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MATERNAL MORBIDITY FROM GUINEA WORM IN NIGERIA AND ITS IMPACT ON CHILD SURVIVAL



WATER AND SANITATION
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Prepared for the Office of Health,
Bureau for Science and Technology,
U.S. Agency for International Development
under WASH Activity No. 424

by

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EXECUTIVE SUMMARY

Studies have been done on the prevalence of and disability from guinea worm in the general population, but little information exists about how the disease specifically affects women. Such data would have serious implications for child survival and development. In January 1988 a team of researchers sponsored by the Water and Sanitation for Health (WASH) Project designed and carried out a pilot study to determine the impact of the disease on maternal and child health.

The study was based on two areas in Nigeria where guinea worm is endemic: Idere Town in Oyo State and several small villages in Asa and Moro Local Government Areas in Kwara State. Mothers of children aged 24 months and younger were the primary target. Focus group interviews helped determine the parameters for study and provided ideas for an in-depth interview guide. Forty-two women who were suffering from guinea worm took part in the in-depth interviews. Their experiences with guinea worm were developed into case studies. Careful analysis of the 42 case studies produced the study results--that is, trends and patterns in four major variables: self-care functions, child-care duties, domestic activities, and economic pursuits.

Thirty-eight percent of the mothers were bedridden during their bout with guinea worm, while 28 percent could move only with the use of a stick. Self-care suffered greatly during this period. Most experienced loss of appetite and had difficulty bathing and moving outside to defecate. Most of the women (71 percent) could not perform normal domestic chores at some point in their illness, while 24 percent were limited to cooking and other home-based duties.

In terms of child care, all mothers tried to continue breastfeeding but one had to stop due to a guinea worm ulcer on her breast. Of 15 who defaulted on their babies' immunization, eight were directly the result of guinea worm. Of 15 ulcer episodes among the children, six received no treatment because of their mothers' guinea worm infection. The rest were given mostly home treatment or drugs bought in local shops.

Women in the study communities played a major role in generating income for the family, especially for the children. Most women could not continue with their regular work (farming, trading, crafts) during guinea worm. Those who could work estimated income loss averaging US \$70 during their illness. This compares to an annual per capita income of US \$125 for the area.

Disabled mothers received help from family and friends but, where guinea worm prevalence was high, less help was available. Even in lower prevalence areas, economic activities took well family members out of the house leaving the sufferer and her child alone.

The study reached six major conclusions:

1. Guinea worm has a definite and observable negative impact on women.
2. The case study approach to the research was appropriate for highlighting the dynamic process of guinea worm suffering and disability.
3. There was an observable impact from maternal disability on some children, but greater long-term effects are likely.
4. The financial impact on mothers, the children, and families is large and affects nutrition.
5. Social support systems are severely taxed when guinea worm prevalence is high.
6. Even in areas where there is less guinea worm, traditional helping networks have been weakened due to economic pressures.

Policy implications of the study include the need to link guinea worm control and water supply projects closely with child survival programs. Women's participation will be essential in such programs. Guinea worm control is an investment that will yield dividends in maternal health and family economic well-being.

RESUME ANALYTIQUE

Des études ont été effectuées sur la prévalence du ver de Guinée (draconculose) et l'invalidité qui en résulte pour la population en général, mais on dispose de très peu d'informations sur la manière dont la maladie frappe les femmes en particulier. De telles données renfermeraient d'importantes implications pour la survie de l'enfant et le développement. En janvier 1988, une équipe de chercheurs parrainée par le Projet Water and Sanitation for Health (WASH) a conçu et réalisé une étude pilote visant à déterminer l'incidence de la maladie sur la santé maternelle et infantile.

L'étude a été réalisée dans deux régions du Nigéria où le ver de Guinée est endémique: la ville d'Idere dans l'Etat d'Oyo et plusieurs petits villages dans les collectivités locales d'Asa et Moro de l'Etat de Kwara. Les mères ayant des enfants âgés de 24 mois ou moins constituaient le groupe cible primaire. Des réunions d'expression ont permis de déterminer les paramètres de l'étude et de dégager des idées pour un guide d'interview approfondie. Quarante-deux femmes qui souffraient de la draconculose ont participé aux interviews approfondies. Leurs expériences ont ensuite été élaborées en études de cas. Une analyse attentive des 42 études de cas a permis de dégager les résultats de l'étude, à savoir, les tendances et profils au niveau de quatre variables principales: les soins auto-administrés, les soins infantiles, les travaux ménagers et les activités économiques.

Trente-huit pourcent des mères étaient alitées pendant leur épisode de draconculose et vingt-huit pourcent ne pouvaient se déplacer qu'à l'aide d'une canne. Les soins auto-administrés ont été difficiles pendant cette période. La plupart des femmes souffraient d'un manque d'appétit et avaient des difficultés à se laver et à sortir à l'extérieur pour déféquer. La majorité d'entre elles (71%) ont dû à un moment ou à un autre de la maladie abandonner leurs activités ménagères normales et 24% étaient limitées à faire la cuisine et à s'occuper des autres travaux à la maison.

Pour ce qui est des soins infantiles, toutes les mères ont essayé de continuer à allaiter au sein mais l'une d'entre elles a dû s'arrêter suite à un ulcère au sein causé par le ver de Guinée. Sur les 15 qui ont omis de faire vacciner leurs bébés, 8 cas étaient le résultat direct du ver de Guinée. Sur 15 épisodes d'ulcères parmi les enfants, 6 n'ont reçu aucun traitement car leurs mères souffraient de l'infection par le Ver de Guinée. Le restant a surtout reçu un traitement à domicile ou des médicaments achetés dans les magasins locaux.

Dans les collectivités étudiées, les femmes jouent un rôle important au niveau de la génération de revenus pour leurs familles, surtout pour les enfants. La plupart d'entre elles ont dû interrompre leur travail régulier (agricole, commercial ou artisanal) pendant la maladie. Celles qui pouvaient travailler ont estimé que les pertes de revenus subies pendant leur maladie s'élevaient en moyenne à 70 dollars EU. Ce chiffre prend toute sa signification quand on le compare au revenu annuel par habitant qui est de 125 dollars EU dans la région.

Les mères handicapées ont bénéficié de l'assistance de la famille et des amis, mais dans les régions où la prévalence du ver de Guinée était élevée les secours n'étaient pas aussi disponibles. Même dans les régions qui connaissaient une prévalence plus faible, les activités économiques appelaient à l'extérieur les membres de la famille bien portants, laissant ainsi les affligés et les enfants seuls.

L'étude est arrivée à six grandes conclusions:

1. Le ver de Guinée a une incidence négative, précise et observable, sur les femmes.
2. L'approche étude de cas adoptée par la recherche convenait très bien pour mettre en lumière le processus dynamique des souffrances et de l'incapacité dues au ver de Guinée.
3. Il y avait des répercussions observables de l'incapacité maternelle chez certains enfants mais des conséquences plus graves sont probables dans le long terme.
4. Les répercussions financières pour les mères, les enfants et les familles sont importantes et affectent la nutrition.
5. Les systèmes d'entre-aide sociale sont mis à rude épreuve quand il y a forte prévalence du ver de Guinée.
6. Même dans les régions où le ver de Guinée est moins répandu, les réseaux d'entre-aide traditionnels sont affaiblis par les pressions économiques.

La portée politique de l'étude concerne notamment le besoin de relier étroitement les projets de lutte contre le ver de Guinée et d'approvisionnement en eau avec les programmes de survie de l'enfant. La participation des femmes est d'importance capitale pour de tels programmes. La lutte contre le ver de Guinée est un investissement qui rapportera des dividendes pour la santé maternelle et le bien-être économique de la famille.

Chapter 1

BACKGROUND INFORMATION

1.1 Purpose of the Research

The goal of this research project is to link the impact of guinea worm to child survival. Guinea worm is a disabling disease, and during the time of disability a pregnant woman or nursing mother may not be able to care adequately for herself and her child. As a consequence, both may suffer. Documentation of actual guinea worm cases is needed to verify the nature and extent of the threat guinea worm may pose to mothers and children.

This study is the first to focus specifically on nursing mothers with guinea worm disease and their children. It is hoped that it will help develop an understanding of the opportunities and problems which may face efforts to control or prevent this disease and provide some conceptual and methodological guidelines for the collection of further information.

The research was carried out by Dr. Susan Watts and William Brieger and conceptualized, supervised, and directed by Dr. May Yacoob from the Water and Sanitation for Health Project (WASH). Dr. Watts had conducted research in population migration and guinea worm transmission in Kwara for five years prior to undertaking this research for WASH. During her stay there, she worked on guinea worm transmission with Prof. Luke Edungbola from the Faculty of Health Sciences at the University of Ilorin. The data from that state is therefore the result of a long collaborative effort.

William Brieger has been working with the University of Ibadan for 12 years in the Africa Regional Health Education Center. He has been involved in training medical students in health education and disease prevention in Oyo State over a period of at least ten years.

The backgrounds of the researchers and their investigative mode affected the way data were collected. The Kwara data is primarily the result of three weeks' investigation using focus group discussions to analyze the current situation. In contrast, the investigation in Oyo State was based on an approach developed with the community and medical students over a much longer time period. As such, the background information tends to be more detailed than for the Kwara area.

Since focus group discussion* was the primary method for eliciting information, trained facilitators in this methodology were part of each of the field teams. In both cases, data already collected under different projects were used as the starting point.

* "Focus group" comes from the marketing field and is a technique used by marketing specialists to elicit information about a product. This methodology resembles in-depth interviews used by anthropologists. Briefly, it is an informal discussion about, in this case, the topic of guinea worm, where the group participation of four to six people tends to encourage spontaneity and honesty about the topic.

In addition, through the use of focus group discussion, greater reliance was placed on the mothers' own perceptions of their feelings (physiological and psychological) rather than objective clinical analysis.

1.2 Basic Facts about Guinea Worm Disease

Dracunculiasis is a parasitic infection caused by human ingestion of a larval nematode contained within the body of a copepod vector, the water flea commonly known as "cyclops." Copepods are typically found in shallow pools, ponds and stepwells used for drinking and washing in rural areas of developing countries. Within the body the larvae are released, molt twice, and mate when mature, approximately 3 months after initial ingestion. The male worm(s) die at about 6 months of age, while at about 8 months of age the female worm(s) migrate to the subcutaneous tissue, 85 percent of the time in the lower extremities. Approximately one year after initial infection, the female worm is ready to emerge and emit larvae, and the disease symptoms first become apparent to the infected individual.

