In his/her presence: 1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

26.2 Behind his/her back: 1. Possibly 2.Yes 0. No 99. Uncertain 8. NA

27. What do you think he/she does to overcome this condition?

____

If vignette "married", go to 28. If vignette "unmarried", skip to 33

28. Do you think this condition will affect his/her marriage?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

29. How will it affect hi/her marriage?

Effect on marriage				
29.1 Quarrels	2. Yes	0. No	8. NA	9. NK
29.2 Infidelity	2. Yes	0. No	8. NA	9. NK
29.3 Spouse desertion	2. Yes	0. No	8. NA	9. NK
29.4 Divorce	2. Yes	0. No	8. NA	9. NK
29.4 Other specify				

30. Do you think his/her condition will make it difficult for others in his/her family to get married?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

31. OPTIONAL: Do you think this condition will affect sexual relations with his/her spouse, or any other aspects of sexual life?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

32. How will it affect his relations with his spouse?

____

33. If this person were not married, do you think this condition would make it hard for him/her to find a spouse?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

34. Do you think that this condition could make it difficult for others in his/her family to find a spouse?

1. Possibly 2. Yes 0. No 99. Uncertain 8. NA

SEMI STRUCTURED INTERVIEW FOR PATIENTS WITH FILARIASIS IN THE WINNEBA DISTRICT

Greetings. We are continuing with our work on Akonumnsuand Etwow.This time
we are interested in finding out from you all the places that you have been
to for health care (both traditional and modern) since you had the condition.
We are in and all places you have been to inside and outside the district.
As we have always done, we would like to record the interview.

1. BASIC DATA

1.1 Name ________________________ Community____________________________

1.2 Age [ ] [ ] 1.3 Sex 1. Male 2. Female

1.4 Marital status 1. Single 2. Married 3. Divorced 4. Widowed

1.5 Number of children [ ]

1.6 Educational status 1. No education 2. Primary 3. JSS 4. SSS 5. Tertiary

6. Other specify…………………………………………………………………………

Pathology group

1. Hydrocele 2. Elephantiasis(1) 3. Elephantiasis(2)

CONDITION

2.1 How did you get your condition?
1. Mosquitoes 2. Water we step in 3. Water we drink 4. Nkrodoo 5. Hereditary

6. A curse……………………..7. Other specify_________________________

2.2 What causes this type of condition?
1. Mosquitoes 2. Water we step in 3. Water we drink 4. Nkrodoo 5. Hereditary

6. A curse ………………………….. 7. Other specify_________________________

2.1 For how long have you had this condition? [ ] [ ]

2.2 Have you done anything to seek relief? 1. Yes 2. No

2.3 I would like to know from you all the places that you have been to since you had this condition
(places in and out of the district)

PLACE	IN DISTRICT	OUT OF DISTRICT
Hospital/Health centre		
DHMT Offices		
Traditional Healer		
Herbal Clinic		
Acupuncture		
Self Medication		

2.4 From what you have told me it means you have been to [ ] [ ] places since you had the condition is that right?

2.5 I would like to know what was done for you at each of the of the places you have mentioned. We shall take them one after the other.

PLACE	ACTION TAKEN
Hospital/Health centre	
DHMT Offices	
Traditional Healer	
Herbal Clinic	
Acupuncture	
Self Medication	

2.6 I would like to know the reasons why you changed the various places that you went to. Lets start from the first place

PLACE	REASON FOR CHANGE
Hospital/Health centre	
DHMT Offices	
Traditional Healer	
Herbal Clinic	
Acupuncture	
Self Medication	

2.7 Do you think your condition is curable? 1. Yes 2. No

2.8 If yes or no, what are your reasons for saying so?
1. Someone had it and got cured 2. The healer said I could get cured

3. The disease is not curable 4. The disease is too far advanced

5. Other specify …………………………………………………………………..

2.9 How do you feel about your condition?
1. Sad 2. Sorry for myself 3. Embarrassed 4. Burden on the family

5. Worried 6. Other specify …………………………………………………..

2.10 What is the reaction of your family members towards you because of this condition?

2.10.1 **Spouse** 1.Divorced me 2. Separated 3. Quarrels all the time 4. Loving and caring

