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Learning from local knowledge to improve disease surveillance: perceptions of the guinea worm illness experience

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Abstract

Surveillance is an essential tool in any campaign to eradicate disease; guinea worm (dracunculiasis), which is targeted for eradication before the year 2000, is no exception. One criterion of an eradicable disease is that it be easy to recognize as the program advances. Few experts doubt that the experience of a meter-long subcutaneous worm protruding through a painful ulcer can be missed or confused with another disease, thus ensuring that guinea worm meets this criterion. Field experiences of anthropologists and health educators have shown that one should never assume that community perceptions of illness experience coincide fully with medical case definitions of disease. This paper describes efforts to learn how the Yoruba people of southwestern Nigeria perceive *sobia*, the local name for guinea worm. Qualitative methods including informal interview, village discussion and participant observation were used to discern a pattern of illness presentation and progression. Interestingly, local perceptions were found to include a variety of illness manifestations beyond the common clinical case definition of an emergent worm, thus creating the potential for a high level of false positive reports. Local knowledge was then used to design a pilot project that trained volunteers to become part of the surveillance network for the national eradication program. The volunteers, who were largely illiterate, were able to distinguish between cultural and clinical definitions, and submit quite accurate reports on the guinea worm status of their villages. Among the 164 volunteers, only two submitted false reports due to incorrect disease definition. In contrast local government health workers who were conducting village searches during the same period were significantly more likely to register false positive reports. The culturally sensitive training based on local knowledge received by the village volunteers is thought to have contributed to their superior performance.

Introduction

Eradication of disease, i.e. the "total elimination of a disease worldwide" (Mausner and Kramer, 1985), is a concept that has intrigued and challenged public health authorities for over a century, but the potential for eradication did not become reality until quite recently when the global elimination of smallpox was declared in 1978 (WHO, 1989). Experts contend that surveillance activities were the major force behind the elimination of that disease (Henderson, 1987). Lessons about smallpox surveillance are guiding the current global effort to eradicate guinea worm (*Dracunculus medinensis* or dracunculiasis) (Richards and Hopkins, 1989).

This paper describes the grounding of a surveillance program in the local perceptions of the illness experience, a major aspect of a pilot scheme in Ifeloju Local Government, Nigeria, to involve the community in guinea worm surveillance. The approach of learning from local knowledge contrasts

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with the usual development planning efforts that place in opposition traditional culture and modernization (Robertson, 1984).

Nature of the problem

Guinea worm is a waterborne helminthic disease endemic to Africa and south Asia. It has been called a neglected disease of neglected people since it strikes the remote rural populations that have often been passed over by national development efforts (Hopkins, 1983; Paul, 1988), and is thus an indicator for poverty and underdevelopment (Watts, 1986). Another reason for neglect is that guinea worm does not kill. Instead the meter-long subcutaneous parasite disables its victims, most of whom are the food producers for a nation (Ward, 1985).

Guinea worm, often called 'the fiery serpent' (a Biblical reference to this ancient disease), attacks millions annually but could be completely eliminated by the provision of safe drinking water supplies (United Nations Development Program, undated). National eradication programs have been established in India (Sehgal *et al.*, undated; National Institute of Communicable Diseases, 1987), Pakistan (Paul, 1988), Nigeria (Nigerian Guinea Worm Eradication Program, 1989) and Ghana (Centers for Disease Control, 1991) with hopes that the world will be free from this disease before the year 2000 (United Nations Development Program, undated). As a result there has been an increase in information about the extent of the problem. Nigeria reported only 1693 cases in 1980 and none for the next 6 years (Richards and Hopkins, 1989). A dramatic change was visible after active surveillance began with more than 650 000 cases documented in 1988 during the first annual national case search.

The surveillance process

Mausner and Kramer (1985) define surveillance as "the regular collection, summarization, and analysis of data on newly diagnosed cases of any infectious disease for the purpose of identifying high-risk groups in the population, understanding the mode(s) of transmission of the disease, and reducing or eliminating its transmission." This definition implies action with the data being used to 'eliminate' a disease, not just filed for bureaucractic purposes. Speed, accuracy and continuity are important in establishing surveillance as a dynamic system of interchange among planners, implementers and the community (Richards and Hopkins, 1989).

Surveillance can be characterized as either an 'active' or a 'passive' process with the latter being most common and least costly. Passive surveillance is a regular accumulation of data on target problems that filter up through the established reporting mechanisms between different levels of the health system (Mausner and Kramer, 1985). Active surveillance reaches out into the community to determine both presence of disease as well as the demographic characteristics and behaviors of the population (Mausner and Kramer, 1985). While active surveillance provides a more complete and accurate picture of the disease situation in the community, it is more expensive, requiring trained interviewers and transportation (Richards and Hopkins, 1989). This approach can be further divided into comprehensive searches in all potentially affected communities and sample surveys (Richards and Hopkins, 1989).

Active surveillance matches methods with the needs of an eradication program at its particular stage of development (Richards and Hopkins, 1989). Sample surveys can determine the initial importance and extent of a problem (Henderson *et al.*, 1988; Sokal *et al.*, 1988), and gather valuable descriptive data about the persons affected by the problem (Richards and Hopkins, 1989). Qualitative methods are particularly useful for understanding the human behaviors involved in disease transmission (Dunn, 1979), and yield information that can be used to help design surveys and interventions (Coreil *et al.*, 1989).