Dracunculiasis is recognized and well known by local names in endemic areas. Symptoms begin with a characteristic painful blister caused by a secretion from the emerging worm. Secondary symptoms caused by host reaction to the worm antigens include urticaria, nausea, vomiting, diarrhea, asthma, giddiness, and fainting. Later symptoms may be produced by secondary bacterial infection after the blister bursts. Finally, if the worm is injured or lacerated while lying in the subcutaneous tissue, additional local and systemic reactions may occur. The affected area often becomes extremely painful, inflamed and edematous. Cellulitis may result from secondary growth of staphylococci and streptococci, and gangrene is not uncommon. Arthritis, synovitis, epididymitis, contraction of the tendons, and ankylosis of joints are among the crippling conditions that may ensue. In a small percentage of cases death can result due to systemic bacteremia or tetanus.

The disease cycle is perpetuated through release of hundreds of thousands of larvae by the female worm when the ulcer with the protruding worm is immersed into water by the infected individual when fetching water or to relieve the pain and burning sensation. The released larvae are then ingested by copepods where they go through additional development stages. In approximately 14 days the third-stage larvae contained in the cyclops are able to reinfect humans and produce another generation of worms which will emerge one year later.

1.3 The Study Areas

The study was conducted in two guinea-worm-endemic areas of Nigeria--(1) Idere Town in Ibarapa Local Government Area of Oyo State and (2) Asa and Moro Local Government Areas in Kwara State. Ibarapa is in the southwest corner of Oyo State in western Nigeria. Idere Town and its rural hamlets are located about 110 kilometers west of the state capital, Ibadan, and about 160 kilometers north of the national capital, Lagos. This is a characteristically urban area.

The second area is entirely rural; it covers rural settlements in Asa and Moro Local Government Areas of Kwara State which are currently highly endemic for guinea worm, or which had once been endemic but now have protected water supplies which are utilized by all or some of the population. Before the study was conducted, there was already a considerable amount of information about the general status of guinea worm in this area.

Both study areas are Yoruba in culture; as such there are similarities. Nonetheless, the religious affiliation of Idere Town is about 50 percent Christian while Kwara is predominantly Moslem.

1.4 The Idere Area

1.4.1 General Description

Like many communities in the predominately Yoruba area of Southwestern Nigeria, Idere consists of a main settlement and many satellite farming hamlets. In this case, approximately 8,000 people live in the town while the remainder are dispersed among more than 20 surrounding hamlets.

The closest hamlet is five kilometers from town, the farthest more than thirty. Farm residents maintain links with their extended family compounds in town and visit home many weekends and most holidays. But because of relatively expensive and infrequent transportation, the farm dwellers are effectively isolated from the town and its amenities. Daily health care depends on home remedies and itinerant medicine peddlers of both modern and traditional medicine.

The government maternity center and dispensary in Idere lack basic supplies and often run out of medicines; therefore, many adults who have the time and money for transportation visit the Igbo-Ora Health Center, leaving the Idere dispensary to provide mostly palliative treatment for schoolchildren. The Igbo-Ora Health Center, an Oyo State Ministry of Health facility, is also the base of the University of Ibadan's Ibarapa Community Health Program. Since 1963, health science students and faculty from the main campus (110 kilometers to the east) have delivered services, conducted research, and provided training in the district for 150,000 people.

Because of the paucity of health services available in Idere, medicine selling has become a lucrative business. There are five major shops which are accessible at almost any hour, unlike the dispensary which is open about eight hours a day six days a week. The town also boasts 33 traditional healers, from basic herbalists to persons trained in the complex skills of divining. In addition, both syncretic Christian churches and traditional Moslem sects offer healing and health guidance.

Idere residents have a wide variety of choices in health care, but this array of services can scarcely be called a comprehensive health system. There are many gaps. Consequently, easily preventable diseases persist and simple illnesses develop to a crisis stage before effective treatment can be obtained. It was a preventable disease, dracunculiasis or guinea worm disease, that helped draw attention to Idere's poor state of health care.

1.4.2 Guinea Worm Prevalence

Guinea worm prevalence data do not exist specifically for Idere prior to installation of a piped water system in 1967-68. District-wide prevalence was recorded at 12.3 percent in 1971, and in 1978 a medical student survey in Idere Town found that 18 percent of the population was affected in the 1977-78 dry season. This high rate was perplexing to the students because Idere had supposedly enjoyed piped water since 1967. Closer investigation revealed that the piped water system had been faltering since about 1975. The system, which served four towns, was overextended even when it was commissioned. Subsequently problems led to the temporary shutdown of the system: pipes burst during road construction, and spare parts were difficult to find for worn out equipment. Often Idere residents were unable to obtain water from the twelve public taps.

Farm residents who had never had access to tap water reintroduced guinea worm to the ponds surrounding the main town during their weekend visits. When the town's water system broke down, these ponds were the only options available to most residents.

Concerned about the state of affairs in a community so near, staff members of the Igbo-Ora Health Center, assisted by the student interns from the African Regional Health Education Center at the University, met with Idere's leaders to discuss options for controlling guinea worm and filling the gap in health care.

District intervention began in some of the farm hamlets in 1978 with the training of volunteer primary health workers. These workers mobilized village resources to dig wells or prevent infected persons from wading in ponds. Prevalence dropped in these villages but remained high in the main town. Annual campaigns were conducted in the main town. In 1983, over 50 people from the town itself attended primary health worker training. In fact, in the same year, an intensive school health education program against guinea worm began.

The primary health workers formed their own association and embarked on the construction of two model cement ring dug wells for the town. These were constructed in March 1986. By that time, the number of private wells had increased from 7 prior to 1980 to over 80 in 1985. The primary health workers sold monofilament nylon cloth filters in 1985 and 1986 to people in areas where wells were economically or geologically impracticable. Guinea worm declined from its 1980-81 high of 43 percent down to 10 percent in 1986-87 in the main town and was no longer common in some of the farm hamlets where the primary health care program was active.

The pilot efforts in Idere attracted attention both within the university and beyond. In 1981, the United Nations Development Program (UNDP)/World Bank/World Health Organization (WHO) Special Program for Training and Research in Tropical Diseases (or TDR) funded a three-year project in Idere to examine the potential for control of four endemic diseases in the context of primary health care. The grant was coordinated from the African Regional Health Education Center which drew upon the talents of people from many disciplines within and outside the University of Ibadan.

The remaining pockets of guinea worm in the Idere area cannot be ignored, as they constitute a continuing reservoir that threatens the whole community. Studies like the current one on maternal morbidity during guinea worm should give impetus for continued control efforts.

1.5 The Asa/Moro Area

1.5.1 General Description

The second study area is the Asa and Moro Local Government Areas of Kwara State. Moro lies immediately to the north and Asa immediately south of the city of Ilorin, the state capital, which has a population of about 250,000. The people in rural Asa and Moro are predominantly Moslem Yoruba, as are most of the indigenes of the old walled city of Ilorin. A few rural people are Christian, but belief in the Yoruba gods is widespread.

Rural settlements are small, with a median size of between 250 and 300 people. Villages consist of clusters of houses, mostly of mud with corrugated iron roofs. Larger villages have a primary school, a mosque, maybe a church, a four-day market and, more rarely, a clinic or dispensary.

The basic social unit is the extended family, the idile, under the authority of a male household head. Members of the idile share responsibilities for others in the group who, for one reason or another, cannot provide for themselves. An idile is a voluntary association. Brothers or parents and sons who do not get on together will not form an idile but will go off and establish an independent household in the same or another village. The idile is thus the best unit for the study of maternal and child well-being, as the well-being of one member of the idile is the concern of all.

When a woman marries she moves to her husband's house, but a very young girl may stay with her natal family until after her first child is born. For the first year, the mother-in-law may cook for a young wife. Women seldom move far on marriage, many staying in the same village, so they are able to interact frequently with their own, as well as their husband's, relatives.

Except in the few villages which are close to a maternity center or among the few residents with a formal education, women give birth in the village, with the help of local women. Except in villages close to clinics, children rarely complete the full series of immunizations, and mothers rarely attend clinics regularly for ante- and post-natal care. In Asa and Moro Local Government Areas, EPI (Extended Program of Immunization) coverage is currently estimated at 10 percent and 2 percent respectively, compared to 98 percent in Ilorin Town. ORT (oral rehydration therapy) programs have been initiated in only six clinics in Asa and eight in Moro. Traditional remedies, mostly herbs collected in the bush, are widely used, as are proprietary medicines, ointments, and aspirin-based pills.

1.5.2 Guinea Worm Prevalence

Guinea worm disease is endemic in 10 of the 12 Local Government Areas in Kwara State and is highly endemic in Asa and Moro. In the 1984-85 dry season, a survey of 20 villages in Asa revealed that 50 percent of the population had active guinea worm. People of all ages are affected. Although the disease is less common among children under ten years of age, it has been recorded in those as young as 18 months.

The high prevalence of guinea worm disease in affected villages is an indication that all or most of the population share the same contaminated water source, usually a stagnant pond. Infection is seasonal and occurs during the dry season when villagers depend for their drinking water on stagnant ponds or drying-up streams. During the wet season they draw water from streams and shallow wells. Villagers rarely, if ever, effectively treat their drinking water.

The dry season, which is when the disease is most patent and is most easily transmitted, is the busiest time of the year, especially for women. During this time they work with their husbands harvesting the crops and preparing them for marketing. In addition, water collection at this time of year is especially arduous, as the water sources may be far from the villages.

In Kwara State the United Nations Children's Fund (UNICEF)-assisted Rural Water Project began drilling boreholes in Asa in mid-1984 and in Moro in early 1985. An assessment of the impact of the boreholes in Asa has shown that the prevalence rates in affected villages can be reduced from over 50 percent to zero or near zero within three years of the installation of a borehole, provided that the borehole continues to function and is accessible to all the people in the community.

Chapter 2

METHODOLOGY

Existing information on the impact of guinea worm to date has been mostly speculative. Little documentation exists on what actually happens to families and individuals when they are infected. The present study is exploratory; it employs the case-study approach to identify some parameters that need to be examined further in detail. Four study methods were employed--a review of existing data, an opinion survey, focus groups, and in-depth interview/case studies. The latter method was the heart of this study, with the other methods being supportive.

2.1 Review of Existing Data

Since guinea worm in the Idere community has been under study for over 15 years by various researchers from the University of Ibadan, data exists on disease prevalence. This is presented in Section 1.4.2.

