

Delay in Presentation in the Context of Local Knowledge and Attitude Towards Leprosy—The Results of Qualitative Fieldwork in Paraguay¹

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ABSTRACT

Objective. The primary objective of our research was to explore help-seeking behavior in the context of knowledge, attitude, and practice as factors contributing to delay in presentation in leprosy. The secondary objective was to demonstrate the value of basic qualitative research methods in this context.

Methodology. Fieldwork was based at the Hospital Mennonita Km 81, the referral center for leprosy services in Paraguay. We adopted exclusively qualitative methods for fieldwork, effectively carrying out a rapid assessment of factors contributing to delay. We relied on multiple sources of information and the use of multiple methods to ensure the validity of our findings.

Results. Our findings linked delay in presentation to traditional beliefs, lack of awareness of the early symptoms of leprosy, stigma, seeking help from natural healers, and to interactions with the health services. Traditional beliefs diminish the importance of the early symptoms of leprosy. Stigma has an impact on decisions to seek help. Natural healers have maintained their traditional status in society; their preferred treatments for leprosy are ineffective. Only rarely do natural healers refer to the health services. Once presented to the health services, some individuals affected by leprosy experienced lengthy delays in diagnosis and start of treatment.

Discussion. To address the traditional values of a society and provide effective public health initiatives is a clearly a major challenge for program organizers and for health education. Increased awareness of leprosy and sensitivity to its social consequences among health service practitioners is a further priority.

RÉSUMÉ

Objectif. L'objectif principal de notre étude était d'explorer le comportement de recherche d'assistance dans le contexte de la connaissance, l'attitude et les pratiques usuelles, comme facteurs contribuant au délai précédant la consultation initiale de lèpre. L'objectif secondaire était de démontrer l'intérêt de développer des méthodes de base de recherche qualitative dans ce contexte.

Méthode. Le travail de terrain a été basé sur l'Hôpital Mennonita Km 81, le centre référant des Services Anti-lèpre au Paraguay. Ce travail de terrain a été effectué en utilisant uniquement des méthodes qualitatives, afin de permettre une évaluation rapide des facteurs contribuant au délai avant consultation. Nous nous sommes basés sur plusieurs sources d'information et l'utilisation de plusieurs méthodes afin d'assurer la validité de nos données.

Résultats. Nos données indiquent que le délai avant consultation initiale est lié aux croyances traditionnelles, au manque d'informations sur les symptômes précoces de lèpre, à la stigmatisation, à l'assistance demandée au guérisseurs, et aux interactions entre les différents services de santé. Les croyances traditionnelles minimisent l'importance des symptômes précoces de la lèpre. La stigmatisation a un impact sur les décisions pour demander de l'aide. Les guérisseurs traditionnels ont conservé leur statut social ; leur traitements contre la lèpre sont inefficaces. Les guérisseurs ne réfèrent que rarement aux services de santé. Une

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fois présentés aux services de santé, certains individus souffrant de lèpre vivent des délais souvent très longs avant le diagnostic et le début du traitement.

Discussion. L'apport de propositions efficaces d'amélioration de la santé publique tout en tenant compte des valeurs traditionnelles d'une société est clairement un challenge pour les organisateurs du programme et pour l'éducation sanitaire. Une meilleure prise de conscience de l'importance de la lèpre et de ses conséquences sociales est également une priorité pour les professionnels de santé.

RESUMEN

Objetivo. El objetivo principal del estudio fue el explorar los factores que contribuyen al retardo en la presentación de los casos de lepra. El segundo objetivo fue el demostrar el valor de métodos cualitativos básicos aplicados en este contexto

Metodología. El trabajo de campo tuvo como base el Hospital Mennonita Km 81, el cual es el centro de concentración de los servicios de la lepra en Paraguay. Adoptamos métodos exclusivamente cualitativos tratando de establecer de manera efectiva una rápida valoración de los factores que contribuyen al retardo en la presentación de los casos. Nos basamos en muchas fuentes de información y en el uso de varios métodos para asegurar la validez de nuestros hallazgos.

