GUINEA WORM: AN IN-DEPTH STUDY OF WHAT HAPPENS TO MOTHERS, FAMILIES AND COMMUNITIES

SUSAN J. WATTS, WILLIAM R. BRIEGER, and MAY YACOOB

1350 Benefit Street, Providence, RI 02903, U.S.A., 2African Regional Health Education Center, Department of Preventive and Social Medicine, University of Ibadan, Ibadan, Nigeria and 3Water and Sanitation for Health Project (WASH), Arlington, Virginia, U.S.A.

Abstract—This paper reports on the impact of maternal morbidity due to guinea worm, dracunculiasis, on the care and health of children under 24 months old, and the ways in which the mothers and the family coped with the often extended periods of disability. This qualitative study is based on observation and in-depth interviewing, supplemented by focus group discussions. Of 42 mothers with guinea worm in two hyperendemic areas of Oyo and Kwara States, 28 were either bedridden or only able to hobble short distances, with an average period of incapacity was 9 days. The four maternal roles identified (child care, self care, domestic tasks, income generation), the women gave priority to child care; 34 of the 42 mothers helped in child care. Coping networks operated principally within the extended family, but also included women in other households, and women from beyond the community. Thus the impact of a mother’s illness extended beyond her children and family to the wider community. This qualitative study thus reveals the multifaceted impact of a disease on individuals and on the community. The study stresses the need for, and availability of, effective methods for controlling guinea worm by utilizing community cooperation to provide protected water sources and other preventive measures against the disease.

Key words—guinea worm, maternal morbidity, maternal roles, coping networks

INTRODUCTION

Dracunculiasis, guinea worm disease, affects people living in many rural areas of Africa and India who do not have access to protected water supplies. Although rarely fatal, it can incapacitate sufferers for 3 months or more. The disease may have a serious impact on the social and economic life of the community, especially in hyperendemic areas of Africa where 50% or more of the population of a single community may be affected. Here, guinea worm infection can result in marked declines in agricultural production [1-3]. Children are kept from school if they have the disease, or if they are needed to help with household tasks when adults are afflicted with guinea worm [4,5].

Guinea worm is a waterborne helminthic disease transmitted solely by drinking pond water containing the intermediate host, a small crustacean, cyclops. Approximately a year after swallowing the infective cyclops, the meter long subcutaneous parasite breaks through the host’s skin in a painful blister. When an affected subject is collecting drinking water in a stagnant pond or stream remnant the larvae are expelled into the water. A simple cloth filter which prevents infective cyclops from entering domestic water storage containers, and protected water supplies which do not allow people to step into the water such as wells, boreholes and, of course, pipeborne water, can prevent the disease [6].

Mothers incapacitated by guinea worm and caring for young children are often observed during visits to affected communities. The study from which this paper derives was the first to explore the linkage between guinea worm and child survival [7]. This paper explores the nature and extent of the impact of the disease on the mothers, their families and the community as a whole. It gives an indication of the possible benefits which might accrue from controlling or eliminating the disease in a community, and at the same time provides some information about familial roles and coping strategies which might be utilized in such control efforts. The study of such coping strategies also provides an indication of the impact of guinea worm on the community as a whole.

This pilot study provides a qualitative perspective, derived primarily from case studies based on observation and in-depth interviews in hyperendemic settlements in two areas of Nigeria. The focus here is on exploring the processes associated with incapacity due to guinea worm, and the nature of its impact on the community. The qualitative approach reveals many dimensions not readily apparent in quantitative studies which may, for example, gauge the impact of disease on agricultural production by translating days lost due to incapacity from guinea worm directly into production losses [1,2]. The picture is certainly more complex than this, as the disease affects a whole range of activities to which villagers must assign priorities. In addition, our experience in Nigeria has shown that women, especially, often withhold information during formal surveys [8].

Qualitative surveys are necessary to paint a full picture of the dynamics of disability. Observation and in-depth interviews can identify what actually happens during an attack of guinea worm, the coping mechanisms used, what tasks are sacrificed and which are given priority, and the impact of disabilities lasting for varying lengths of time. Although this
pilot study cannot answer all these questions, it does suggest some strategies which might be useful for disease control, and some themes for future studies of the impact of the disease.

The study was carried out in December 1987 and January 1988 in Idere town, in Ibarapa Local Government Area of Oyo State, and in a number of villages in Asa and Moro Local Government Areas of Kwara State. Most of the people in both areas are Yoruba, of the Oyo sub-group, and have a similar social structure. Idere town has a population of about 8000, with a further 2000 living in dependent hamlets up to 30 km from the town; the population is equally divided between Christians and Muslims. The villages and hamlets in Asa and Moro are small, with a median size of between 250 and 350 people; the vast majority of the people are Muslims.