This study concentrates on women; therefore a portion of the old questionnaires from the 1980-81 TDR Baseline Survey had to be hand-analyzed. Questionnaires from 12 satellite farm hamlets were analyzed. Thus, it was possible to gather data on days lost due to guinea worm by mothers or grandmothers.

The TDR Project provided a wealth of knowledge of local perceptions and practices. Guinea worm has been a part of life in Idere for as long as the elders can remember, so that a full system of beliefs surrounds the disease.

Idere people say that guinea worm is part of one's body, something like a tendon. Most say everyone has it, and a few believe it is inherited, but all agree it is part of the body. Even educated members of the community cannot fully dismiss this possibility. Many people can now recite back health talks that they have heard about how guinea worm is caused by bad water, but in-depth interviews reveal that they still hold fast to the traditional beliefs about the disease.

According to these beliefs, a few key factors cause the guinea worm to emerge. The most common reason is that a person's blood is weak. Second, if the guinea worm inside one person's body smells an open guinea worm ulcer on another person, it will want to come out. Finally, when guinea worm reaches epidemic levels, as has happened in recent years, people blame Soponna for its emergence. Soponna is a Yoruba divinity who represents the wrath of the Supreme Being. Soponna causes hot, rash-like diseases including measles and boils. He was most famous for smallpox. The initial symptoms of guinea worm--swelling, rash, fever--and the fact that guinea worm emerges in the dry season when Soponna is most active cause people to blame this divinity.

People do not say they are sick with guinea worm. They say Sobia (the worm) has "knocked them down." Traditional songs and proverbs exist to discourage Sobia from its harsh attacks, but people really do not believe guinea worm can be prevented.

People rightly believe there is no western medicine for the disease, but neither do they claim a traditional cure. Treatment is palliative and comes in two phases. When the worm is about to emerge and while it is still present in the ulcer, people rub oil on the site to soothe the pain. Palm oil and shea butter are most commonly used. They are often mixed with strong-smelling herbs in hopes that the smell will bring the worm out faster.

After the worm has finally emerged, boiled Oluganbe leaf is used to dress the ulcer. People are very precise about this. If an ulcer is dressed before the worm emerges, they believe that Sobia will fight them and make an alternative ulcer. Any dressings placed on the active ulcers at clinic are quickly removed when patients reach home.

Idere people tend to cooperate with efforts to provide new sources of water, but they are skeptical about methods that are geared only toward preventing guinea worm such as filtering. However, the fact that one-third of the families bought filters when these were sold and nearly half have sunk wells or contributed to community well projects shows that some change in perception is slowly happening.

2.2 Opinion Survey

In order to learn whether the experiences of women interviewed were common, a survey was designed and implemented with the assistance of medical students from the University of Ibadan. It consisted of a series of open-ended questions followed by specific prompts. For example, the broad question, "How did guinea worm affect your ability to care for your child?" was followed by a prompt like, "Were you able to breastfeed?" if such information did not come out in the first instance.

Idere has five major wards. From east to west these are Malete, Onigbio (the largest), Oke Oba, Koso, and Apa. While the overall prevalence of guinea worm in town is 10 percent, Koso has the highest at 20 percent and Malete the lowest at 3 percent. In order to find women to interview, medical students were assigned to do a population survey of all Koso women of reproductive age who were at home at the time of the interview. The students interviewed 200 women of child-bearing age in Koso. Most women (80.5 percent) had experienced at least one episode of guinea worm in their lives.

Those affected mentioned the following common symptoms: swelling of the affected part (98.1 percent), pain (94.4 percent), ulcer (60.2 percent), immobility (47.2 percent), itching (45.3 percent) and fever (20.5 percent). They said the disease results in weakness (50.9 percent), loss of appetite (28.6 percent), illness (24.8 percent), and insomnia (5.6 percent).

All agreed that guinea worm inhibited them from working and taking care of their children. Most (96.3 percent) said it prevented sexual intercourse, and a few (13 percent) said a woman with guinea worm cannot breastfeed.

Over one-quarter of all interviewed had experienced guinea worm during pregnancy. They lost appetite, could not attend ante-natal clinics, and felt their health worsened generally. Some (76.9 percent) felt the pain from guinea worm even worse during pregnancy.

A small portion (13.5 percent) of all women said guinea worm hit them during the post-natal period. All of these agreed that they lost appetite, could not care for themselves or their new baby, had to depend on others for everything, and could not take the child to clinic for immunization or for treatment if sick.

A similar survey was conducted in the Asa/Moro study area. All mothers surveyed were familiar with guinea worm, recognizing early symptoms--fever, swelling, and the sensation of the worm "walking around" before it emerged.

Most of the women made some effort to treat their guinea worm or to obtain help from a relative in doing so. In villages in Moro, some of the women called in a man who pierced the swelling with a red-hot iron rod about 15 centimeters long. This was done at the time when the blister, a whitish spot, appeared on the swelling, and the operation was said to relieve the "pressure."

After the wound was opened, either by piercing or when the worm emerged of its own accord, it was covered and softened with local oil, either shea butter or palm kernel oil, both of which were available in an unrefined state from the bush. Some mothers used Robb, a widely sold Nigerian patent medicine originally intended for catarrh (main ingredients--camphor, 11 percent, and menthol, 5.5 percent, in an ointment base). They often added pounded or boiled leaves to this mixture. A few women reported that Phensic relieved the fever associated with guinea worm infection. The women asked the researchers to give them tablets to relieve the pain and inflammation of guinea worm, but they knew that no drugs would prevent the guinea worm from emerging. This is the main reason, apart from their remoteness from clinics, that women who might have been physically able did not visit clinics for treatment.

2.3 Formative Focus Groups

2.3.1 Focus Groups in Idere Proper

Since the issue of maternal impact was a relatively new perspective on the guinea worm problem, it was necessary to identify some of the important variables for study. Discussions with Idere women themselves were thought to be a good way to find out if guinea worm had actually affected people's lives. Data collected in the discussions would help frame survey questions and be a guide for in-depth interviews.

Focus group interviews were planned using two experienced research assistants--a female as interviewer and a male as recorder. One interview was arranged with the help of the midwife at the local government maternity center in the east of Idere Town. Women attending an immunization clinic were targeted. A second group was arranged in the town with the help of the chairman of the Primary Health Worker Association in the west end of Idere. In both cases, women of varying ages were to be recruited.

General prompting questions were asked--personal experience with the disease, effects on housework, child care, occupation and health generally. All participants were encouraged to share their own concerns.

All women agreed that guinea worm can occur in pregnancy and soon thereafter. They believed that the worm usually does not emerge until after delivery even though the signs of the potential ulcer site (a small bulge) are evident during pregnancy. Although symptoms of the disease are the same for pregnant women as for the general population, the mothers felt that pregnancy is a more dangerous time to have guinea worm. They said that the Yoruba people believe that the blood becomes diluted during pregnancy, and the guinea worm takes advantage of this temporary weakness to exacerbate the symptoms. The mother will begin to lose weight. This is attributed to decreased appetite, increased worrying, and the fact that the disabled women cannot cook for herself but must eat whatever is provided by others, not the food she really wants.

While guinea worm is considered troublesome for a pregnant woman, it is thought to be even worse for the mother of a newborn. The mother is miserable and cannot move around and attend to her baby's needs. Breastfeeding is stopped because the mother feels feverish and full of pain. Generally, the Yoruba believe that a sick mother should not breastfeed, as sickness can be passed on through breastmilk. The mother also wishes to keep her baby away from the smells of pus from the guinea worm ulcer and of the oil-based medications put on the sore, as these, too, are believed to make the child sick. Hence, the baby is cared for by other women in the house and fed on maize porridge and infant formula.

Another post-delivery problem is said to arise from the traditional practice of bathing the mother daily in hot water for the first month after childbirth to help her body return to normal and make the "bad blood" come out. The mothers said that the guinea worm does not like hot water and retaliates with multiple ulcer sites and delayed expulsion. No direct effects of guinea worm on the fetus or newborn were reported.

Four women interviewed had suffered from guinea worm during pregnancy. Three said the blister did not break open until after delivery. These women all had ulcers on the lower limbs and complained of the problems noted above, including those associated with hot baths. The fourth woman explained that her guinea worm emerged right in her vagina. She was referred to the district hospital for care, and the delivery was quite painful. The women supported her, saying that guinea worm can emerge anywhere, even on the tongue or breast.

These views and experiences suggest areas for further research in maternal and child health. The potential impact of guinea worm disease on the nutritional status of mothers and children requires study, particularly with reference to changes in feeding behavior brought about by guinea worm and the effect of guinea-worm-induced disability on other child care activities.

2.3.2 Focus Groups in the Idere Area Where Guinea Worm Has Been Eliminated

Focus group discussions were held in two small villages: Ajelanwa and Onileka. Ajelanwa was among the pilot primary health care villages in Idere, training its first primary health worker in 1978. The hamlet is about ten miles from Idere, on the road to Onileka, northeast of town. Two unsuccessful well projects have been attempted there, but soil conditions caused both to collapse. Still, people have been active in preventing guinea worm. Prevalence of the disease dropped when the wells did function and, since filters were introduced in 1985, few local cases have been reported. Among the sixty residents, only two had guinea worm this season. One was an older man who has lived in the village for many years, while the other was a young woman who had moved from Idere to the village about seven months ago. This woman was interviewed separately.

Eight women were interviewed. None had experienced guinea worm in the past three years. All looked healthy and active and were engaged in such tasks as melon shelling, hair plaiting, and clothes washing when the research team arrived in the mid-afternoon. Farming was the occupation of all eight.

The consensus of the group was that now that guinea worm is no longer rampant, they are all in good health. They said that the only women who have guinea worm now are those who have brought it in from outside, as the woman mentioned above. The women said they are now able to take better care of their children and spend more time with them. Their harvests are better now that they are working at full strength.

The women grow melons, cassavas, maize, tomatoes, peppers, and beans. They say their gain from these crops has more than doubled since guinea worm has gone. They now have money to pay for their children's school fees and other needs.

The women indicated that they are still taking precautions to prevent guinea worm. The village pond is fenced. The gate has a lock. During the dry season, the pond is dug somewhat like a well so that people lower a bucket into it instead of wading in. Village women also volunteer to collect water for anyone who may have guinea worm.