Resultados. Nuestros hallazgos asociaron el retardo en la presentación de los casos con las creencias tradicionales, la falla en la observación de los síntomas tempranos de la lepra, el estigma, el tratamiento con remedios naturistas, y las deficientes interacciones con los servicios de salud. Las creencias tradicionales reducen considerablemente la importancia de los síntomas tempranos de la lepra. El estigma tiene impacto sobre las decisiones para buscar la salud. Los remedios naturistas han mantenido su estatus tradicional en la sociedad pero no han sido efectivos contra la lepra. Raramente los remedios naturistas y quienes los proveen tienen que ver con los servicios de salud. Una vez que se presentan en los servicios de salud, algunos de los pacientes experimentan largos retardos en el diagnóstico de la enfermedad y en el inicio de su tratamiento.

Discusión. Tocar los valores tradicionales de la sociedad y al mismo tiempo proporcionar iniciativas efectivas de salud pública, es todo un reto para los organizadores de los programas de salud y de educación de la salud. El mayor y mejor conocimiento de la enfermedad y sus consecuencias sociales entre los trabajadores de los servicios de la salud es así una necesidad preponderante.

The purpose of our research in Paraguay was to explore help-seeking behavior and the context of knowledge, attitude, and practice as factors contributing to delay in presentation in leprosy. In many leprosy-endemic countries, people remain unaware of the significance of the early symptoms of leprosy and of the importance of early diagnosis and treatment⁽²¹⁾. When people do recognize the possibility of leprosy, they are subject to the traditional fears and stigma associated with the disease⁽⁴⁾. Although multi-drug therapy (MDT) is well established as the effective cure and is widely available, an important minority of patients continue to delay in presentation. Those who delay have an increased risk of nerve involvement⁽²³⁾ or disability^(8, 16, 24, 26, 29, 31). Those with active disease continue as a source of infection, threatening progress towards the goal of elimination⁽³⁰⁾. In contrast, the acute symptoms of reaction en-

courage early presentation⁽¹⁰⁾. As the recognized indicator of progress towards leprosy control⁽²⁹⁾, the WHO Grade 2 disability rate is used as a proxy measure for delay in presentation. While it is apparent from the annual statistics published by the International Federation of Anti-Leprosy Associations (ILEP) that substantial progress has been made in reducing this rate⁽¹⁾ and also reducing delays in presentation, it is also the case that there are important differences between and within countries and even within individual locations.

From their work in China, Chen, *et al.*⁽⁶⁾ reported that delay in presentation had decreased steadily over 20 years but was greater among MB cases, among farmers rather than factory workers, and among some ethnic, economic, or demographic groups. Anthropological studies provide insights into factors that may contribute to such differences. Bainson and van den Borne⁽⁴⁾

wrote that every society considers health and disease, life and death in different ways, resulting in widely varying attitudes toward specific diseases. In communities where leprosy is endemic, traditional beliefs may persist^(2, 18, 20), with leprosy recognized only as a series of acute and unrelated disorders⁽²⁸⁾. There may be a continuing reliance on alternative or traditional medicines⁽¹³⁾. Normal behavior may be for people to present to health services only after traditional methods have failed^(18, 19). Decisions to seek help may be the domain of a single authority individual or of the family as a whole⁽¹⁸⁾. Some individuals may be unable to seek help because of their low status and exclusion from decision-making⁽¹⁷⁾. In some cultures, gender issues may further contribute to delay^(12, 21). This context also has an impact on interactions with local health services. People may remain unaware of the services offered^(5, 22). Poor compliance may be common^(7, 11, 14). People do not always respond to seemingly well-organized public health initiatives⁽²⁰⁾.

The impact of stigmatizing attitudes has also been reported. Stigma can be a barrier to help-seeking behavior due to personal shame or fears of the negative attitudes of health workers^(3, 17). It can affect all aspects of leprosy control and is a threat to achieving the goal of elimination⁽⁴⁾. Lever, *et al.* note that the delay in disabled new cases studied in Ethiopia related to the level of stigma in the community⁽¹⁵⁾.

Van der Weg, *et al.*⁽²⁷⁾ recognized that these many factors result in highly localized and personalized help-seeking behavior, and a variety of routes taken by people as they finally make the decision to present and start treatment. This was the starting point for the present research. The primary objective was to explore help-seeking behavior in the context of local knowledge, attitudes, and practices as risk factors for delay in presentation. The secondary objective was to demonstrate the value of basic qualitative research methods in such a context.