There are contrasts in guinea worm endemicity, and in the past and present sources of drinking water in the two areas. In Idere, people used to depend on a piped water supply, constructed in 1967, but this no longer functions effectively and today residents in both the town and surrounding hamlets depend primarily on wells and ponds for their drinking water. In 1980/1981, the prevalence rate for guinea worm in the town was 40% [9]; but health education and the constructing of wells had reduced the prevalence rate to between 3 and 20% in the various wards of Idere by 1987.

Until recently, all the villages studied in Asa and Moro depended on small ponds for dry season drinking water. However, two, Sapati Ille and Su, now share a borehole although villagers frequently resorted to a contaminated pond [10]. The overall prevalence of guinea worm is higher than in Idere, reaching 60 and 58% respectively in the two largest villages of Budo Ayan and Ogun Edun. Point prevalence figures of this magnitude are not uncommon in hyperendemic areas of Nigeria [4, 11-13], or in other areas of West Africa [14].

METHODOLOGY

The main research technique in this pilot study was the use of in-depth interviews and observations of mothers in family settings. This was augmented by a series of focus group discussions with married women. Specially trained local health workers and secondary school leavers conducted the interviews, observed the mothers and acted as moderators and observers for the focus group discussions. They worked under the close supervision of two of the authors, who had known their respective study areas for over 10 yr.

Women who had active guinea worm lesions and had children of 24 months or less were selected for in-depth interviews and observation. This group was identified because it is the target group for the Expanded Program of Immunization, and also enabled us to explore the larger issue of child survival. The women were asked about the degree and duration of their incapacity, who had helped them, and problems encountered in performing economic tasks, and in caring for themselves, their child and their family. Observations focused on the condition and health of mother and child, and who was carrying out various activities around the compound at that time.

In Idere, 21 women were selected from all sections of town. Assuming approx. 10% of the total population were mothers of children 9-14 months, and 10-20% of the total population had guinea worm, this represents about one quarter of the total number of affected women. Each woman was visited at least once every 2 weeks between mid-December 1987 and the end of January 1988. In Asa and Moro, 21 mothers were interviewed and observed during the last 2 weeks of January, 1988. A preliminary demographic survey identified 12 affected mothers in the villages of Budo Ayan and Ogun Edun who were interviewed within 2 weeks. Later, affected women were identified in nearby smaller villages in Moro, or in the northern part of Asa.

The first focus groups, conducted in Idere town, were designed to discuss how women felt that guinea worm affects a pregnant woman and a new born baby. It was possible to distill from these shared experiences four maternal roles that were affected by guinea worm attacks; domestic duties, child care, self care and income generation. Later, focus group discussions were held in former endemic villages in both study areas, to provide information about the impact of guinea worm on the women, their families and young children, and any changes they had noticed in their lives since the elimination of guinea worm in the village. Women also talked about beliefs, practices, and treatment of the disease.

Both in-depth interviews and the focus group discussions in formerly endemic villages were organized around the tasks women were expected to perform, their maternal roles. Observers were asked to note carefully what sick mothers could and could not do, who helped and with what tasks, as there may be a difference between behavior, which mothers in group settings, such as focus group discussions, claimed was expected and what actually happened in practice.

MATERNAL INCAPACITY AND THE PERFORMANCE OF MATERNAL ROLES

The preliminary focus group discussions identified four categories of maternal roles: self care, child care, domestic tasks, and economic tasks. Self care included washing, eating, defecating, and the treatment of guinea worm. Child care encompassed feeding the child, washing the child and her clothes, playing with the child and carrying her around. Domestic tasks included cooking and, preparing food for the family, fetching water and firewood, washing clothes, and cleaning the house and yard. In addition, all women are expected to engage in income generating tasks to provide for many of their own and their children's needs. Most women were traders, food processors and/or farmers. Only 2 women, a typist and a goldsmith in Idere, were involved in occupations which might regularly involve physical separation from their very young children during the hours they were working. Many women who were farmers and traders worked with their babies strapped to their back, or kept an eye on toddlers playing nearby.
A mother with guinea worm was less likely to even if it was painful and a helper had to hold the baby to the breast. At least 3 mothers were forced to abandon breast feeding, and here the health of the baby was severely affected. One mother who was forced to stop breast feeding said, "I could not breast feed my child because of the pain." Mothers made great efforts to breast feed their babies, but the presence of guinea worm made it difficult. Breast feeding by sick mothers may transmit disease, all the more so because of the close human contact. In spite of their belief that breast feeding was best for the child, many mothers resorted to alternative feeding methods.