The women clearly perceive an improvement in their lives, and they and their children look healthy. Whether health translates directly into wealth is another issue, as family social obligations (funerals, weddings, and other ceremonies) may consume the newly-found time and energy.

Onileka was the first village to join the Idere primary health care program in 1978. It is located about 12 miles from town and has a population of about 70 people. A primary school is located nearby. The village has enjoyed well water since 1979 and has also used filters (monofilament nylon) since 1985. No cases of guinea worm have been reported among residents in the past several years.

Four women were interviewed. All had previously had guinea worm, but none in the past six years. All women were traders, with one each selling salt, palm oil, cold pap, and farm products at the nearby five-day market and from their homes on non-market days. They also help on their husbands' farms.

The women described what it is like for a woman to have guinea worm. She cannot do any work and therefore cannot make money to send her children to school. She may be in bed for days. A person attacked by guinea worm must rely on those not affected to help her.

Since they have been relieved of the annual guinea worm attacks, the women say they have been enjoying their work. They are now in good health and able to fetch water and go to work and farm regularly. They feel their annual profits have now doubled. Generally, they have seen the village improve. Ten out of 14 huts now have iron sheet roofs, 8 of which have been added in recent years, a fact that the women attribute to greater family income arising from no guinea worm disability. Also children are now able to go to school since neither they nor their parents are attacked by guinea worm.

The lethargy and fatalism seen in many a guinea worm village were not present in Onileka. The women clearly believe that the well water has eliminated the disease and improved the quality of their lives.

2.3.3 Focus Groups in the Asa/Moro Area Where Guinea Worm Has Been Eliminated

Focus group discussions were held in three villages in Asa, Ajaqusi, Kankan, and Ita Raufu, where guinea worm had once been common but is now rare. Earlier prevalence studies revealed the following rates during the season of peak potency:

	1983/4			1986/7		
	number examined	number infected	percent	number examined	number infected	percent
Ajaqusi	184	121	65.8	148	7	4.8
Ita Raufu	256	138	53.9	168	4	2.4
Kankan	218	135	62.0	241	0	0

The focus of the discussions was on mothers' recognition, care, and prevention of guinea worm; on the problems they had encountered with guinea worm previously; and their current perceptions of their own and their children's health status. Using the information thus obtained, the researchers were able to identify a wide range of coping strategies, to learn about how guinea worm affects mothers and children, and to gain considerable insight into beliefs about guinea worm and its treatment.

The women generally recognized that the various tasks did not take as long now as they had before; they estimated that the time needed to perform various domestic tasks was now half of what it had been when guinea worm was common in the village. In Kankan, where guinea worm prevalence had been reduced from 62 percent to zero since the drilling of the borehole, women said that a healthy mother can take care of her children and the family and does not expect a difficult pregnancy. That was not the case when the mother had guinea worm.

Some mothers in Kankan acknowledged that guinea worm made a pregnancy and delivery more difficult than it might be, but they believed that guinea worm could not harm the fetus or the newborn child "unless God says it will." However, other mothers considered that if you had guinea worm while pregnant the baby would probably be thin and listless.

In three villages in Asa which formerly had prevalence levels of 50 percent or more but where boreholes had reduced prevalence to almost nil, women were clearly aware of the improvement in their own and their children's health and well-being since the scourge of guinea worm had been defeated.

Probing women's beliefs about guinea worm revealed another set of beliefs about the cause--a set of beliefs which survive from the time before they were told about the role of water in disease transmission. This set of beliefs also operated on another level of generalization, for it sought to explain why all people who drink pond water did not get guinea worm. Ultimately, the women believed that whether or not a person gets guinea worm depends on the blood. Good, or bitter, blood, eje kokoro, repels the guinea worm, whereas sweet (i.e., bad) blood, attracts it. Whatever the case, all people have guinea worm in the blood, but only a combination of good blood and fate (or God's blessing) will protect a person from guinea worm. This helps to explain why some people who drink pond water have never had guinea worm, while others get it every year. However, if God wills it, even a combination of sweet blood and borehole water can make the guinea worm emerge from some people. Thus, some people in villages with access to a borehole remained unconvinced that borehole water provided complete protection against guinea worm; even if a person drinks borehole water and has bitter blood, if God wills it, he or she can still get guinea worm. But most did appreciate the message; use the borehole water, trust in God, and you will be all right. In such a context, strategies such as boiling or filtering were ineffective. What was important was the provision of a well or borehole.

Thus, villagers attempted to reassess a deep-seated belief about guinea worm in the light of current experience, and this indicates their willingness to modify both their beliefs and their behavior in the light of new information. The belief that everyone has guinea worm in the blood was expressed in a number of different ways. Two women who had a guinea worm about to emerge from their breasts were afraid that breastfeeding would give their child guinea worm, and pregnant women were also worried about giving their newborn baby the infection. Women who did not have guinea worm were advised not to spend too much time with guinea worm sufferers, for fear of catching the disease; the guinea worm might emerge if it "smelled" another guinea worm. However, such beliefs did not prevent women with guinea worm from breastfeeding, even when it was very painful, nor did they result in the ostracism of guinea worm sufferers.

2.4 In-Depth Interviews

The main findings of this research were obtained in the in-depth interviews of 42 women suffering from guinea worm disease. The findings are elaborated in Chapter 3 for the Idere study area and in Chapter 4 for the Asa/Moro study area. Appendices A and B consist of detailed sample cases from the two study areas.

Chapter 3

THE IDERE CASE STUDIES

3.1 Study Population

The focus of this study is on women of child-bearing age. In particular, it includes pregnant women and mothers of children under two who suffered from guinea worm in the 1987-88 dry season.

Out of the approximately 8,000 people in Idere Town proper, around 600 are mothers with children under two. Another 200 might have been pregnant at the time of the study. Given current guinea worm prevalence of 10 percent, one would expect to find up to 60 mothers and 20 pregnant women to study.

Due to several factors, however, not all these women were accessible for study. Some were at their farms or in Lagos for trading. Pregnant women tend not to identify themselves publicly as being pregnant until the last trimester, so it was difficult to identify them for study.

Twenty-one women, aged 18 to 40, were interviewed. The average age was 30.1 years and the median, 32 years. Twelve women were Muslims and 9 were Christians. All but two were gainfully employed. Of these, only two were skilled (typist, gold-smith), while the rest traded (14) or farmed (3).

Four women were pregnant at the first interview, but all delivered by the end of January 1988. The children were all under two, with an 8.4 month average and a 9 month median.

Twenty women lived in Idere Town, while one was a resident of a farm hamlet located about 10 kilometers from town.

3.2 Guinea Worm Disease Experience

Eighteen women had experienced guinea worm previously, but only eight had had it in the last dry season (1986-87). The women had on average 3.3 guinea worm ulcers each. Fourteen women had new attacks begin shortly before their first ulcers had begun to heal up.

The average duration of illness up to the end of January 1988 was 11.3 weeks with a range of 3 to 18 weeks and a median of 9 weeks. By the end of January, 11 women were still in the process of recovery or had recently been hit by new attacks of guinea worm. Assuming that each of these 11 would be afflicted for an average of three additional weeks, the overall average time women might be affected in the 1987-88 season would be 14.66 weeks.

The lower limbs below the knee were the areas most affected; 76.8 percent of the 69 ulcers appeared there. Most of these (40, or 58 percent, of the total) were on the feet.

3.3 Effect of the Disease on Maternal Functions

3.3.1 Domestic Duties

For the purpose of analysis, domestic duties are divided into two broad groups. Some are always or usually done inside the home: cooking, sweeping, and washing. Others require going outside the home some distance: fetching water and going to market.

Only two women were able to perform all domestic chores throughout their illness. Six could do home-based chores only. Most women (13) could do none of their normal duties while they had guinea worm. Even though some of these women could walk for short distances, they found regular household duties tedious and painful. Women whose knees were affected suffered especially.

3.3.2 Economic Functions

Of the 19 women who worked, only 3 said their business was not stopped or closed at all during their guinea worm attack. The longest a woman was unable to work was seven months. On average, working women could not function at their jobs for 8.8 weeks. Two women kept their trade going for a few weeks after guinea worm struck by having their children hawk the wares.

Four were unable to estimate their financial loss. One said she kept her shop open but experienced losses because the children attended customers and made incorrect change. She also noted that when she went to the large market to restock her supplies, she was unable to walk around freely to look for the best prices. Two women worked on family farms and could not put a price on the loss of their labor to the family. One woman lost money because she had to harvest her cassava prematurely. The goldsmith was not forthcoming about her income. Daily earnings ranged from ₦2.00 per day up to ₦10.00 daily (U.S. \$1.00 = ₦4.21). Total loss figures ranged from ₦60.00 to ₦800.00 depending on the type of occupation and duration of illness. Total losses for the twelve women who could estimate were ₦3,520 or an average of ₦293.

The women did not generally find other people to help them with their business except for occasional hawking of some wares like cigarettes and kola nuts. Those who sold food commodities had no one to go to the farm markets to purchase stocks. The goldsmith and typist had no apprentices.

Those women who sold commodities suffered a double setback. Not only were they losing income but they were also using their little profits to buy food and to see them through the sickness. By the time they were well, their capital was depleted and it was difficult for them to start up again.

Although most women used traditional medicine for guinea worm, some did buy additional modern drugs--blood tonic, ampicillin, tetracycline, and dressing materials for the ulcers. These expenses should be considered as part of the economic burden. The women who had dressings applied in a local medicine shop spent up to ₦30.00. Those who bought liniment and tonic spent at least ₦5.00 per bottle. Antibiotic capsules cost between 25 k to 50 k each and if one is used daily, ₦1.75 to ₦3.50 per week.

All the women were married, but their income still played a vital role in family well-being, especially in these days of austerity. Husbands work in their farms or in neighboring towns, and the daily income from mothers keeps the family going. Mothers also help with major expenses such as children's school fees.

3.3.3 Self-Care Activities

Only four women did nothing to care for their guinea worm ulcers. The others rubbed various oils on the sites; sometimes herbs were mixed with these oils. Ulcers were covered with cotton wool by four, Oluganbe leaf by two, and a bandage by one. The contents of antibiotic capsules (ampicillin and tetracycline) were sprinkled on the ulcers by four; one each used plain water, scarification, commercial liniment, traditional herb soap, powder from radio batteries, and a cream bought at the local chemist.

Four women complained they could not sleep. One had even tried Valium but to no avail. Five had difficulty defecating since they could not move out of the house to the surrounding bushes. Bathing proved difficult for two women who found standing impossible. Three women looked dirty and unkempt. Only one woman had an additional illness during the period, a breast abscess which she left untreated. She said there was no money.