The Paraguay leprosy control program organized from Hospital Mennonita is linked to government health services throughout Paraguay, but concentrated on the eastern region of the country inhabited by 96% of the population. The main referral hospital is centrally situated and provides

inpatient and outpatient services. Dedicated leprosy outpatient clinics are held in some 50 government-run rural and urban health centers. The number of new cases reported in 2000–2001 was 427. The prevalence rate was 1.1 per 10,000 population and reached the elimination threshold in 2001. While the reported grade 2 level is very low (1%), 30% of new cases report with grade 1 disability, suggesting that a substantial minority of patients are at risk of significant impairment. Paraguay may be considered typical of many countries where leprosy is on the point of elimination, and where general health services are taking increasing responsibility for delivery of leprosy services. The rural economy is primarily oriented to agriculture. In both rural and urban areas the homes and quality of life of the rich minority are in marked contrast to that of the poor majority. The latter live in small and crowded single-room dwellings built with wood. Some houses have roofing of cement sheet, others have a straw roof. Most have electricity and running water but bathrooms and sanitary arrangements are basic. Around 80% of the poorer segment of the population are literate, with elementary education up to class 6. In rural areas people earn their living through small scale farming and keeping livestock.

METHODOLOGY

In planning our research in Paraguay, we set out to demonstrate the value of chosen methods of social research in providing reliable information with minimum commitment of specialist skills and time. Our approach was participatory, drawing on locally available knowledge and skills. We planned to complete fieldwork within a self-imposed limit of 2 months. This approach is similar to that used in the planning and evaluation of health-related programs⁽²⁵⁾, effectively a rapid assessment using qualitative methods. Since the objective was to identify factors contributing to delay in presentation it might also be considered part of an evaluation process, producing limited data to support a problem-solving process relating to delay.

To produce reliable results, our chosen approach requires the validation of findings using a variety of sources and methods. We therefore identified potential sources of in-

formation as patients currently receiving MDT, hospital and field staff, and community representatives including schoolteachers, pastors, political leaders, and natural healers. We identified semi-structured interviews, focus groups, observation, and free-listing (°) as appropriate methods for fieldwork. Our matching of methods to sources was governed by the limited time available and was largely opportunistic. The self-imposed time constraint meant we were unable to select and interview patients from among all those currently registered. Specific fieldwork activities and the time committed to each were as follows:

- A first series of semi-structured interviews of in-patients and out-patients at the main referral hospital. (20 working days, 36 interviews).
- Semi-structured interview with senior staff, focus groups and free-listing exercise with hospital and clinic staff. (One day).
- Semi-structured interviews with pastors in towns within 50 kilometers of Hospital Mennonita. Focus group discussion with the 20 staff members of a school. Semi-structured interview with a natural healer and with a local political leader. (Total one day).
- A second series of semi-structured interviews with patients currently receiving MDT. The interviews were held in leprosy clinics run from government sub-centers across the eastern part of Paraguay, three located in rural areas and one on the outskirts of a large city. We also had the opportunity to observe the impact of the leprosy diagnosis on 2 new patients. (15 interviews, 5 days).

Each of the interviews in the second series began by asking the patient to describe the series of actions taken in response to their symptoms. The remainder of the interview focused on: (a) practices relating to health and help-seeking, (b) knowledge and awareness of leprosy, (c) routes to presentation, and (d) the impact of leprosy on those affected. Finally, (e) we asked each patient to identify their main reason for delay.

In interviews with community representatives and group work with teachers, we began by asking for a description of the problems associated with leprosy and then

moved on to the same five areas of questioning listed above.

In the free-listing exercise we asked staff to respond to a series of open-ended sentences designed to explore their understanding of how people responded to leprosy. These included, "For me to suspect I may have leprosy means. . . ."; "For me to be diagnosed with leprosy means. . . ."; "For me, the main reasons I delayed in starting treatment were. . . ." Individual responses were prioritized and explored through group discussion.

Fieldwork was led by local staff using Guarani, Spanish, or Portuguese language, as appropriate. Group work with staff was conducted in German. English translation was provided in each case.

We were aware that some patients would find it difficult to describe potentially traumatic experiences of which they may never have spoken before. We ensured that patients were willing to participate in the interviews, ensured privacy, and provided care where it was needed.