In the planning phase, a comprehensive case search targets communities for intervention and establishes an accurate baseline (Nigerian Guinea Worm Eradication Programme, 1989; Centers for Disease Control, 1989). During intervention, surveillance provides needed feedback to determine success and to trigger investigation into areas where progress is lacking (Richards and Hopkins, 1989). Finally if the

goal of the program is elimination of the disease, surveillance must be carried out for a predetermined number of years after the last known case to certify that no new cases of the disease are occurring in a country (WHO, 1990).

"Surveillance is not an alternative to properly conducted surveys but rather is a tool for continuous monitoring of changes in health status" (Smith, 1989). Surveillance is a special case of survey research and as such it is necessary to understand some of the problems surveys face in order to design appropriate surveillance methods, especially in developing countries. One major issue is the influence of culture and language on instrument development (Lucas, 1976).

Culture, language and questionnaires

Proper surveillance depends on a case definition of disease that is easy to recognize and free of ambiguities. For example, experts believe that the painful experience of a meter-long subcutaneous guinea worm emerging from a skin ulcer is something that few people will have difficulty in recognizing and recalling (Richards and Hopkins, 1989), but naming this experience in a local language may not be easy. Recent efforts to define the extent of guinea worm in northern Cameroon found the illness being called by two non-specific local terms, *ngoudi* (misery) and *tiga* (worm) (Greer, 1991).

The challenges posed to surveillance activities by folk perceptions of disease are several. Simple direct translation from a national language (e.g. English or French) into a local dialect is fraught with problems. Not only are certain clinical disease entities expressed as several local words, but one local word may denote a disease concept which has broader scope than is clinically accepted. "How do you explain . . . chickenpox versus measles when there is only one general word for 'rash'? The lack of equivalency in type and extent of vocabulary can be a major hurdle in the often very difficult process of translation" (Brownlee, 1978). For example, in Honduras and India mothers often perceive several folk illnesses as having diarrhea-like symptoms (Kendall *et al.*, 1984; Bentley, 1988), and in Nigeria the Yoruba word *iba* can be termed 'malaria' but also includes diseases with jaundice and related symptoms (Ramakrishna *et al.*, 1988–89).

Because of the cultural, logistical and clinical problems associated with accurate surveillance reporting as described above, the US Centers for Disease Control (1989) proposed the following standard guinea worm case definition for surveillance activities, which was adopted internationally:

> A case of dracunculiasis is defined as a person exhibiting or having a history of a skin lesion with emergence of a guinea worm (the parasite *Dracunculus medinensis*).

As was found in Ifeloju, even this seemingly simple and straightforward definition is not without its problems.

Methods of study

The overall pilot study in Ifeloju was a test of the validity of using local village volunteers to report disease occurrence whenever they attended the local farm markets. The market was seen as a convenient central communication point in contrast to more ambitious and costly data gathering alternatives like monthly visits by health staff to all endemic villages. The project utilized both ethnographic and epidemiological methods to study four issues. In the formative stage of the project, qualitative methods helped determine (1) local perceptions of the guinea worm illness experience and (2) organization of the local market system. During implementation, quantitative methods measured (3) the accuracy of the volunteer reporting system and (4) reporter attendance behavior. This paper focuses on the first area of study and its subsequent relation to the accuracy of reports.

The relatively short start-up time frame of the project (August and September 1990), simulated the real time constraints local planners may face in setting up a surveillance system between transmission periods. Thus there was need for focused ethnographic study, frequently known as 'rapid assessment procedures' (Scrimshaw and Hurtado, 1987). The term focused is preferred here, as rapid can imply methodological laxity. A traditional ethnography, i.e. the full study of a culture, may take years. Focused

or 'rapid' inquiry looks in depth at one main feature of a culture, while keeping an eye out for how that feature fits into the overall cultural milieu.

The concept of theoretical sampling (Glaser and Strauss, 1967) undergirds the qualitative activities in this study. Emphasis is on theory building, not testing, so the goal is to seek data until no additional different information is observed or obtained. This is known as 'theoretical saturation' where one does not stop interviewing or observing until new ideas cease to emerge. Sampling and analysis proceed together, not in a linear fashion, as the investigator is open to new data. As Mullen (1978) observed,

> In using the grounded theory approach the problem is allowed to emerge from the data and is thus defined by the actors in the situation. This is consistent with the traditional philosophy of health education . . . Thus, an approach which concerns itself with the meanings, definitions, and interpretations which are made by the subjects of the study has greater potential for depicting their world and priorities more accurately than methods which begin by preconceiving that world and its meaning. And it is this which helps practitioners to see an ill person's or community's situation holistically.

Theoretical sampling, which aims to discover concepts and categories and their inter-relationships, differs from statistical sampling, which tries to obtain accurate evidence on the distributions among categories (Mullen, 1978). Each approach has its critics, but the best solution is to recognize the strengths and purposes of each, and use them appropriately, and if possible, in combination. The results of a well designed sample survey often yield deceptively accurate frequency data, but if the basic concepts around which inquiry is formulated do not match the perceptions of the community, the findings may be reliable, but not valid. Thus qualitative or grounded field work can be used to learn how the community defines the issue under study and to provide a valid basis for the concepts or categories used in a formal sample survey questionnaire (Ramakrishna and Brieger, 1987).