Fifteen women experienced loss of appetite. The smell of the ulcers nauseated some. Others did not feel hungry since they were inactive. Some did not want to eat much since it was difficult to go outside to defecate. One said the disease made her mouth bitter. A few admitted that their reduced financial condition made them curtail their diet.

3.3.4 Child Care Duties

In traditional extended families, many people are involved in child care, from young siblings to elderly grandparents. Therefore, some help for mothers was expected to be available even if they were not attacked by guinea worm.

Six mothers stated clearly that they had no problem carrying out all their child care duties. Six said they were completely dependent on others. The remaining nine indicated they could do simple tasks like feeding but required help for bathing the child and washing the baby's clothes. See Section 3.4 for more information on child care.

3.4 Effect of the Disease on Child Health

When a mother is sick her child may also suffer, especially when the illness is of long duration, as in the case of guinea worm. One must be careful in attributing blame, however, as some current problems facing children may have their roots in other causes. Three specific child health variables may be discerned--immunization status, feeding problems, and care during illness.

3.4.1 Immunization

Defaulting or non-participation in immunization programs is a common problem throughout the world, not just in areas where there is guinea worm. The EPI program operates in Ibarapa Local Government Area and at the Maternity Center in Idere Town. Many times the system disappoints the mothers because vaccines do not arrive on the appointed day. Also, the business activities of the mothers interfere with the immunization schedule. Some who have delivered at home fear coming to the Maternity Center later to have their child immunized.

For these reasons, seven of the children studied had either never started immunization (4) or stopped part way through (3) before their mothers had ever been attacked by guinea worm.

Two of the newborns had received their BCG and were not yet due DPT. It is important to note that in one case, the vaccine was not available at the first attempt. A friend had to help bring the child back the next week.

Fortunately, four children had been fully immunized before their mothers fell ill. That left eight who could not start or were caught in the middle of their immunizations when guinea worm struck. Five were due for the different doses of DPT. One mother had called her sister to help the child resume immunization, but when she got to the clinic she found no vaccines available. One child was due for measles immunization, while two had been unable to start at all.

3.4.2 Feeding

All but two children (21 and 24 months) were still breastfeeding. Breastfeeding was affected for three of these children. One mother of a 12-month-old child stopped completely due to guinea worm on her breast. She gave the child only watery pap with a little sugar because she could afford nothing else. This same condition caused another mother to reduce breastfeeding and substitute a very expensive chocolate/malt beverage for the 14-month-old child. Even so, the child lost weight noticeably while the mother was ill. A third felt so much general pain that the child (4 months) could breastfeed only occasionally if the mother was lying down on her mat. Another child was still breastfeeding at 11 months and looked very pale. Her mother had lost ₦80.00 that month because she could not continue her trade. A nine-month-old baby looked thin. The mother could breastfeed but the child depended on the grandmother to prepare maize starch pap for it. His mother had to send his older siblings to another relative because she could not find the physical and financial resources to care for them. The mother of the 21-month old who was no longer breastfeeding said she had reduced the child's diet due to monetary constraints.

Fifteen children seemed to be feeding normally and looked normal. However, since the financial reserves and appetites of most mothers had been reduced, there may still be some future impact on the diet and growth of these children.

3.4.3 Illness Episodes

Ten children experienced at least one illness episode while their mothers were down with guinea worm. Three of these had problems twice. There were four episodes of fever (possibly malaria), three of diarrhea, and three of boils. Other problems included ear discharge, rashes, and slight temperature following circumcision.

No treatment was sought for five episodes. Traditional medicine was used for one. Drugs were bought at local medicine shops for five, and two were taken to the local Maternity Center/Dispensary. (The latter is chronically short of drugs, which might partly explain why medicine shops are more popular.) Also, the mothers who used traditional medicine and one who did nothing said their response was prompted by lack of money.

None of the mothers used ORT for diarrhea. Two did nothing, and one bought a patent medicine. One child had noticeably lost weight by the next week. In two episodes of fever, mothers bought chloroquine. Another bought medicine but did not know the name. The fourth used no treatment. Severe undernourishment was evident. Two of the children who had boils were taken to clinic while the third received no treatment. Traditional medicine was used for the ear discharge. No treatment was given for the rashes, and medicine was bought for the child with a slight temperature after circumcision.

Guinea worm impact must be viewed in light of existing poor utilization of modern clinic services. Patent medicine shops and home medication would certainly be more convenient alternatives for the disabled mothers even if the clinic were functioning well. The lack of funds to buy drugs seems to have a close link with guinea worm attacks.

3.5 Role of Helpers

Most of the 21 women were able to draw on the human resources of the traditional extended family system in their time of need. Four women complained that no one was around to help them. In these cases, relatives had gone to work in their farm hamlets some five or more kilometers from town. One woman moved to her parents' home. As mentioned, another sent her older children to her parents so she could cope better with the baby and her own needs.

As the prevalence of guinea worm has decreased in Idere over the years, there were few families where a large number of members were infected at one time. In those few examples, it was possible to see that the helping network was severely taxed. Women tried to care for their babies as much as possible and relied on others only when they were in extreme pain. When needed, help in washing, feeding, and bathing the baby came from grandmothers and sisters-in-law living right in the house. The most common child care need mothers desired and received from others was for someone to take the baby out for play and fresh air.

Only four women sought help for their business. These relied upon their sons, daughters, and nieces to hawk goods around town until supplies were exhausted. Financial assistance was mentioned as an important form of help by five women. This was received from husbands, mothers, sisters, and neighbors. Of course, help in kind (e.g., food) was provided by most relatives.

Domestic chores required the most assistance. As can be expected in a traditional society, most help came from female relatives and friends. There were isolated cases of husbands collecting firewood, ironing clothes, and cooking. Younger brothers sometimes helped collect water, washed clothes, and swept.

No clear pattern emerged as to division of tasks. Mothers, sisters, mothers-in-law, sisters-in-law, daughters, nieces, aunts, neighbors, and friends helped with all tasks--cooking, washing, marketing, sweeping, collecting water. The issue seemed to be mainly one of who was present at home or living nearby. The fact that a woman was married did not keep her own mother and sisters from visiting regularly to help.

Chapter 4

THE ASA AND MORO CASE STUDIES

4.1 Design of the Study

Prevalence studies were conducted in December 1987 in two villages in Moro, Ogun Edun and Budo Ayan. In January 1988, detailed in-depth interviews and observations of 21 nursing mothers with guinea worm infections were conducted in 20 idile in these two villages and in other highly endemic villages in Asa and Moro Local Government Areas to identify the effects of their infection on child health. The villages and number of mothers interviewed is shown below.

<u>LGA</u>	<u>Community</u>	<u>No. of Nursing Mothers</u>
<u>Moro</u>	Budo Ayan	3
	Ogun Edun	9
	Ajewole	1
	Alassa	3
	Ilu Alfa	1
<u>Asa</u>	Sapati Ile	3
	Su	1
		—
		21

4.2 Description of the Study Villages

The villages studied in Asa and Moro Local Government Areas varied in size and in distance from health care facilities, although all were within easy daily reach of Ilorin by all-weather roads or tracks. The villages in Moro relied exclusively on contaminated ponds for their drinking water. The two villages in Asa shared a borehole but many villagers still used an adjacent pond as a source of drinking water.

Ogun Edun village had a population of 264, of whom 154 (58.3 percent) had active guinea worm in the December 1987 survey. Nine nursing mothers in eight idile were observed. This village was among the most severely affected that members of the research team had ever seen in Kwara State. However, the oldest members of the community were able to remember a time in their youth when the village had not been affected by guinea worm. The pond, which is the only source of water for the village in the dry season, is only about seven minutes walk from the edge of the village, but, because some women must fetch water five times a day, this task may take them an hour or more daily. The villagers anticipate that the pond will last them through the dry season, but if it gets very shallow and dirty they will dig it out and clean it. Most of the people coming to the pond were groups of women and girls; they usually come in groups so that they can help each other lift the pails of water onto their heads.

Budo Ayan village had a total population of 368, of whom 222 (60.3 percent) had guinea worm. Three women, in three idile, were observed; there were 34 idile in the village. The people of Budo Ayan noted guinea worm for the first time about eight years ago in some of the Hausa drovers who stop overnight on their way to Ibadan with their cattle. They pass through the village every year during the dry season, but this was the first time they had appeared with guinea worm.

4.3 The Study Population

Twenty-one nursing mothers were interviewed in 20 idile, ranging in size from 3 to 24 people. Although all but six of the mothers with guinea worm ought to have been able to call on other adult females in the same household for help, this was not always possible. The extremely high prevalence of guinea worm in these families meant that the few healthy ones had to care for all those who were sick. In the 20 idile 56 of those over the age of 15 and 36 of the 86 children currently had active guinea worm ulcers. Three of the mothers were staying apart from their husbands; two had become afflicted with guinea worm while visiting in-laws and another had returned to her parents' home to be cared for.

4.4 Guinea Worm Disease Experience

The mothers' incapacity was as follows:

totally immobile	1
crawling	8
hobbling a short distance	
with the aid of a stick	8
severe limp	1
unable to use one hand	2
minimal	1

In all cases but one, in which a worm was about to emerge on a nursing mother's breast, the women had active, emerging, guinea worms. Six had one worm; seven had two, two had four, three had five, and two had more than five. All women had been incapacitated for at least a week, nine for between one and three months, and one for more than a year. All but four were currently unable to engage in their usual economic activities, small-scale trading of some kind.

Even mothers who were improving when the researchers saw them had harrowing tales to tell of their incapacity--of the agony of giving birth while having guinea worm, of having to be carried everywhere, of struggling to breastfeed a very young baby.

In Ogun Edun village, 42 of the 76 females between the age of 10 and 39 had active guinea worm ulcers. At least nine of these women were nursing mothers, and seven were unable to perform most of their usual duties. One woman who was unable to move around reported that she could now do a little work but she had been incapacitated for two months. The other woman with guinea worm could now move out of the village but was not yet fully active in her trading enterprises. This study did not focus on women who might have been ill from guinea worm at any time during the guinea worm season, only on those who were ill during the two consecutive days the researchers spent in the village.