Written summaries of interview and group work were collated and subjected to a qualitative analysis procedure involving successive readings of the data and preparation of a summary in which we recorded key words, quotations, categories, and themes. A final reading of the data ensured that nothing had been missed. Using the five headings above, we drew together the information from each source and prepared the present report. Quotations not otherwise attributed come from the second series of interviews. Where statistical tests of significance were appropriate we used non-parametric tests.

RESULTS

Study cohorts and delay in presentation. The first series of interviews provided quantitative information about 24 men and 12 women receiving MDT. Mean age was 47 yrs, mean delay 47 months, and median delay 24 months. Mean delay for men was three times that for women (61 months compared to 19 months, $p < 0.05$). Mean delay among those aged over 45 yrs was 64 months, compared with a mean of 30 months for the younger age group ($p < 0.05$). Mean delays by WHO gradings 0, 1, and 2 were 16, 57, and 82 months, respectively ($p < 0.01$).

In the second, more detailed series of interviews, there were 8 men and 7 women from Spanish, Guarani, and Portuguese-speaking communities. Six individuals were aged 35 or less. Using an estimate based on total time committed to help-seeking actions, we found delays ranged from around 6 months up to 15 yrs, with a mean of the order of 48 months and a median of 36 months. Seven individuals had grade 2 disability, 1 had grade 1 disability, and 7 had no disability.

Health beliefs and help-seeking behavior. Traditional belief in Paraguay is that significant disease is always accompanied by pain. A disease that does not cause pain is considered unimportant. Of those interviewed, one young man said he felt no pain so did not seek treatment. An older man said he only decided to do something when he got pain. Through the free-listing exercise, staff confirmed the absence of pain as a significant factor contributing to delay. One of the pastors reported that people say, "It doesn't hurt, so why should I go for treatment?"

We found that other traditional beliefs and health-related practices have the potential to add to delay. There is a belief that rapid change from hot to cold affects health. Another traditional belief is that all the blood in the entire body changes at the end of each winter season (August), making people susceptible to disease. Local people see the high death rate at that time of year as evidence that this is true. Traditional beliefs persist that maintenance of health is not within an individual's own control. Blessings from God sustain health, and witchcraft may adversely affect health. In this context, seeking any form of treatment may seem inappropriate or inadequate.

In Paraguay, such attitudes and practices are sustained through well-established traditions of natural medicine. Practices include reliance on herbal medicines, known as "médico nana," where the practitioners provide a form of public service and no charge is made. The practice of "médico naturalista" also relies on herbal remedies, but may involve some spiritual rituals. Practitioners are referred to as doctors and are paid for their services. The practice of "Espiritualista" always involves some spiritual ritual. Practitioners are considered to

be specialists. They advertise their services and treat disease as a spiritual as well as a physical manifestation. This practice has its roots in the indigenous culture of Paraguay where every sickness was blamed on a spiritual power and the priest was called upon to break the spell. Over time there has been a trend toward greater reliance on natural cures, but people still expect herbal remedies to be accompanied by certain kinds of rituals.

We interviewed one such practitioner who had worked for 37 yrs, treating diabetes, cholesterol, heart attack, cancer, and leprosy. He uses preparations of roots, herbs, and leaves, though he does buy and use ointments and medicines from pharmacies. His training in Brazil included occultism and is recognized by the Macumba group in Paraguay. This is the preferred training for Espiritualistas in Paraguay. He attributes leprosy to the eating of specific forms of food, to inheritance, to punishment, or to a curse. He makes his diagnosis by looking at the patient's urine. His treatment involves expelling the spirit causing leprosy by using prayers and rituals. He prepares drinks and makes ointments to clear the blood or to make patches disappear. The patient's faith in the cure is essential. The cost is around US \$2 per consultation lasting 30 minutes but involves daily visits over an extended period. He claimed a 100% success rate for his leprosy treatment. Staff told us that in some areas the status of such healers allows them to insist that their patients stay away from health service doctors, saying their treatment is incompatible with any other treatment. In contrast, there is free access for prospective patients to health centers, to health service practitioners, and treatment irrespective of any on-going contacts they may have with natural healers.