Basic anthropological methods are used in focused ethnographic study. In this case they include formal and informal interviews, key information interviews, conversation, careful observation, participant observation, and group interview (Scrimshaw and Hurtado, 1987). All data acquired were scrupulously recorded in notebooks or diaries throughout the 6 months of field work and formed the basic records of the research.

The focused study on guinea worm illness perceptions was used to design the training of the village volunteer. Data gathering began in the four markets with discussions with the chief of the market, known as *Baba Oja* (father of the market), together with his council of 5–10 elder males. They provided descriptions of their own experience of guinea worm, and permitted the researcher and field assistants to conduct further interviews among market attenders.

Initial market based interviews were aimed at learning more about the organization of the markets, and thus interviews were conducted with both male and female hamlet members, transporters who carried goods and sellers from the hamlets and external traders who came to buy produce or sell consumer items. Interviews that were more focused on guinea worm followed the hamlet based group discussions as described below.

The *Baba Oja* were also helpful in identifying the surrounding *abule* (farm hamlets) that patronized the market. Each *abule* (164 in the study area) was visited. These averaged 12.5 huts and approximately 90 residents each. In each hamlet, the chief (*Baale*) was interviewed, after which he called together the residents for a village meeting. Attempt was made to include all available adults, male and female. One field assistant led the discussion while the other served as recorder. The nature of the project was explained. Residents were asked to share their experiences with guinea worm, noting how they recognized the illness and its natural progression.

Although these discussion groups cannot formally be called 'focus group interviews' because the members are well acquainted with each other, many of the procedures and concepts of focused group discussion were employed (Krueger, 1988). With the hamlets themselves being small, the number of adults available to participate in discussion was usually small, thereby allowing input from all. A prepared

list of focused, but open ended questions encouraged participants to share their own perceptions. The field worker who led discussion encouraged all to speak. Interaction occurred when one person explained her bout with guinea worm and others became eager to share their own experiences.

Also at the village meetings, residents were encouraged to select their volunteer to report guinea worm cases. It was suggested that they chose someone who would attend market regularly so that the person would be reliable and not find the duty to be an imposition. The local term used for these volunteers was *asoju* or representative.

Data analysis

Analysis of qualitative group interviews should begin "by going back to the intent of the study", and if the purpose of the study is narrow, an elaborate analysis is inappropriate (Krueger, 1988). In this case the purpose was clearly to elucidate the local perceptions of the presentation and progression of the guinea worm illness experience. Even though the data are qualitative, the process of analysis must still be systematic and verifiable (Krueger, 1988). In this case the process began by reviewing the interview experiences with the field workers who facilitated and recorded the discussion to obtain their views on factors that animated or inhibited discussion.

More detailed analysis began with the researcher reading the minutes of the village meeting. During the first reading notes were made of major concepts. A second reading utilized a system of 'open coding' (Mullen, 1985–86), where specific symptoms and broader illness processes were underlined using different colors. Next, the symptoms and descriptions of guinea worm experiences were collated into a master list. A re-reading of the texts was done to discern patterns in the ordering and clustering of symptoms to learn about the locally perceived presentation and progression of the disease. The ultimate goal was to find the 'big ideas' (Krueger, 1988) that emerge from the collective views of hamlet residents.

The information from these meetings stimulated follow-up questions, which were asked during more focused interviews at market. In this way it was possible to link guinea worm with general concepts of how the body falls ill or keeps well. Effort was made to identify traditional healers, who frequent the markets to sell their herbal powders, to learn if their recognition of different phases of the illness corresponded with community perceptions. The final description of guinea worm case progression from the Yoruba perspective was written up by the researcher and then read by field staff to determine whether it was a valid representation of what they had heard during their investigations.

Qualitative methods were continually employed even during the reporting phase to monitor project implementation activities and problems as well as to enhance preliminary data about illness perceptions. Whenever reporting mistakes were made, the field assistants interviewed the village volunteer and other village members to determine why the mistake had occurred.

Description of the study community

Ifeloju Local Government Area (LGA) is located in the southwestern-most corner of Oyo State, Nigeria. Nigeria, the most populous nation in sub-Saharan Africa (over 100 million inhabitants), is also one of the richest, deriving its wealth from oil, cocoa, palm products and groundnuts. Nigeria is also the most highly endemic country for guinea worm in the world (WHO, 1989), lying in the middle of the African 'guinea worm belt' (Watts, 1987).

The Ifeloju lies approximately 100 km from Ibadan, the state capital, and contains some 150 000 people, divided among five major towns and 300 scattered farm hamlets. Ifeloju has reported the most guinea worm cases in Oyo State during the past three national case searches ranging from 0.3 to 4.0% annual prevalence in the town, while up to one-third of hamlets are affected (according to unpublished results of the national case search covering the 1989–90 transmission period).

Pipe-borne water from a reservoir was installed in Igbo-Ora and Idere towns in 1968; however, by the mid-1970s service to Idere was intermittent or non-existent. This was responsible for the dramatic upsurge in guinea worm prevalence in Idere to over

40% of the 1980–81 dry season (Adeniyi and Brieger, 1983). Currently virtually no piped water reaches Idere and service to Igbo-Ora is sporadic. A few government borehole wells have been sunk with little success, but no hamlets have ever been served by reliable safe water sources except through their own hand-dug wells. Generally people rely on ponds, streams, rivers and rainwater.