5. Avoids me 6. Otherspecify…………………………………………………

2.10.2 **Children** 1. Quarrels all the time 2. Loving and caring 3. Avoid me

4. Other specify…………………………………………

2.10.3 **Other relatives** 1. Quarrels all time 2. Loving and caring 3. Avoid me

4. Other specify ………………………………………………….

2.10.4 Other community members

1. Quarrels all the time 2. Loving and caring 3. Avoid me

4. Other specify………………………………………………

2.11 What do you think you can do in this community to help prevent this Community
…………………………………………………………………………………………
…………………………………………………………………………………

THANK YOU VERY MUCH FOR YOUR COOPERATION

3. DATE [ ] [ ] [ ]

SEMI STRUCTURED INTERVIEW FOR HEALTH CARE PROVIDERS IN THE WINNEBA DISTRICT

Greetings. My name is .... I am doing some work on behalf of the ministry of health. For some time now we have been working with people who have various diseases in the district and have sought their opinion on various aspects. We think it is important that since you provide care in this community, we talk to you and find out your opinions too. I will show you some pictures of the disease we are interested in today and will tell you something about them. I will then ask you some questions in order to understand how you would deal with such a problem. I would also request your permission to record the information.

1. BASIC DATA

1.1 Name ________________________ Community____________________

1.2 Age [ ] [ ] 1.3 Sex 1. Male 2. Female

1.4 Marital status

1. Married 2. Single 3. Divorced 4. Widowed

1.5 Number of children [ ] [ ]

1.6 Educational status 1. No education 2. Primary 3. JSS 4. SSS 5. Tertiary

2. GENERAL INFORMATION

2.1 There are several health care providers in this district. In terms of health care how would you call yourself.

1. Herbalist 2. Spiritualist 3. TBA 4. 1&2 5. 1&3 6. 2&3

7. Other specify…………………………………………………………………….

2.2 How did you become this type of healer?
1. Taught by dwarfs 2. Taught by parents 3. Taught by another healer 4. Through a

dream 5. Other specify………………………………………………

2.3 What do people in this category of health care providers normally do?

1. Heal all manner of diseases 2. Take care pregnant women 3. Protect people

4. Other specify…………………………………………………………

2.4 What are the main problems that people usually see you for

1. Swellings 2. Pregnancy related 3. Childhood related illnesses 4. Fever

5. Other specify……………………………………………………………

2.5 As part of your practise, do you go out and advertise yourself?
1. Yes 2. No

SHOW PICTURE
Picture Number [ ]

3. THE CONDITION
3.1 What would you call this condition

1. Etwow 2. Gyempim 3. Other specify……………………………….

What are the things about this picture and the story I told you which convinces you that this condition is (name given by healer)
1. One leg is bigger that the other 2. The big leg is very shiny 3. The scrotum is very big

4. Other specify…………………………………………………………….

3.3 Do people with this kind of condition come to you for help? 1. Yes 2. No

3.2 What do you do for them?
Hydrocele 1. Give herbs to drink 2. Give enema 3.smear herbs
4. Other specify…………………………………………………..

Elephantiasis 1. Smear herbs 2. Scarification 3. Herbs and bandaging
4. Other specify…………………………………………………..

3.5 If someone came to you with this condition, what do (would) you do for him/her?

Hydrocele 1. Give herbs to drink 2. Give enema 3.smear herbs
4. Other specify…………………………………………………..

Elephantiasis 1. Smear herbs 2. Scarification 3. Herbs and bandaging
4. Other specify……………………………………………….

3.6 Did (would) this condition cure the person completely? 1. Yes 2. No

4. Do you think there is an effective treatment for this condition? 1. Yes 2. No

5. What is it?…………………………………………………………………………..

6. If someone came to you with this condition but you did not have this effective treatment, what would you do?

1. Send them to another healer 2. Send them to the hospital
3. Other specify………………………………………………

7. If you treated a person with this condition and he/she came back after some time with the same problem what would you do

1. Send them to another healer 2. Send them to the hospital
3. Other specify…………………………………………………

8. In addition to or instead of treating this person, would you refer him/her to another health care provider or somewhere else? 1. Yes 2. No

9. What type of health care provider would you refer him to?
1. A herbalist 2. A spiritualist 3. The hospital
4. Other specify…………………………………………………………………..