Knowledge of leprosy. We heard leprosy attributed to causes relating to the context of health beliefs. Four patients attributed their leprosy to washing in cold river water or being caught in heavy rain when working outdoors. One individual understood that exposure to cold had changed his blood and so caused leprosy. Inheritance, infection, punishment for sins, and not eating the right food were reported as potential causes by teachers, pastors, and others. There was a similar attribution of cause in the first se-

ries of interviews where causes included cloudburst (7), food eaten (30), and work or living conditions (3). Fifteen individuals said they did not know the cause. Only 5 individuals spoke of infection. In this group, those explaining the cause in traditional terms had a mean delay of 56.4 months compared with a delay of 16.0 months for those referring to infection, but the difference does not reach statistical significance.

Pastors identified ignorance of the disease as the main reason why people in the community fear infection and fear those affected. Historically, these stigmatizing attitudes were reinforced by a policy of isolation and the church's teaching that leprosy was unclean or a punishment from God. These beliefs are traced back to the time of Spanish colonization. People also believe the disease to be highly contagious. The fear extends to the graduates from those medical schools that fail to address misconceptions about the disease.

From teachers and pastors, we heard about effective national health education programs relating to tuberculosis (TB) and AIDS, but there was agreement that published or broadcasted information about leprosy was very limited. The school teachers said there was a lack of information in the whole community. People recognize leprosy only in the advanced symptoms of ulcers, deformity, and wounds, and is therefore considered incurable. One patient suggested that because leprosy is feared, no one will listen to attempts to educate the public on the facts of the disease. The mayor said that changing attitudes is a huge task, "Leprosy remains a taboo subject. It is a disease of society, not of people."

Routes to presentation. Of the 15 individuals in the second series of interviews, 10 had sought help from natural healers and 11 had presented to private or general health service doctors, including 9 individuals who had sought help from both. Only 3 individuals reported that they had never been to either.

For the 11 individuals seeking help from general or private health services, the number of visits ranged from one or two upwards, one woman claiming she had been to more than 50 different doctors. Four individuals reported that leprosy had been diagnosed or suspected or a referral made,

though only 2 of these completed treatment without further delay. Two individuals reported that a series of visits to skin specialists had not led to a diagnosis. Another was diagnosed through a referral route that included a local doctor, a university doctor, an ENT doctor, and a skin doctor who referred to the leprosy clinic.

When interviewed, the individuals who sought help from health services said the cost of consultations was high. One man sold all his animals to raise enough cash. Another said he had spent a "small fortune." A professional woman was forced to sell the family car and possessions and spend her savings to pay her bills. Nevertheless, staff at the leprosy clinic reported increasing numbers of referrals from the health services.

Four of the 15 people interviewed reported occasions when they had denied the leprosy diagnosis. All were women. Three of these gave fear as the reason. The son of the fourth denied the diagnosis since she had not been in contact with "dirty people." This woman presented to a natural healer who provided her with an acceptable diagnosis, a fungal infection. All four women started treatment after lengthy delay, in one case extending to 9 yrs.

References to "not being treated properly" suggests people are uncomfortable with the health service environment. Staff contrasted the health services with services offered by natural healers who were unpretentious, relatively affordable, well understood, and locally accepted within the community.

As a result, in many areas the services of natural healers are preferred to general health services. This was confirmed in the first series of interviews. First reported actions included 7 individuals who said they did nothing. Eighteen individuals relied on some form of herbal cure. Of these, 16 presented to natural healers and 2 relied on family medicines. One person took a bath using herbs. Five used some form of self-prescribed ointment. Only 5 went to a doctor. The data suggests a tendency for individuals relying on natural healers or herbal treatment to have longer delays, though the difference fails to reach statistical significance.

The second series of interviews confirmed that people committed much time to natural healers. The 10 individuals involved

reported numbers of visits ranging from 2 or 3 upwards, one woman claiming to have visited every week for 3 yrs. Four individuals reported that natural healers had suspected leprosy. None was encouraged to present for treatment, though one healer referred to an unspecified "big disease," requiring treatment elsewhere.