4.5 Effect of the Disease on Maternal Functions

4.5.1 Domestic Duties

At least half of the women were unable to perform any domestic functions and depended totally on others for help in food preparation, washing of cooking and eating utensils and clothes, fetching water and firewood, and cleaning the house and compound. In one household, the woman, her husband, and two older children were afflicted with guinea worm. The woman was forced to crawl around in agony preparing food and looking after the baby. In other idile, women so severely affected were able to call on others for help in these tasks. Even in this sad case, unrelated women from the village voluntarily fetched water for the family.

4.5.2 Income-Generating Activities

In all but four cases, the 21 women interviewed were unable to perform any economic tasks, and all reported that their ability to perform such functions had been impaired by guinea worm. The time that women were not able to work ranged from a few days to three months. Even though financial exchanges do regularly take place between members of an idile, the researchers did not come across any cases of guinea worm sufferers paying for help. This would have been seen as contrary to the ethos of voluntary cooperation within the idile and the village community.

All adult women are expected to be engaged in economic activities and are allowed to move around freely. Although most are Muslim, very few are in seclusion. Most women are traders, processing foods such as cassava flour, cooking snacks for sale in the village or the local market, or selling crops from the family farm or small quantities of manufactured goods used by villagers on a daily basis. A few women have their own irrigated vegetable farms, and all help with certain tasks on the family farm.

4.5.3 Self-Care Activities

All the mothers who were suffering from guinea worm were experiencing, or had recently experienced, difficulties in performing various self-care functions. In the most severe cases, the mothers were distressed by their inability to provide for their own intimate personal needs. Except in one case, in which the mother was completely immobilized and had to use a pot, they all managed

to crawl or hobble with the aid of a stick or were helped to the bush to relieve themselves. Severely afflicted women who wished to wash had to rely on helpers to fetch water for them, and often to help them wash. Women who were able would hobble to the pond to wash themselves. However, all women, fit or ill, said that they washed themselves rarely because they were afraid of using too much precious water. Two women had severe guinea worm ulcers on their hands, which prevented them from eating in the usual fashion (with the right hand--the left being reserved for 'unclean' personal functions).

4.5.4 Child Care Duties

Babies are breastfed, often until they are two to three years old. Formula is occasionally given as a supplement to breastmilk, even from the time of birth, and by the time the child is five to six months old he or she will be handfed a local pap made of maize or guinea corn flour mixed with water. The nutritional content of the traditional pap is low, 24 carbohydrate calories per 100 grams). Hand feeding often also involves force feeding, in which the mother blocks the baby's nostrils and forces water or pap into the baby's mouth. Babies are never left alone, but carried around on the mother's back and fed on demand. This human contact and warmth are deemed essential to the development of the children and, if the mother cannot carry the child, an elder sibling or a co-wife will do so. Even infants of three and four years old are carried if they are sick. Infant and child mortality is generally high in these rural areas; the Nigerian rural infant mortality rate is about 125 per 1,000 live births.

Very sick mothers made great efforts to breastfeed their babies, even where this was obviously painful. Two women who had guinea worm ulcers on their hands could not hold their baby to the breast and had to be helped to do so. Two women who were confined to their mats before we met them said that they had to have help in holding their babies to their breasts. The continued ability to breastfeed was important because formula was extremely expensive and often regarded as an inadequate replacement for breastmilk. It did not appear to be the custom here for mothers to stop breastfeeding if they had guinea worm, as it was in the Idere study area.

Because of the limited coverage of EPI in the study villages, no women directly blamed their inability to take their children for the complete sequence of immunizations on guinea worm. They probably would not have gone for the immunizations even if they had been healthy. However, the women in Sapati Ile and Su, in Asa, close to Ilorin City and to Gama Maternity and Dispensary, made more use of the clinics than did the women in the more remote villages in Moro. One woman from Sapati Ile delivered at Gamma Maternity, and, although she had guinea worm when the baby was born, she was able to complete her schedule of immunizations. Another woman, also from Sapati Ile, gave birth five months earlier in a private clinic in Ilorin, but the baby was not given BCG after birth, and the mother was not told to return with the child for other immunizations.

4.6 Effect of the Disease on Child Health

In relatively poor villages, such as those studied, where mothers and their young children face a multiplicity of health problems, it is clear that guinea worm puts a serious extra burden on mothers and children. At least four of the 21 mothers reported difficulty breastfeeding, but all persisted in the face of considerable pain and discomfort. One mother, whose two-and-a-half-year-old daughter had a recently healed guinea worm scar, said that she had fed her Celarac, made with boiled water, right from birth as a supplement to breastmilk; but this appeared relatively uncommon. Most mothers did not use formula, but began feeding their children with pap at the age of five to six months; the pap was mixed with boiling water to make it soft.

One 18-month-old child was clearly severely malnourished, with the classic signs of thin, sticklike arms and legs, a wizened face, and a swollen belly. The mother's general health had been poor for a long time, and she was confined to a chair. She was worried that her son did not get enough milk.

Five children under five, of a total of 32 in the 20 idile, had active cases of guinea worm, the youngest aged 18 months. These children could have got guinea worm from the drink they were given from the time they were a few days old. This usually consisted of agbo, an infusion of herbs.

4.7 Mothers' Perceptions of Guinea Worm

Only two (of the 21) mothers were unable to identify the relationship between guinea worm infection and "bad" water, and most knew that the ponds they used in the dry season were the main culprits. A number were aware that the disease could be spread if a person with an open guinea worm lesion stepped into a pond. Others knew of villages in which guinea worm had disappeared after the drilling of a borehole. This may have been the result of interactions between villagers and members of research teams who visited the village.

In spite of this awareness of the role of drinking water in guinea worm infection, most mothers did not treat their domestic drinking water supply which they draw from the ponds. However, in one household case, the mother-in-law regularly brought drinking water from Ilorin, and in another the mother claimed that all drinking water for her baby and herself was boiled. This does show that some mothers considered that actions they took themselves could have some effect on their health.

4.8 Role of Helpers

Helpers from within the idile or from the village community were usually able to provide basic care for the afflicted mothers and their children, but in most cases this was not as complete as the care that a healthy mother would provide. Also helpers were taken away from other tasks of benefit to the idile and the village.

In only one case was the husband reported as the main helper in domestic and child care, and this was regarded as a strategy of last resort, as men are not usually directly involved in domestic and child care tasks in Yoruba society. In the idile, tasks and patterns of cooperation are usually sex-specific. Women are the main care-givers.

Where possible, tasks were shared by helpers; one helped with the care of the child, and the other with domestic tasks. In general, a daughter, co-wife, or husband's brother's wife, in order of priority, would help with child care, and more distant relatives, or older women such as mothers-in-law, would help with domestic tasks. A daughter of about ten was considered old enough to wash, dress, feed, and carry the baby around, but a girl of this age does not cook except to reheat food for her own use. In all three cases where the school-age daughter was the main helper in child care, the daughter had been taken out of school. In only six cases was help offered a mother by women from outside the idile, and only in two cases did a woman from beyond the village come to help.

Helping and support networks often extended beyond the village and incorporated people who had left temporarily to seek work in cities such as Lagos and Ilorin.

All the women depended, or had recently depended, on financial assistance during their current episode of guinea worm, primarily from their husbands. In six cases the husbands were also incapacitated and therefore unable to help, and in one large idile the only person able to make any money at all was the aged father. In four cases, neighbors in the village helped. No mother reported that she failed to receive financial help if she needed it. However, because of the small scale of trading, the amount of money involved in such exchanges was very small, and the idile and the community clearly lost much-needed income-generating capacity because of guinea worm. The high prevalence of guinea worm in these communities meant that scarce material resources and farm production suffered as people had to give priority to the care of those incapacitated by guinea worm.

Chapter 5

CONCLUSIONS

5.1 The Idere Study

The Idere study shows that guinea worm has a definite impact on women and their children. The focus groups in villages where guinea worm is no longer common provide a sharp contrast to the suffering found in the 21 case studies.

During the period of study, the impact on the mothers was more marked than on the children. A complex of interrelated effects was observed in the mothers-- economic loss, reduced nutritional intake, secondary infections, increased dependence, personal neglect. Survey results reinforce that these experiences are not unique to the 21 women receiving in-depth interviews.

The case study approach allowed one to see how guinea worm's impact evolves over time. It was important to find that consecutive ulcers keep a woman incapacitated for months at a time. The 1981 survey data showing an average of 15.4 weeks lost was verified and was near the 14.6 weeks projected for the women currently studied.

The financial impact speaks most clearly. The annual per capita income in Idere was estimated at US \$125 or N 500 from TDR data. In this environment a woman's income plays a crucial role in family survival. Large portions of family earnings can be lost when the mother is attacked by guinea worm. Guinea worm not only eats up her immediate profits but also destroys her capital and seriously sets her back when she tries to revive her abandoned trade. Mothers were already seen cutting corners in food purchases and health care. There are bound to be longer-term problems as a result.

Affected mothers seemed to devote whatever little energy they could muster to care for their children, and so the immediate impact on these children was mild to moderate. However, as most mothers were breastfeeding and had restricted their own diets, one would expect more problems in the children down the road.

Right now, with a relatively lower guinea worm prevalence rate, Idere families are able to function when guinea worm attacks a mother. The network of friends and relatives usually responds to handle domestic chores and child care (but not occupational duties). However, as the experience of several families shows, when several family members are affected by guinea worm, help is not easily forthcoming. Now it is possible for a sick person to move in with other relatives, but if the community-wide rate were higher, to whom would one turn? Also, living in town, some women with guinea worm become isolated when their housemates go to the farm or the city for work and trade for weeks at a time. Under such circumstances, the sufferer's nutrition, hygiene, and general welfare would suffer much more.

The study highlighted the multi-causal nature of child health problems. For example, guinea worm could be blamed for only about 50 percent of immunization defaulting. A mother's job or her attitudes toward the health clinic, as well as irregular vaccine supplies, also played a role.

The study included only four pregnant women, not enough from which to generalize. Their experiences seemed relatively mild, and, upon delivery, they received copious attention from relatives which would have been forthcoming, guinea worm or not. Some ante-natal visits were missed, but Idere women usually wait till the third trimester to register, and so miss much of the value of ante-natal care anyway.

Several issues arise for further inquiry. A more extensive longitudinal study might reveal more long-term effects. How does the woman who lost her income during guinea worm re-capitalize? How long does this take? What would weight monitoring of the child over six or more months reveal (with a control group, of course)?

The variations in impact and coping strategies in communities with different levels of endemism would be useful to study. Idere women are primarily business women. An examination of the impact of the disease in communities where women have other primary roles is needed.