10. If such a person did not seek care at all for his/her condition, what could happen to him/her?

1. He could die 2. The condition would be worse
3. Other specify…………………………………………………………..

11. In your opinion, what do you think has caused this condition

1. Nkrodoo 2. Food related 3. Work related
4. Other specify…………………………………………………………..

13. In your opinion is this a serious condition? 1. Yes 2. No

14. What are your reasons for saying this?………………………………………..

15. In your opinion, how do you think this person will feel about himself because of his condition?……………………………………………………

16. In your opinion what will the attitude of others in the community be towards a person with such a condition?……………………………………….

15. In your opinion how best do you think we can deal with a problem such as this in this district?…………………………………………………………………

16. What role do you see yourself playing in the drive to get rid of this disease……………………………………………………………………..

17. Do you think this condition makes him/her dangerous to other people? 1. Yes
2. No

18. Please explain……………………………………………………………………………….

THANK YOU VERY MUCH FOR YOUR COOPERATION

Appendix III a

KEY INFORMANT INTERVIEW GUIDE FOR SOCIO ECONOMIC STUDIES

The information from this interview was used to generate further questions for the focus group discussions.

1. What is the term used to describe a person who has a large scrotum and who gets fevers, chills, and pain from time to time.
2. What is the term given to the condition where a person has normal legs/arms but once in a while, the limbs swell, become hot and shiny, are painful to touch and the person has fever
3. What is the term used to describe a condition where one of a persons limbs has become bigger than the other and once a while the person gets fever, chills and the affected limb becomes hot painful and untouchable.
4. Where would such people go to for treatment.
5. What would be done for them
6. Would the treatment be effective
7. What is the communities attitude towards people with such conditions?

FOCUS GROUP DISCUSSION GUIDE FOR SOCIO ECONOMIC STUDIES

After collecting background information from all participants in the group discussions ask the following questions.

1. What are the duties performed by men in this community
2. What are the duties performed by women
3. What social activities do people engage in in this community
4. What economic activities do people engage in in this community
5. What are the commonest diseases that affect adults in this community Probe for the most important among the ones mentioned and find out reasons why.
6. What are the commonest diseases that affect children in this community. Probe for the most important amongst the ones mentioned and find out reasons why
7. Where do people seek health care from in this community. For each source of care, probe for
   How one gets there, cost of care, quality of care and effectiveness of care.
8. How does a person get Hydrocele
9. Which people are most likely to get it. Probe for reasons
10. Where does such a person go for health care
11. What is done for such a person
12. Is the treatment effective
13. Are there any taboos associated with such a condition
14. How does it affect your life. Probe for marriage, school, work, leadership position etc.
15. What is the attitude of the community towards a person with such a condition.

Go through questions 8-14 for elephantiasis

(Several of the questions in this guide were used in case studies.)

Appendix III a

Questionnaire For Pre And Post Training Examination For Health Workers.

Number..Community...................................

Occupation.................................Date.......................................

Cause

1. What causes Lymphatic filariasis?
2. What is the incubation period?

TRANSMISSION

3. Human Lymphatic filariasis is transmitted by

SIGNS AND SYMPTOMS

4. List 3 signs and symptoms of lymphatic filariasis

   1.____

   2.____

   3.____

COMPLICATIONS

5. Mention two complications of lymphatic filariasis

   1.____

   2.____

PREVENTION

6. Mention three ways of preventing lymphatic filariasis

   1.____

   2.____

   3.____

7. Mention two specific ways of treating lymphatic filariasis

   1.____

   2.____

8. What can you say about community participation
9. What can you say about communication skills
10. What can you say about working with groups in the community that you work in?
11. What do you know about IEC Techniques

Appendix 3: DAILY FEEDBACK FORM (DAY 1 WRAP UP)

DATE________________

Please circle the most appropriate responses based on today's session and explain your responses.

1. Do you think today's sessions were helpful?

   i. Not helpful ii. Somewhat helpful iii. Very helpful

Please explain:

____

____

2. Do you think today's sessions were clear and understandable?

   i. Not at all ii. Somewhat iii. Very

Please explain:

____

____

3. How well do you think the sessions were taught?

   i. Not well ii. Average iii. Very well

Please explain:

____

____

4. Was enough time allocated for todays session?

   i. Not enough ii. Enough iii. More than enough

Please explain:

____

____

5. One thing I learnt was

____

____

6. One thing I am still unsure of is

____

7. What suggestions do you have to improve the workshop?

Evaluation for IEC

Have you heard about any program for ………(use local name)