A variety of formal health services exist including local government maternity centers and dispensaries, a general hospital and several private clinics; however, when it comes to guinea worm, few sufferers take advantage of the services. A study in the Idere community found that less than 3% of people who had guinea worm presented at the dispensary or hospital. Most relied on home remedies because people did not believe that Western medicine was effective in treating *sobia* (Ramakrishna *et al.*, 1985–86). This experience reinforces the need to undertake active surveillance in the case of guinea worm instead of relying on passive reports from clinics.

Efforts to provide more comprehensive primary care to the hamlets began in 1978 under the guidance of faculty, staff and students from the University of Ibadan (Akpovi *et al.*, 1981). An initial training targeted volunteers from 10 hamlets associated with the town of Idere and included an emphasis on involving the community in guinea worm control, which was one of the community's strongly felt needs. Expansion of the training in 1983–84 eventually reached 29 of Idere's 40 hamlets. The present study built on these primary care and community involvement approaches.

Results: a local case definition

Although *sobia* is the guinea worm according to the Yoruba farmers of Ifeloju LGA, it does not present in the simple form described in Western clinical definitions. The classical progression from a localized swelling, formation of a blister, bursting of the blister (usually on contact with water), to the emergence of a white thread-like worm is present, but the Yoruba embellish these symptoms and recognize other symptoms that project the onset of illness months or even years prior to the relatively short period when guinea worm disease becomes a visible skin lesion.

Through the variety of personal experiences narrated during interviews it was possible to distinguish five usually sequential, but often independent, phases in illness progression. Villagers clearly believe that *sobia* is active within a person when any of these stages are present. The stages, as shown in Figure 1, begin with (1) a generalized or systemic phase and progress to (2) localized pre-swelling symptoms, (3) local swelling at any point on the body, (4) the emergent phase and (5) post-emergence with disability.

Ideas of causation

The credibility of these phases is based largely on the local notion of 'cause'. *Sobia* is considered to be naturally inside the body residing in the *isan* (tendons and veins) (Ramakrishna *et al.*, 1985–86; Ogunniyi and Amole, 1990). The normally dormant *sobia* can be dislodged by a number of factors including 'weak' or 'bad' blood, eating a food that is 'toxic' to the *sobia*, the 'smell' of an emergent *sobia* on another person or the work of *Soponna*, the Yoruba divinity who represents the wrath of the Supreme Being and causes rash-like afflictions (Idowu, 1962).

The *Baba Oja* at Konko Market explained:

> If you have *egbesin sobia* (rashes), then surely you will have guinea worm. You can treat the rashes with ashes or alcohol, but this will not prevent the worm from coming out. If you do not have the rashes, then the only alternative is *sobia awoka* (guinea worm pains that move). *Sobia* comes out when it is ready to die. *Sobia* is present in any human body. Anyone who has blood must have guinea worm, but it is unpredictable when the worm will come out.

Since a person always has the worm in his body, he can experience the expanded range of guinea worm symptoms at any time. Once the worm becomes loose, people reason that it can travel all around the body, since the veins and tendons which house the worm are all over. Any place where the