To make inferences about how pregnancy and newborns are affected by guinea worm, a larger number of pregnant women in different stages of pregnancy would have to be studied. Cultural barriers to identifying pregnant women in the early months would have to be overcome. The interviewer in this case was specifically looking for pregnant women, and yet the four that were found were all in their last month.

Even without guinea worm, rural African populations are poor and in ill health. When guinea worm is added to the existing mix of parasites and poverty, the effects can be both dramatic and subtle. On the one hand, a woman may lose a substantial amount of her annual income. On the other, an unattended illness in her child may retard its growth slightly, adding another small measure to the disadvantage the child will experience later in life, if he or she survives. Guinea worm has been called a neglected disease in a neglected segment of the population. Hopefully, the case studies and experiences described herein will shake some out of the habit of apathy and neglect.

5.2 The Asa/Moro Study

Areas most severely affected by guinea worm are usually poor and remote. For nursing mothers, guinea worm is one more problem that they have to face in a daily life of poverty and hard work. This study identified 21 nursing mothers with guinea worm; only 4 of the 21 were able to move around outside the house and its immediate surroundings. All these mothers had experienced difficulty in looking after their baby at some time during their illness; only one out of the 21 was no longer relying on the help of members of their family or village community to perform some, if not all, of their maternal functions.

As nursing mothers had many other responsibilities in addition to looking after their young children, the tasks which their helpers so willingly undertook had to be prioritized. Child care was usually given the first priority. Where the mother was severely incapacitated, her own self-care suffered.

In all cases, income-generating tasks were given the lowest priority, and all the 21 women had had to rely on money from their husbands or from female relatives in order to buy small essentials for themselves and their children. While the mothers and many other adults in the community suffered from guinea worm, much time which might have been spent making a little money from trading and food processing or tending the farm was spent caring for those who were afflicted with the disease. Thus, the burden of nursing mothers who suffered from guinea worm disease was borne by the whole community, and the whole community was impoverished by the disease.

The severity of the effect of guinea worm infection on nursing mothers is related to the severity of the incapacity of the mother, the size of the idile, and the number of people in the idile, especially women and girls of ten and older, affected by guinea worm.

Even when all members of an idile who could help an afflicted mother were themselves suffering from guinea worm, help was usually available from neighbors or from relatives in nearby villages, or from Lagos or Ilorin. But however effective the coping strategies of the extended family and the community, the nursing mothers and their children still suffered considerably from this preventable and painful infection.

5.3 Policy and Programmatic Implications

- Mothers provide the needed care and feeding for infants and children. In addition, they are decision-makers and "front line" providers of health care. With an increasingly important focus placed on child survival, the role of mothers and caretakers becomes critical for implementation of EPI, ORT, nutrition monitoring, and control of illness (malaria). The lengthy and continued incapacitating effect caused by guinea worm interferes and seriously hinders a mother's ability to ensure the survival of her children. The linkage and interdependence of a mother's well-being and her ability to care for her infant need to be given more attention.
- There is every indication that the infection by guinea worm is continuous. People in Yorubaland believe that the worm can remain inside the body causing suffering without coming out. It has been blamed for stomach disorders, dizziness, and nodules. There is some clinical support for these attributions in that guinea worms have been found lodged in joints and the spine without being able to emerge to the skin, causing crippling and discomfort. The clinical effects of the disease on pregnant women include fever, loss of appetite, weakness, dizziness, pains all over the body, and cold. Women say they have no appetite and, in some cases, have mentioned their loss of economic activities and funds as the reason for not being able to buy food.

- It became evident from the research that belief and practice are at odds. In some cases, in accordance with cultural beliefs, breastfeeding is stopped because it is believed that sickness can be passed on through breastmilk. Yet, in practice, women in the sample knew it was important to breastfeed and, despite the discomfort and the pain, made every effort to continue breastfeeding. Similarly, despite the belief that a guinea worm emerges because it can smell the worms in other people, kin and community do not shun those badly infected.
- Mothers are acutely aware of the problem of guinea worm, and they know methods of diagnosis, treatment, and possible prevention. They can modify their beliefs and behaviors in the light of new information and do not regard guinea worm as an inevitable part of their life, to be accepted passively.
- Studies in Kwara, Oyo, and Anambra States have already shown that protected water supplies can reduce the prevalence of guinea worm in highly endemic villages (with prevalence rates of over 50 percent) to zero or near zero within three years of the introduction of protected water supplies. However, the linkage of the disease to water must be identified and recognized by the community.
- The social network of kin, which consisted of relatives outside Idere in Oyo, or the idile (extended family unit) in Kwara, assist in the essential functions of fetching water, wood, or providing some help in the house (i.e., cooking). However, what is not clear is the cost of repayment for the infected woman nor the difficulties of locating kin when prevalence is 60 percent and above.
- In this brief and exploratory study the average economic loss, estimated at ₦500, or \$125 per year, has been shown to result in decreases in food purchases. An impact on the nutritional intake of mother and infant can be expected.
- There are a number of programmatic implications for policy-makers. This study showed that communities are receptive to taking action against guinea worm. They are willing to use filters when available and show support for involvement in community water schemes. In the Oyo State area, because of continued exposure to university medical students and neighborhood primary health workers, women knew they could protect themselves against the disease.

APPENDIX A

Sample Case Studies from Idere

APPENDIX A

Sample Case Studies from Idere

CASE STUDY 1

Olubunmi, 20 years old, lives in the south central portion of Idere. She makes her living by making and selling cold pap (corn starch) and attends the Baptist church. She still lives with her parents, a junior brother and two junior sisters. All except her father have guinea worm, including Olubunmi's first child (three years old).

Her guinea worm attack started in November. By December 17 she was finally able to sit up and was found sitting in the company of other women outside the house. The ulcer was on the left foot and she felt pain and smarting. By December 24, her own ulcers were healing, but since her three-year-old child now had guinea worm, she was still bound at home to care for him. By the end of January, her ulcers were completely healed. In all, she herself was affected for about six weeks.

Olubunmi could not do anything during the first few weeks of the disease. By mid-December, she was walking slowly and was able to collect vegetables from the small garden near the stream at the back of the compound. Her mother and friends helped wash clothes and do other chores. The surroundings of the house look dirty, but only the grandmother is left unaffected by guinea worm.

Normally, with her business, she would make ₦5.00 per day. She may have lost up to ₦180.00 during the period of serious illness. Her mother was giving her money during the illness, so the mother was losing in the process also.

Olubunmi was able to feed and bathe herself but not her four-month-old child. During the early period of attack, the guinea worm was so painful that Olubunmi could not sit up and breastfeed. Therefore, the baby was placed next to her on the bed to try to breastfeed. The grandmother and tenants in the house took the child out.

The baby was able to get BCG immunization, but Olubunmi was not able to go back for further shots because of the guinea worm. Also, the child had developed a boil under its arm shortly after the BCG immunization. Olubunmi took the child to the local maternity center at the east end of town. Seven daily injections were prescribed, but due to her illness, Olubunmi requested friends to take the baby for the remaining injections. The child still did not recover. Toward the end of December Olubunmi was able to take the child to the Igbo-Ora Hospital, seven kilometers away. The child was given ampicillin and began to improve. By the end of January both the mother and child were well.

CASE STUDY 2

Jemilat is a 23-year-old goldsmith. She lives in the center of Idere and is a Muslim. Besides herself, her husband's elderly parents had guinea worm.

Her guinea worm attack began in early December with four ulcers--left leg and ankle, right leg and foot. She could not walk, but could only lie on a mat outside. She had to crawl to move within the house. By December 24, another ulcer appeared on her right knee. This was very painful and kept her in bed. She could not sit for long because of the pain in the knee. By the end of January Jemilat was seen walking normally but the ulcers had not healed.

All household duties such as cooking, washing clothes, and collecting firewood were carried out by her husband's junior sisters (two) and one elderly aunt who live in the house. Jemilat's own sister also came over to help, particularly with washing clothes. Small children were able to run errands.

Jemilat could not open her shop for nearly two months. She had no apprentices who could keep the work going.

She found it difficult to care for herself. She had to bathe sitting down. Her food intake was reduced because she could not go far from the house in order to defecate. Her wrapper looked dirty, as did the bedsheets.

On the first visit, she had put palm oil on the ulcers. Later, she began using shea butter with lapalapa and orange leaves. Toward the end, she returned to using palm oil.

Her one-year-old male child was due for his measles vaccine when guinea worm attacked his mother. This vaccine was delayed. Her husband's sister helped feed and bathe the child. Jemilat breastfeeds the child regularly. On December 23 the child developed a fever but Jemilat did not take him anywhere for treatment. The child reportedly vomited whenever he ate and this kept him small. Jemilat had not yet discussed this with the child's father, so no action could be taken until he returned from work. The child had recovered by the last visit (January 26) and was seen playing.

CASE STUDY 3

Ayisat, a 35-year-old Muslim, lives at the west end of Idere and sells cold pap. Both she and her husband, as well as two of their five children had guinea worm. Her husband's parents are dead, but his aunt who lives in the house also had guinea worm.

Ayisat came down with guinea worm in October. Four ulcers were seen in December - left foot and leg, right ankle and leg. She was experiencing high temperature, dizziness, and rashes. She could walk with the support of a stick, but not well. By late December the right leg was swollen with pus discharge. By late January new guinea worm ulcers had formed on her breast, left elbow, and another on the right leg.

Ayisat was incapacitated for at least four months up till the last interview with prospects of a longer illness ahead.

Her eldest daughter (17), who was free of guinea worm, fetched water, prepared the food, and looked after the house. Her brother's wives also helped.

Ayisat was not able to work and had no one to help with her business. She may have lost ₦30.00 per week, or nearly ₦500.00 during her illness.

When first seen (December 18), she looked relatively healthy, but her appetite had fallen off, and she was eating only once or twice a day. By the next week, she was looking weak and lean. At one point she was depending on her brother and his family for food. Since both she and her husband were affected, they had to depend on the charity of relatives. She applied palm oil and tetracycline to the ulcers. Her own room was untidy and dusty.

Her one-year-old son also suffered in the process. On the first visit, the child had diarrhea and a cough, but due to guinea worm, the mother had not taken him for treatment. She was unaware of ORT. The child was still breastfeeding at this time. By the second week, the child had recovered but had obviously lost weight. The mother complained she could not buy him adequate food due to her financial loss through illness. After the guinea worm emerged on her breast, Ayisat stopped breastfeeding. The child then got only watery corn starch pap with a little sugar added. At the last visit the child had rashes on his head. She would not allow anyone to take the child to the clinic because she had no money for fees and drugs. The child had not received any immunizations.