For how long has this program been going on

What has been going on during the course of the program

Probe for IEC techniques

What technique did each community come up with

For each community which of the messages did you like best

Probe for

Content

Clarity

Which techniques would you have used

Which techniques did you like the least

a. Ask for reasons

Any comments on the procedures used

How can the message be spread further

Community Directed Treatment For Filariasis Control
Interview With Household Head. Comdt01

PLEASE CIRCLE ALL ANSWERS AND WRITE IN CAPITAL LETTERS

SITE CODE:	DISTRICT CODE:
COMMUNITY CODE:	TYPE OF COMMUNITY: 1 2
HOUSEHOLD NUMBER:	DATE:
INTERVIEWER:	

ASK FOR THE HEAD OF HOUSEHOLD OR REPRESENTATIVE

NAME OF HEAD OF HOUSEHOLD/ REPRESENTATIVE :	
1. How old are you? [ ] [ ] years	
2. Sex: 1. Male 2. Female	
3. What is your marital status? 1. Married 2. Single 3. Divorced 4. Widowed 5. Other, specify ………….. …	
4. How many children do you have? [ ] [ ] 8. N/A	
5. What is your level of education? 1. No education 2. Functional literacy 3. Primary 4. Middle/JSS/SSS	
6. Are you aware of any distribution of drugs in the community during the Last three months? 1. Yes 2. No	
7. If yes, by who? 1. Health worker 2. Community leader 3. Teacher 4. Other, specify………………………… 8. N/A	

8. What was the drug for? 1. filariasis 2. Onchocerciasis 3. Other specify………………………………………………………..	

Interviewer: Ask To Talk With All Those Who Are Present In The Household At The Time Of Interview (Mother/Main Carer To Answer For Child Under 10 Years)

Name	Sex	Present Yes/No	Age in years	Received Yes/No	Swallowed Yes/No	No of tablets received	Side Effects (Enter Codes)*

*Did anybody have any problem within two days after taking the drug?

0	No problem
1	Giddiness
2	Fever
3	Headache
4	Vomiting
5	Myalgia

9. Would you be interested to take the drug again? 1. Yes 2. No 3. Don't Know 8. N/A	
10. If no, why? 1. Don't like the medicine 2. Don't take modern medicine 3. Is not necessary for me 4. Fear of reactions / complications 5. Don't like distributor 6. Other, specify 8. N/A	
11. If the drug were given again, would you want it to be distributed the same way as this last time? 1. Yes 2. No 3. Don't Know 8. N/A	

12. What suggestions do you have for future mass distribution of drugs in the community? …………………………………………………………………………………… ……………………… …………………………………………………………………………………… ……………………… …………………………………………………………………………………… ……………………………………………………………………………………	

COMMUNITY DIRECTED TREATMENT FOR FILARIASIS CONTROL

FOCUS GROUP DISCUSSION GUIDE

SITE CODE: DISTRICT CODE: COMMUNITY CODE:
TYPE OF COMMUNITY: HF=1, NHF=2,
STUDY ARM: HST=1 COMDT=2
DATE: INTERVIEWER:

AWARENESS OF DRUG DISTRIBUTION

Has there been any mass drug distribution in this community recently?
How long ago was this done?
What was the purpose of the drug?
How did you get to know about the distribution exercise?
Was the information provided adequate enough?
Who did the distribution?
How was/were this person/people selected?

PROCESS OF DRUG DISTRIBUTION

How was the distribution done? Probe for
Pre distribution exercises
Time of day and feasibility
Strategy used and feasibility
Was there a change of strategy?
In your opinion did everyone in the community receive the drugs?

OPINION ABOUT DRUG DISTRIBUTION

Were you satisfied with the present way of drug distribution?
What was your opinion of the drug distributor ?
What suggestions do you have for improving future distribution exercises in terms of Sensitisation, strategy, timing, distributors.

Curriculum vitae

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Education

Dates	Schools	
1984-1987	University of Ghana	BSc. Home Science
1994-1995	Brunel University of West London	MSc. Medical Anthropology
1995-2000	Swiss Tropical Institute	Phd Epidemiology

Working Experience

Dates	Employer	Position
1988-1990	Ghana Med. School	Snr. Research Assistant
1990-1992	Ghana Vitamin A. Supplementation Trials	Ast. Head of Fieldwork
1992-1994	Navrongo Health Research Centre	Research officer
1995- Present	National Health Research Unit	Research officer

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