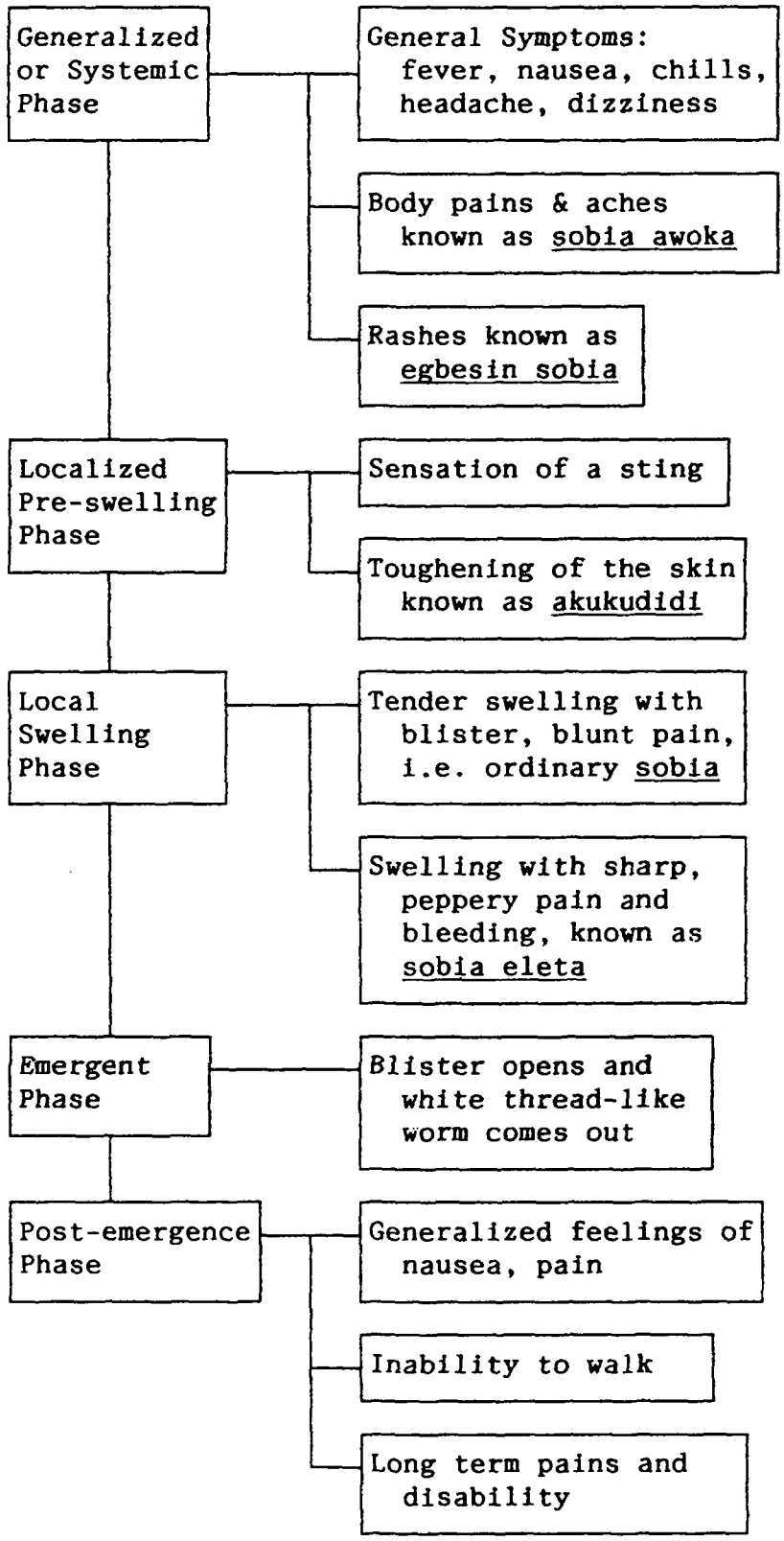

Fig. 1. Yoruba perceptions of guinea worm illness progression.

isan come together in a bunch is a place where the worm can be stopped. Hence swelling will start, and the worm may come out.

People in Alabi were often heard to say, "*Ti ounje ba koro fun sobia, sobia yoo jade*". That is, "If the food we eat is bitter (toxic) for guinea worm, the worm will come out". This occurs when a person eats a less than optimum diet (see Brieger, 1985, on the traditional Yoruba food groups and diet), e.g. monotonous meals of a single starch staple and few ingredients in the stew, a common problem for farmers during times of economic hardship.

There is never talk of preventing guinea worm *per se*. Some elderly people report taking traditional medicine that prevents the worm from coming out, but they add that the worm is still inside causing pain to the body.

Farmers at market narrate a variety of experiences with *sobia*. One young man said, "I am a good one to talk to about guinea worm. I am a man of *sobia*. It used to come out, but now it still troubles me here (pointing to his left side). The pain makes it difficult to breathe. Then it moves causing pain here (pointing to his right shoulder)." One elderly man in the *Baba Oja* council in Alagba complained, "*Sobia* is all over my body, and particularly here (pointing to a knot on his upper arm)." A second man added, "I had itching on this (right) side. I scratched it, and after some time a guinea worm came out. At times the worm will be moving around inside my body for years, and may not come out, but just gives pain."

The reason why some people experience *sobia* and others do not is due to individual 'nature', as expressed in the proverb, "*ara o ni kalu ku yato si ra won*" (the body, *ara*, of each person is different), but more precisely people talk about the 'blood' of each person being different. The 'strength' of one's blood determines degree of susceptibility to disease and a person's temperament. The consensus of opinion from the numerous individual and group interviews is that if the worm is going to come out, it inevitably will.

Generalized phase

Three groups of symptoms are experienced at the generalized or systemic phase. Even though no worm is seen at this point, persons experiencing the symptoms are convinced that *sobia* is acting up in their bodies. The generalized phase can be divided into three subgroups of symptoms, (1) general symptoms, (2) aches and pains, and (3) rashes.

(1) *General symptoms* include fever, coldness, dizziness, headache, nausea, vomiting, stomach discomfort, weakness, sleeplessness and bitter taste in the mouth. These may persist for days or weeks until the next phase develops, but some people describe a quick 'knock down', where they feel healthy one day, then become too weak to walk the next, followed immediately by local swelling.

(2) *Body aches and pains* may appear separately or in conjunction with the above symptoms. Such pains characteristically last several weeks or months and may or may not be followed by subsequent phases. People distinguish the pain caused by *sobia* and the pains of arthritis and rheumatism, known as *lakuregbe*. The body pains of *sobia* are distinguished by the sensation that the worm and the pain is moving around. Thus this stage of the disease is called *sobia awoka*, since *awoka* describes the slithering movement of a snake. *Awoka* can come and go for years, producing no visible worm, and yet those who suffer have no doubt that guinea worm is the cause. Once people knew that the research team was at market, a steady stream of complainers approached the staff to present various shoulder, back, leg and general pains that were said to be *sobia*.

(3) *Rashes and itching* are supposed to herald the onset of emergent guinea worm. These raised spots (up to 5 mm in diameter) cover the entire body and are called *egbesin sobia*. They are said to last anywhere from a few hours to a few days. Within hours or days of their subsiding, the next phase of the illness will likely, but not necessarily occur.

During village visits in late August, the research team observed a man in Elegun hamlet with such rashes, and all villagers were certain that the man, who had never suffered from guinea worm before, would soon come down with the illness. The rashes

lasted a couple of days, but no further progress was seen until the rashes reappeared 6 weeks later. Again the rashes subsided and until March no guinea worm ever emerged.