Disability experience

The great majority of the guinea worms emerged at or below the knee, causing painful swellings of the knee and ankle joints as well as secondary infection, and making moving around difficult or impossible. One woman in Kwara who could walk had a very swollen right hand, with four guinea worm lesions, which made it difficult for her to hold her child and to feed herself (food is eaten with the right hand, after the Moslem fashion). Two women in Kwara, and three in Idere had ulcers on the breast which interfered with breast feeding (Table 1).

The duration of incapacity ranged from a few days to 3 months or more; the average being almost 9 weeks. The women had an average of three lesions; four or five at one time were not unusual. New lesions would often appear just as earlier ones were healing, thus extending the period of incapacity. Thirty-seven of the 42 women had had dracunculiasis before, often year after year.

Self care role

Of the maternal functions, self care was the most likely to be neglected as the mothers did not like to ask for help, even if it was available. They did not wash themselves and their clothes if this meant asking someone to fetch water for them. They often ate sparingly because they were nauseated by the guinea worm, or they did not want to spend their limited money on food for themselves. Also, some of the more disabled women were reluctant to eat and drink as they did not want to go out into the bush to defecate. Six of the women were unable to move from the house and others had to ask for help or crawl painfully with the aid of a stick.

The women treated their guinea worm lesions with local palliative oils and herbs. In Moro women often resorted to asking a local man to come and punch the ulcer, just before the worm was due to emerge, with a red-hot metal rod; this was believed to relieve the pressure and encourage the worm to emerge. One woman in Kwara who could walk had a very swollen right hand, with four guinea worm lesions, which made it difficult for her to hold her child and to feed herself (food is eaten with the right hand, after the Moslem fashion). Two women in Kwara, and three in Idere had ulcers on the breast which interfered with breast feeding (Table 1).

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Child care role

Sick mothers gave priority to child care, above all other tasks. Thirty-four of the 42 mothers interviewed needed help in some child care tasks, especially carrying the baby around to provide it with fresh air and human contact. In spite of their belief that breast feeding by sick mothers may transmit disease, all mothers made great efforts to breast feed their babies, even if it was painful and a helper had to hold the baby to the breast. At least 3 mothers were forced to abandon breast feeding, and here the health of the babies suffered severely. One mother who was forced to reduce breast feeding was giving her 14-month old child a chocolate/malt drink. Formula was expensive and a mother with guinea worm was less likely to have the financial resources to purchase it than a healthy mother.

Coping strategies in times of stress

Often epidemiological studies focus on individuals, or on an aggregate of individuals, who are exposed to...
to environmental hazards, rather than on social groups coping in a context of poverty, ineffective government planning, and the economic imperatives of long-term migration [17]. Although the study described in this paper started by looking at individuals, the impact of guinea worm on these women cannot be adequately understood without seeing them as part of the household, lineage and larger community.

The ethic of cooperation which links individuals in the community is primarily based on the extended family, sharing many tasks and obligations but not necessarily sharing monetary resources. The definition of the co-residential extended family or 'household' used in this paper is based on a unit recognized by members of the community. This co-residential unit is generally referred to as an idele in the Kwara State study. In Idere the term idele is the term for the extended family compound of contiguous houses. Such regional contrasts in usage are not unusual among the Yoruba [18].

The family unit is a complex entity focusing on both consumption and production activities; it varies in size and composition in place and time and reflects the fluidity of social groups characterized by high rates of population mobility. The brief working definition of a 'household' as a 'group of people eating from a common pot', which is used in many West African questionnaire surveys and censuses, including the uniform questionnaires used for all the World Bank Agricultural Development Projects in Nigeria [19, 20], may not correspond to any observed reality in a Yoruba setting, or in many other parts of West Africa [21, 22].

Focusing on women, as members of a multi-dimensional, task-oriented extended family group [21], also avoids the often questionable assumption that the 'head of the household' (usually a male), controls the economic activities of the adults in the household. This is clearly not the case in the study area, or, indeed, in many areas of tropical Africa [23, 24].