CASE STUDY 4

Abibat is 23 years old and had just delivered her first baby the day before the interview (December 22). She had recently finished high school but had no job. She attends the Baptist church and lives with her husband's family in the east central part of Idere. No one else in the household was affected.

Her guinea worm began on her right buttock about a week before delivery. She had put palm oil and an herb mixture on the site as provided by her mother-in-law. She could walk properly, but limped. By the second week of January, she was improving and able to walk, but then toward the end of the month, she got a fresh attack on her right foot. She could walk only by using a stick. The new ulcer was treated with a mixture of ewe imin and bomubomu leaves in shea butter and palm oil.

Abibat received help from several quarters. Her husband's mother took the lead in making sure the clothes were washed and the cooking done. Also friends came over to help wash. The child's father and his junior sister helped carry the child. Abibat's own two sisters came over to help wash clothes. She was able to do some cooking herself between guinea worm attacks.

Abibat looked generally healthy and well fed throughout. She looked clean also.

Her baby was delivered at home because of the painful guinea worm ulcer on her buttock, but her friends took the child to the Maternity Center the next day for weighing. They were told to bring the baby back in a week for BCG, but due to the child's naming ceremony, no one could bring her back. When Abibat was temporarily relieved of guinea worm, she took the child for BCG in mid January. It seemed there were people to help her continue the immunization, even if the second attack of guinea worm were to keep her down for a while.

The baby breastfed from the beginning and experienced no major problems in its first month. Her friends and mother-in-law helped bathe the child.

APPENDIX B

Sample Case Studies from Asa/Moro

APPENDIX B

Sample Case Studies from Asa/Moro

CASE STUDY 1: ALASSA VILLAGE

Ayisatu, aged 30, a nursing mother, had been ill for 15 days when first seen by the researcher. Her son, Dauda, aged 18 months, was breastfeeding while she was lying down; it was clearly an effort for her to sit up. Dauda appeared healthy, although a little anemic. Unfortunately, Ayisatu's husband, Ayinla, had four guinea worms and could only crawl from his mat. Their son, Jimoh, aged ten, and daughter, Afusa, aged eight, moved around with great difficulty. As nobody in the idile was able to work, they all depended for a little money on the generosity of neighbors.

Because this small idile, which consists only of the parents, the baby, and two older children, is situated about 100 meters from the rest of the settlement, Ayisatu could call on little help in her predicament. As Ayisatu was born in a nearby village, Seji, she could not call on anyone in Alassa to help her on a regular basis. Fortunately, a number of women in the village brought water from the pond for the family. Ayisatu had to care for the baby herself and also to cook as best she could. She kept a stick by the side of her mat and could crawl around painfully. Clearly, she was not able to care for herself and her baby adequately. In a household where help was available she would not be expected to have to do so.

Every few days her husband's mother, who regularly stays in Ilorin, visited and did what she could to help. She also brought a jerry can of water from Ilorin for the family to drink. The family had been drinking Ilorin-piped water for the last few months. Ayisatu understood that guinea worm is caused by water and that the best prevention is a borehole. A borehole has recently been installed in her natal village of Seji, and since then there has been no guinea worm in that village.

CASE STUDY 2: OGUN EDUN VILLAGE

Yetunde Akande, aged about 40, lives with her husband, Amuda, and their two children, Yenusa, a son aged 12, and Kamaru, a son aged one month. Yetunde was so sick from guinea worm when she gave birth that she had to be carried. Although she can walk only a few meters with the aid of a stick, she is able to wash and relieve herself. The baby appeared to be healthy, but Yetunde's general health was poor, and she had a bad (tubercular?) cough and slight fever.

Since before giving birth, she had had two regular helpers, her senior sister, Abike, and her husband's junior brother's wife, Aya, from another household in the village. Abike came from a nearby village every day, arriving by about 10 a.m., and she washed clothes and dishes, cooked the food, and took care of the

house. She also carried the baby around on her hip during the day and force fed the baby with water. Earlier in the morning, Aya came to wash and dress the baby. Yetunde's husband, Amuda, also had an active guinea worm, but he was able to do a little work on the farm. Yetunde had to rely on him for money to buy some things, as she could not work at her usual occupation, making eko, a maize meal snack. Her son, Yenusa, also had guinea worm.

Yetunde complained that she had had guinea worm every year for the past five years, and usually she could not work for at least a month. If she had guinea worm at the time of her pregnancy, she got dizzy and had iba, fever. In 1986, while she had guinea worm, she had a child which died after a few days; at that time she was so sick she could hardly move. She thinks perhaps the child died because she had guinea worm, but she doesn't really know.

Yetunde knows that guinea worm is caused by drinking bad water, and that it can be prevented by boiling water. Since Kamaru's birth, she insisted that he be given only boiled water. She kept boiled water in a covered pot in her room for her own and her baby's use; other members of the family drank pond water. She believes that people in the village who do not get guinea worm are just lucky, and that people on visits to the village may not get it. Yetunde recognizes guinea worm by a pressure sensation and says she can feel it walking around in her body before it comes out. By the third day after the onset of the pressure sensation, a painful swelling appears. When the area becomes soft and whitish, it is pierced with a red hot rod.

CASE STUDY 3: OGUN EDUN VILLAGE

Arinola Jimoh, aged 30, was visiting her husband's family from Lagos, with Kayode, her son, now four months old, and another son, aged four, when she was incapacitated by guinea worm. She had been sick for a month and was totally immobilized at the time of the researcher's visit. She had three guinea worms emerging on the right foot, one on the left foot, and one on the right knee. Although Kayode appeared reasonably healthy, Arinola admitted to having trouble breastfeeding. Her most serious problem, however, was personal hygiene, as she could not bathe or leave the room to urinate or defecate. She had to use a pot.

Kayode was being carried around the compound by Asiawu, the wife of her husband's brother, Solomon. Asiawu is the youngest of Solomon's three wives and does not yet have a child of her own. One other wife performed domestic tasks and fed and cared for Arinola and her other child. The third wife, Sueba, could not help much, as she too had guinea worm. Solomon's elderly mother was not able to help much either, so the whole family depended on Solomon to provide them with a little money.

Arinola is familiar with the symptoms of guinea worm, and she knows it is caused by bad water. She thinks, however, that she was infected on this visit. She did admit to having visited Ogun Edun a number of times during the last dry season. Arinola knows that people get guinea worm from drinking water which infected people have stepped in; she learned this from members of the research team. She knows of villages which once had guinea worm but no longer do so because they have boreholes. Last year the people in this household did not boil their drinking water, but now they do.

CASE STUDY 4: OGUN EDUN VILLAGE

Ayi, aged about 20, is a nursing mother with a baby girl, aged one year. Ayi usually lives with her husband in Ilorin, and visits her in-laws frequently. When she got guinea worm and was unable to care for her baby and her husband in Ilorin, she came back to Ogun Edun for three months to stay with her in-laws, leaving her husband to look after himself in Ilorin. Ayi had four guinea worms on her right hand, and the hand was so swollen and painful that she could not flex her fingers. She said she was a little better than she had been, so she returned to Ilorin last week and later visited her in-laws in Ogun Edun. She still could not eat with her right hand (the right hand is used for eating, as the left hand is regarded as unclean), and she still could not perform her usual work as a trader, but she was able to hold her son to the breast to feed. Earlier she had to be helped to do this.

When she returned to Ogun Edun she came with her nursing baby, a son who looks quite healthy except for a slight skin rash, and her three-year-old daughter. While in Ogun Edun the daughter sustained a small, deep burn on the side of her face, from getting too close to a pot or amala on the fire. The scar was clearly visible. (Burns from unattended open fires are common hazards for toddlers everywhere in Nigeria.) Although Ayi's husband's parents, Abake and Kaliyatu, were both over 60 and had guinea worm, they appeared reasonably sprightly.

CASE STUDY 5: BUDO AYAN VILLAGE

Ayinka Shehu, aged 30, was immobilized by guinea worm. Her son, Kadiri, aged 18 months, was very undernourished, with thin legs and a swollen stomach. Ayinka complained that the child had difficulty breastfeeding. As Ayinka was immobilized, her main problem, besides caring for Kadiri, was personal hygiene. She had to crawl out to the bush to relieve herself and could not take a bath. Her main helpers were her father-in-law's two wives. The senior wife, her husband's mother, took care of the baby, and the junior wife did the domestic tasks, but both also had guinea worm. Both women are elderly and clearly were not able to do as much as they would like for Ayinka; they also had to give up their trading activities.

As Ayinka's husband was also totally immobilized because of guinea worm (he also has leopard skin on his leg, a sign of onchocerciasis), he was unable to work and required care. He spent his day miserably on a mat in an inner room. Thus the only person in the idile able to earn any money is Ayinka's father-in-law, who is around 60 and complains of a cough.

Ayinka had been incapacitated by guinea worm every year for the past five years, so she had no difficulty in recognizing the symptoms of the infection. It was especially painful this year, as she had five worms. Both legs were affected. A worm was about to emerge on the left knee, making it very painful and swollen. For treatment of guinea worm, the wound was cleaned with a piece of cotton dipped in hot water, and Robb was applied; sometimes the wound was punched with a red hot rod when the swelling appears soft enough.

CASE STUDY 6: SAPATI ILE VILLAGE

Aminatu Adisa, aged 35, is a nursing mother with a son, Rasaki, aged 18 months, and three other children living in the house, a son aged 17 who is at school, and a daughter aged six. She lives with her children and her husband, Lamidi, a farmer. At the time of the researcher's visit, she had been severely incapacitated for three months, with two active guinea worms, one on each leg. She has guinea worm every year. Last year, when Rasaki was very young, she was incapacitated for five months. However, she did deliver at Gama Maternity and although she was sick, she took him for the full course of immunizations. Her main helper was Ayisatu, the wife of her husband's junior brother, who came from Lagos to help her. Ayisatu cared for the child, while the older children fetched water and performed other household tasks. Her husband's mother came from another idile in the village to help, especially with the cooking. The two daughters, aged 13 and 6, pounded cassava and washed clothes. Although Aminatu was sick, finding it very difficult to rise from a low stool even with the aid of a stick, she was making every effort to breastfeed her son. He was taking quite a lot of pap, but she did not feel he was old enough to be weaned completely from the breast.