Even then the man was certain that he would have *sobia* sooner or later and said, "The rashes will last for a day or two, then the swelling will start at one spot, but not everyone who has rashes will have guinea worm right away." He explained that *egbesin sobia* was different from the itching that accompanies *Narun* (onchocerciasis). "*Narun* itches in one spot, and the area will turn black when you scratch it."

Localized pre-swelling phase

Sobia may progress from Phase 1 to Phase 2, skip Phase 2 or even begin at Phase 2, according to descriptions of actual experiences. One of the first localized symptoms is the feeling of a sting or bite as from a bee or scorpion. Others describe it as being stuck by a pin. The area begins to itch and scratching leads to the next phase (local swelling). Guinea worm is said to be capable of emerging anywhere on the body, thus the 'sting' may occur from head to toe.

Another localized symptom that may later lead to swelling is called *akukudidi*. It is described variously as a thickening or toughening of the skin at a spot. The skin may also have the appearance of having been burnt. One man said that this symptom may also indicate that the worm has died under the patch of skin, implying that this symptom can exist, and be attributed to guinea worm, without a worm ever emerging. A similar symptom, 'hardening of veins' in one place, was mentioned by another villager.

Local swelling phase

Localized swelling may occur after either, both or neither of the above phases. At this point guinea worm dichotomizes into the more common *sobia* and the less frequent *sobia eleta*. These are distinguished by type of pain. The former feels as though the spot had been hit by a blunt object, while the latter gives the sensation of pepper (*ata*) being rubbed into a wound. Regular *sobia* yields the white thread-like worm, while worm rarely emerges from *sobia eleta*. Instead there is bleeding from the swelling or blister. *Sobia eleta* is said to be so painful that the sufferer is reluctant to move at all.

The swelling for regular *sobia* is said to develop over several (3–5) days or even weeks (2–4) and feels tender. People say that part of the swelling becomes soft, a possible reference to blister formation. Some people pick at the blister and fluid or pus may come out.

It is still possible for the illness process to become static or even reverse at this late stage without a worm ever being seen. Swellings of months and years duration have been shown by villagers who are certain that *sobia* is inside.

Emergent phase

People clearly describe guinea worm at this stage as a white thread-like worm that emerges from the sore on the swelling, especially when this comes in contact with water. There are reports that the worm may withdraw soon after emergence, only to come out a few days later at the same spot or even create a new ulcer nearby. This withdrawal of the worm is one reason people fear having the ulcer dressed and bandaged, since they believe that the covered worm will become angry and 'fight' the body while looking for a new place to emerge (Ramakrishna *et al.*, 1985–86).

Examples of 'surgical' emergence were given during village discussion. One occurred when a swelling on the groin was operated on in hospital as a suspected hernia, only to reveal a pocket of pus and a guinea worm. Another person described a swelling on his leg that never opened, so another man cut it with a razor blade and found a guinea worm inside. These reports are in keeping with actual experience at the Igbo-Ora Hospital where, according to the former Chief Medical Officer, guinea worms have been removed from cysts on the knee, elbow and wrist that had been troubling the patient for months. Such experiences reinforce local beliefs about the permanent presence of *sobia* in the body.

Post-emergence phase

People say it takes weeks or months before they are relieved of the worm once it emerges. They mention that any or all of the general symptoms described under Phase 1 may return, especially nausea. The victim may not be able to walk, lose appetite and feel great pain. Eventually the worm works its way

out whole or in pieces with pus. A few people talked about the worm going back inside even at this stage and giving them body pain ever since.

Other long-term consequences of *sobia* are mentioned. One man complained that his leg has remained swollen and does not function well since his last attack of *sobia*. A woman said she is now weak after her attack and cannot carry heavy loads any more.

Traditional medicine

Given an attitude of inevitability and irreversibility, it is not surprising that most actions taken at various stages of the illness are palliative. For example ashes, alcohol, salt or shea butter are said to make the rashes of *egbesin sobia* go, but do not prevent continued progression. One woman noted, "Once you have *egbesin sobia*, you cannot prevent the worm from coming out. Nothing can prevent guinea worm from coming out. We can only use medicine when it is already out." Various powders and oils are rubbed on to give relief from the symptoms of *sobia awoka*. The oils and herbs used for home treatment of active guinea worm have been described elsewhere (Ramakrishna *et al.*, 1985–86). The function of these is to soothe the painful area (oils) and encourage early expulsion of the worm (smelly herbs).

Though few people talk of a complete cure, three different men interviewed at market talked of personal experience of medicines which they had purchased in another town that had prevented any re-emergence of their own guinea worm. None of the three men would divulge further information without payment.

Some use of modern medicine and chemicals was mentioned. A man from Idifa Hamlet reported taking Ambilhar (niridazole) to treat guinea worm, which was giving him 'stomach trouble'. Ambilhar is an anthelminthic drug sometimes used by health workers for guinea worm and (formerly) for schistosomiasis. Some Ifeloju farmers produce cocoa and a strong pesticide used on the trees, Gamalin 20, was reportedly applied on the ulcer to kill the visible guinea worm so it would not re-enter the body and cause *awoka*.

From the above, the exception appears to prove the rule. Most people feel that guinea worm is neither preventable nor curable since it is always in the body. The few people that talk of a cure are so secretive about the medicine that one wonders about the validity of their claim. Surely a medicine that cures would be highly profitable in Ifeloju.