The resident extended families of the women interviewed in Asa and Moro varied in size from 3 to 23 people. Only 6 idele consisted of a nuclear family—a husband, one wife and their child(ren); 5 comprised three generations, and 6 included more than one brother and his wife or wives. In Idere, the average size of a family unit was 6-8, but this increased at weekends, when traders, and farmers from outlying hamlets, returned. Nine of the 21 women in Kwara, but only 2 in Idere, lived in households with their husband's other wives. Some husbands may have had more wives, but they were not staying in the same extended family compound of contiguous houses.

In both study areas a kinship pattern which is partly bilateral enables a woman to keep in contact with her family of origin while living with her husband's family after marriage. She rarely moves far when she marries and thus she is able to keep in contact with female relatives from her family of origin through visits to periodic markets and family festivals. Women maintain rights in their natal compound after marriage; they may stay there until after the birth of their first child and return when they are widowed.

For the first year after moving to her husband's house, a woman's mother-in-law may cook for her but she later cooks only for her husband and her children. In polygynous families wives cook for their husband in rotation, and may share cooking responsibilities if one of the wives goes to the farm or to a market. Cooperation between co-wives, women and their mothers-in-law, and the wives of husbands' brothers, whether they are members of the same extended family or the larger lineage group, increases efficiency and relieves the tedium of repetitive tasks.

Crisis and cooperation

The helping and coping strategies observed in times of crisis, such as illness, should be seen in the context of continuing mutual cooperation, principally between women, but also between women and their husbands. Women are the main care givers although in emergencies men will help with a wide variety of tasks. In the study areas, mothers, mothers-in-law, co-wives, brothers, wives, and older daughters all contribute when the mother is ill, depending on who is available. Because women move to their husbands' house on marriage, the husband's relatives are usually most accessible. Where possible tasks are shared by helpers; one helps with the care of the child, and the other with domestic tasks, or helpers come to the house at different times of the day.

Yetunde, in Ogun Edun, had had two regular helpers since she was knocked down by guinea worm 6 weeks before. Aya, her husband's junior brother's wife, came from another household in the village early every morning to wash and dress Yetunde's 1-month-old son. Later in the morning, Abike, her senior sister, came from a nearby village to wash the clothes and dishes, cook food and take care of the house. In Idere, Olobunmi's mother and friends helped her to look after the baby and did domestic tasks, and tenants in the house took the baby out for fresh air. Thus, in Idere, where traders and teachers from other towns rent rooms, they, too, can be part of the wider coping network.

In general, a daughter, co-wife or husband's brother's wife, helped with child care, and more distant relatives, or older women such as mothers-in-law helped with domestic tasks. A girl of 6 or 7 or another female relative often carries a young child around on her hip even if the mother is not sick; a young child is never left alone and constant human contact is judged essential for her proper health and development. A daughter of about 10 was considered old enough to wash and dress the baby and feed her, but she was not considered old enough to cook, except for reheating food for her own use. In three cases in Kwara in which a school-aged daughter was the mother's main helper, the girl was kept out of school. In Idere, young girls and boys would not be kept away from school, but would be expected to help with their mother's business by hawking goods after school.

Fathers rarely helped with child care; other than carrying the child around. However, fathers did occasionally help with domestic tasks, especially with

1046

SUSAN E. J. WATTS et al.

In a household, children help with various tasks, often helping with the cooking and washing. Children often help their parents with household chores, such as fetching water, carrying the child around. However, fathers did occasionally help with domestic tasks, especially with

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washing and ironing and cooking, tasks which men often performed for themselves when they or their wives were very busy or travelling. Younger brothers and older sons would also help in these tasks, and in water and firewood collection, tasks which were expected of children of both sexes as soon as they were about 7 yr old.

Economic assistance

In the study areas, husbands and wives usually keep their financial affairs separate. Although the husband is expected to contribute to household expenses and child care, this is usually not enough to meet all the family needs. Women who could not carry on their economic activities because of their illness depended on financial assistance from their husbands, female relatives or neighbors to enable them to buy small daily needs, such as prepared food and soap, for themselves and their children. However, the husbands of 6 of the 21 women in the Kwara study were too sick with guinea worm to work; one husband of an Idere woman also had guinea worm. In one household in Budo Ayan where the 4 younger adults were afflicted with guinea worm, the old father-in-law was the only person able to earn any money and his elderly wife bore most of the domestic burdens.

Economic assistance took the form of loans rather than gifts. In normal circumstance, husbands regularly trade with their wives or pay them for services such as selling the farm crops, and many of them helped to establish their wives as petty traders at the time of their marriage. In spite of the monetary exchange between husbands and female relatives within the household, in no cases was any payment recorded for domestic or child care help during illness.