Application to training volunteers

The need to show respect for local beliefs was the guiding principle in designing the orientation session for the volunteer village reporters in the market based case detection project. By being aware of and addressing directly the traditional perceptions of case recognition, the trainers were attempting to help the participants identify those aspects of their own beliefs that were relevant to surveillance requirements and thereby avoid false positive reports.

A participatory approach to training was used to encourage the trainees to share their own ideas and discuss together with the trainer the implications of these ideas. A small pamphlet with hand drawn pictures was distributed that depicted both clinical and traditional aspects of case presentation.

The training began with brain storming all the signs and symptoms by which one can know if a person is suffering from guinea worm. All of the phases and concepts documented during village discussions came to the fore. The participants enjoyed the process and talked freely about personal examples. The trainer then referred them to a page in the pamphlet that depicted *egbesin sobia* and a simple swelling. He asked one literate participant to read the Yoruba language caption that listed additional symptoms such as fever, pains and aches. The participants were happy to see their own ideas depicted. One trainee commented, "This is exactly what we have been saying."

The next page showed the classical case definition, a woman with a worm emerging from a swelling on her leg. After looking at and reading this page, participants agreed that this too was an obvious case of guinea worm. From this point the trainer began the process of distinguishing the various forms of the illness, saying that the research team was most

interested in the form of guinea worm that actually emerges because this is when "*sobia* is most dangerous to the community at large", and the time when it is possible to provide some palliative treatment and measures to prevent disabling secondary infections.

Surveillance reports

The volunteer *asoju* got the message. During subsequent weekly reports at market they themselves were careful to distinguish among the forms of *sobia* when telling the field workers what was happening in their hamlets. "There is no case of guinea worm in our hamlet this week, but two people complained of aches and pains." "I have not seen anyone with guinea worm yet, but one young boy has developed a swelling on his leg."

Weekly reports were received from the *asoju* from early October 1990 through mid February 1991. The goal of reporting was continous provision of correct and timely information on the guinea worm status of the *abule*, the study unit. All positive reports were followed up by field workers within 3 days. All hamlets with negative reports were visited after every four report periods. During the study 54 positive reports were received from the *asoju*, 92.6% of which were correct. Thirteen hamlets were verified by the field workers as having had a case of guinea worm that should have been reported. Thus out of 63 hamlets with verified cases of guinea worm, 79.4% were correctly reported. Likewise, of the 101 negative hamlets, 96% were correctly reported as having had no cases by *asoju* throughout the period. In sum, 17 (10.4%) hamlets were incorrectly identified.

Only two of the four false positive reports were due to incorrect case definition. In both instances the suspected patient had localized swelling. The other two false positive reports were actual cases, but the sufferers were non-residents of the hamlet. When the reporters in these two hamlets were absent, the persons designated by them to make the weekly report mentioned their affected relatives living in one of the main towns in the hope that these people might receive assistance from the project. The problem was uncovered when the field workers visited the hamlets and could not trace the names listed.

The traditional, broad case definition of guinea worm implied a greater likelihood of false positive reports, but this was not the case. Instead false negative reports dominated the mistakes. It was assumed initially that false negative reporting would occur because of negligence. Therefore the orientation pamphlet emphasized the need to check everyone—men, women, children, farm laborers—in the village prior to report day. This assumption, in fact, proved to be the case.

Comparison with the national search

In late November 1990, the Nigerian Guinea Worm Eradication Programme (NIGEP) conducted its third annual national case search to determine cases for the 1989–90 transmission season. The researcher was involved in supervision of this effort locally, thus enabling comparisons in terms of organization and accuracy between the two surveillance activities. Three major problems were observed with the NIGEP search: a greater number of false positive designations, an inadequate list of hamlets and a poor attitude toward the community. The first issue is of prime concern here.

Local government health staff and a few school teachers were used as enumerators for the 2 week exercise. They attended an orientation session in Ibadan, which the researcher observed. As in previous national searches, enumerators were to ask villagers about both cases that had occurred in the last season as well as current cases or 'cases now'. The Oyo State Ministry of Health staff who co-ordinated the search and ran the orientation stressed the need for accurate reporting, and gave each enumerator a case recognition photograph to use in the field. In particular one of the supervisors cautioned enumerators to avoid reporting *sobia awoka* as a true case. According to the speaker this had been a serious problem in the previous exercises.

Not all hamlets (about 300) in Ifeloju were visited, but 101 hamlets overlapped with the market based study area. The researcher was able to review the LGA enumerators' reports of 'cases now' and send the project field assistants to verify these. In contrast

to reports from the village volunteers, the positive reports rendered by local government staff were only 67.4% correct. The LGA enumerators identified 88.6% of all the truly positive hamlets and correctly labeled 77.3% of those that were actually negative as having no cases. The volunteer reporters performed significantly better in the accuracy of their positive reports and their ability to label negative hamlets correctly as seen in Table I. Some actual experiences shed light on possible reasons for these problems.

One false positive report came from Baba Olodo hamlet near Alabi Market. The hamlet *asoju* had not reported any current case in that village. The name of the victim was extracated from the NIGEP form and given to the field worker team for Alabi for verification. They discovered that the name listed on the form turned out to be the *Baale*, an elderly man, who had complained of having guinea worm every time the field workers visited the village, but never had an emergent worm. The verification visit was no different. He said he told the enumerators that guinea worm usually troubled him on the ankle, knee or thigh, and that he was having pain and *akukudidi* then, which he believed was guinea worm. No other case was found in the hamlet.