Women traders, especially those selling manufactured goods in Idere, may work individually and do not always need anyone to help them. They sold in the local periodic markets. One woman in Ogun Edan, immobilized with guinea worm, was sitting on her mat peeling yams. However, her contribution appeared to be minimal and her helpers may well have provided her with a token task in order to make her feel that she could do something for the group.

In both study areas, but more especially in Asa and Moro, the effective coping network often extended beyond the immediate area, to include people who had left to work or trade in towns. A sister was summoned from Lagos to Ogun Edan, in Asa, to help, and one young mother returned from Ilorin with her 2 young children to Ogun Edan and stayed for 3 months with her husband’s parents, leaving her husband in town to look after himself. One mother, who usually lived with her husband in Lagos, was staying with her in-laws in Budo Ayan when she was knocked down with guinea worm; another returned prematurely to Idere when she got guinea worm, being more confident of assistance there than in Lagos.

Some women had very little help. One badly affected mother, Aysatu, in Alassa village, Moro, had no one to help her regularly. She would return home about 100 m from the main settlement with her husband, her 18-month-old son, and 2 older children, a daughter aged 8 and a son aged 10 yr. As her husband and 2 older children were confined to their mats because of guinea worm and could move around only with great difficulty, Aysatu had to cook for the family and look after her baby as best she could. She kept a stick by the side of her mat and crawled painfully around the compound when absolutely necessary. Village women took it in turns to bring firewood and water for the family. Aysatu’s husband’s mother came from Ilorin twice a week and did what she could to help, but she was not very agile and the 50 km journey from Ilorin was tiring and expensive.

In Idere, 4 women complained that no one was around to help them. One woman moved to her parents home when she was laid low by guinea worm; another sent her older children to her parents so she could cope better with the baby and her own needs. One woman was found sitting alone on a mat with her child, as no one would return home from the farm, or from the market until evening. In Idere, in a more urban setting, the smaller resident households, and greater long-term dispersion of the population in farming and trading, severely taxed the coping networks. These networks seemed somewhat less effective in Idere than in the small villages in Asa and Moro, in spite of the smaller proportion of the total population affected by guinea worm.

THE IMPACT OF GUINEA WORM ON THE COMMUNITY

Effective coping strategies may mitigate the impact of guinea worm on the individual and the family, but the social and economic costs are still borne by the community as a whole, as more people will experience some financial losses, and be unable to move around in pursuit of economic gain. Experience in these
and mortality. The maternal roles are interrelated, for one cannot blame all these problems on guinea worm, among the children of afflicted mothers. Although most affected and child care is given priority. Malnutrition of endemic disease in a community.

The pressures of individualism constantly threaten the communal ethic and thus the ability of individuals and communities to protect themselves against the onslaught of the disease. The dispersion of individuals may be increasing as people continue to search for new opportunities in times of economic hardship. Exploratory studies suggest that in Nigeria women and children are the first to suffer in times of austerity [26]. Evidence from Ghana in the early 1980s suggests that at a time of severe recession the extended family is becoming less effective as a coping mechanism and increasingly large numbers of women and children are left to manage on their own [27].

The extended co-residential family or ‘household’ is the primary social unit and basis of cooperation within which women, as care givers, operate. Within the community, women may work together at income-generating tasks, and organize to regulate markets and plan community-based activities. Yet guinea worm clearly saps the economic and social resources which the community needs to mobilize for its control.

Recent studies have shown that protected water supplies, wells and protected ponds supplied by community effort [28, 29], or boreholes provided by government, bilateral or multilateral agencies [10], can reduce the prevalence of guinea worm in highly endemic communities to almost zero within 2 or 3 yr of intervention. In the Idere area, the previously endemic villages of Onileka and Ajelaunwa improved their water supply through self help projects. Even if outside resources were supplied to affected villages, the cost of prevention could be less than the economic cost of the disease itself, in terms of income lost by women alone. Simple technologies like handpumps, hand-dug wells, and water catchment jars can cost as little as $14 per capita [30]; yet 3 women in Idere reported almost $75 in lost income during one attack of guinea worm.

In the study areas, mothers who are, or have been, afflicted with guinea worm recognize that the disease is related to water supply and are anxious to take appropriate action to protect the health of their families. Women, as the main care givers in the community and the people with the primary responsibility for collecting and storing the family drinking water supply, should be actively involved in control campaigns. The strong cooperative ethic among women, which helps them to survive the onslaught of this disease, should be incorporated into strategies designed to prevent guinea worm.
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