Later at the local government health office, one of the project field workers queried the local government staff about the mistake. She said "Your boss is too tough" concerning case verification. She described the old man in Baba Olod. "He pointed to four swellings and claimed they were guinea worm. He also said guinea worm pains were all over his body. What else could I do but mark him down as a guinea worm case?" The field worker asked her about the case identification photo. She agreed that the case did not resemble the photo, but said she was still uncertain. The field worker suggested, "Mark the correct thing. The old man is not going to read the form anyway."

A second LGA staff member went further to add that she was not sure if guinea worm disease is actually transmitted in water. "It probably comes from too much sun." The field worker warned her not to let anyone in the office hear her saying that and later wondered aloud to the researcher, "How can the case search be correct if the workers themselves do not believe the correct thing about guinea worm?"

A verification visit in Origi hamlet also demonstrated this problem. The form filled by the enumerators listed five current cases in three different huts. A house-to-house check by the field workers located only one current case among the names listed, and the worm had actually erupted well after the date of the enumerators' visit. The time difference was less than a week so there was no chance of other cases healing and disappearing quickly. Similarly in Sangote three cases were listed in three houses. On reaching the *abule*, the project field workers found no emergent guinea worm. One of the supposed cases had swelling only. A regular skin ulcer was found in place of a reported guinea worm in Oyakale and only swelling on the legs of two supposed cases in Kooko.

Table I. *Differences in accuracy between village volunteer and local government staff reports*

Accuracy factor	Reporters		Z value	P value
	Villagers (%)	LGA staff (%)		
Proportion of positive hamlets identified (sensitivity)	79.4	88.8	1.287	>0.19
Proportion of negative hamlets identified (sensitivity)	96.0	77.2	3.417	<0.0007
Proportion of positive reports that are correct (positive predictive value)	92.6	67.4	3.200	<0.0014

Conclusion

Yoruba perceptions of the guinea worm experience in Ifeloju LGA are highly detailed. Some, like circulating pains of several years duration, do not appear to conform with biological knowledge that the worm lives for only a year. In fact, some worms die inside the body, become calcified and cause long-term rheumatic pains, as has been confirmed

clinically in India and the Arabian Peninsula (Reddy and Sivaramapa, 1968; McLaughlin *et al.*, 1984; El Garf, 1985). Discussion with the former Chief Medical Offier at the Igbo-Ora Hospital confirmed these experiences in Ifeloju. He also noted that the rashes (*egbesin sobia*), thought to be associated with pre-emergent guinea worm, may be a normal body reaction to foreign protein. One could conclude that the local people in Ifeloju have a better picture of guinea worm symptoms than clinicians, since they have lived intimately with the disease for so many years.

One reason why the full scope of locally recognized guinea worm symptoms receives little attention from health planners may be the fact the disease is not thought to be of epidemiological significance until a worm emerges and begins to discharge its larvae into local water sources. However, this narrow view makes it difficult for epidemiologists to communicate with local people. In the present study both attention to cultural definitions of guinea worm and interactive training helped the trainees feel comfortable with distinguishing the needs of the surveillance system from their wider understanding of *sobia*. A sense of openness was created, because of the respect shown by the staff and trainers to their cultural and personal experiences with the illness. As a result the volunteers were quite forthcoming with information during the reporting process.

Overall, one can say confidently that volunteer reporters, selected by co-villagers, make fairly accurate observations on the guinea worm status of their hamlets, even though the majority have little or no formal education. They appeared to have a clear sense of purpose and an ability to differentiate the required case definition from the myriad of additional manifestations recognized culturally. This distinguishes them from local government staff.

A question arises as to whether local health staff can undertake the ethnographic study of disease perceptions required for this type of surveillance scheme, or is a professional health educator or anthropologist needed? Orientation of the local staff would be needed. A major component should address attitudes needed to overcome the 'cultural distance' between health worker and community (Green, 1988). It has been the authors' experience that local staff often know more about local beliefs and practices than they are willing to admit. Their Western education and status force them to maintain a dichotomy between those 'ignorant' local people and themselves as professionals.

Practical, guided sessions in the markets could help re-awaken health workers' own dormant local knowledge. The positive response by community members when health workers pay attention to their beliefs and concerns should help reinforce an open, ethnographic approach to planning. More interactive training that allows and encourages questions would help them develop a greater interest in and understanding of the eradication program.

Although the Ifeloju project focused on guinea worm, the process by which local knowledge about illness experience was determined and used to plan a program can be applied to other endemic health problems. This process was not new in Ifeloju as it had been applied in training village health workers to recognize and treat common ailments including malaria, where cultural definitions of illness influenced delay in seeking treatment (Ramakrishna *et al.*, 1988–89), and diarrhea, where oral rehydration therapy was initially rejected because people believed one ingredient, sugar, caused a more severe disease (Brieger *et al.*, 1988). In the current project, it became evident that without attention to case definition, over-reporting and potential waste of program resources could occur.

This project has shown that it is necessary to go beyond collection of data on local perceptions and beliefs. That information must be used in a culturally sensitive way to help government planners and community members arrive at a mutual understanding of the problem. The open and respectful discussion of both local and scientific ideas during the interactive training session made acceptance of different viewpoints easier, and ultimately produced a more accurate surveillance system.

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