One male patient said that people still go to natural healers for help first. Only if things get worse do they then go on to the health services. The same man said he had wanted to bring his uncle, a suspect case, to the clinic but his uncle was still involved with a natural healer and not ready to come. Another man said he delayed presentation after lay referral as he wanted to try one final cure offered by his natural healer, a medicine made from cut finger nails. School teachers acknowledged this ordering, saying that people first use house medicines—miscellaneous ointments and the like, second, herbs from a natural healer, and only third go to the local health center. Staff of the leprosy clinic reinforced the message, saying people prefer natural healers because they live in the villages, rely on local knowledge, and their skills are recognized and accepted. Villagers believe natural healers have no delusions of self-importance. In this context, health service procedures conflict with traditional beliefs and practices relating to disease.

Though lay referral failed to achieve early presentation and start of treatment, it was by far the most common form of referral (13 out of 15 cases). Two individuals reported that doctors suspected leprosy and made a referral, but only one of the two presented and started treatment. The other needed the extra impetus provided by a referral from a friend previously affected by leprosy. In total, 6 individuals started treatment because of referrals by people previously affected by leprosy. In one other case such a referral was ignored. Others were referred by relations or friends.

In the first series of interviews, 7 individuals who self-referred reported mean delays of just 20 months. Somewhat longer delays were reported by those referred by people previously affected by leprosy—by family members, by others in the community, or by the health services—but differences failed to reach statistical significance.

Impact of the leprosy diagnosis. We found evidence of continuing stigma, with 5 individuals reporting actual discrimination. One woman reported that on diagnosis, all her family except her husband left her, saying she was repugnant. One man said he was not sleeping with his wife, though he still continued to support the family and had access to his children. One young woman reported angry scenes with her sister. Another had been excluded from school. One man had a minor problem with neighbors. One of the pastors recognized that leprosy could threaten a marriage or other relationships; it might also threaten relationships between boy-friend and girl-friend.

Teachers, pastors, and the local mayor all said that the main problem with leprosy was in the mind. This confirms the balance of findings from the second series of interviews. While only 5 individuals reported actual discrimination, 13 individuals expressed fears about potential problems. Two individuals had changed jobs. One man, a professional singer, had temporarily left the singing group, saying he was unable to sing while he had the disease. One woman reported that she had suicidal feelings after diagnosis. One young woman had twice tried to kill herself following angry arguments with her sister. One woman said she suspected leprosy but at the same time denied it could be true. Another said she had been diagnosed by a doctor, but refused treatment because it is "too much for a person to carry a diagnosis of leprosy." The grandfather of one young woman had recognized her symptoms since he had had leprosy; she denied the possibility and refused to go for treatment because, at age 17 yrs, she didn't want to hear bad news.

Seven people made specific mention of concealing the diagnosis and the possibility of expulsion to a colony. Fear of exclusion from traditional Paraguayan tea-sharing was cited as another reason for concealment. During the interviews we noted people lacking in confidence, i.e., talking very quietly or speaking in a monotone, shuffling their feet, looking down at their hands, often slow to collect thoughts or respond to simple questions. Responses included references to shock, fear, suicidal feelings, and denial. One man said that at the time of diagnosis everything had to be

explained twice because he was so shocked by the news. Another said the diagnosis came as a big surprise; both he and his wife cried much.

Staff members provided further insights into stigmatizing attitudes. Individuals most at risk of stigmatization live in isolated areas with limited communications where natural healers have the power to forbid contact with health services. The impact of diagnosis would be seen in fear, concealment, uncertainty, rejection, insecurity, humiliation, shock, depression, spoiled relationships, and as a threat to the ability to work. As a result, people avoid actions that might make their condition known. Some people conceal the diagnosis and ensure staff do not communicate with family members or neighbors. While strong, unconditional family relationships will cope with the diagnosis and treatment of an individual, there is still a threat to the future of the children of a family, and a risk that the family's participation in the community will be reduced. For this reason, the leprosy diagnosis is concealed from all but family members. Within families, the reported level of acceptance was sometimes limited. In extreme cases, families refused to arrange for burial after the death of the affected person.

In the first series of interviews, 18 individuals expressed some form of fear relating to leprosy, including fears concerning infection of others⁽³⁰⁾ and fears about the impact on relationships within the family⁽³⁾, with friends⁽²⁹⁾, and with neighbors⁽⁶⁾.

Positive outcomes of diagnosis identified by staff included relief at the end of uncertainty and the assurance of cure. One of the men interviewed suggested that the impact was manageable, "leprosy makes a big noise and possibly a big smell. It is big news. The reason is that people believe leprosy is contagious and incurable. Neighbors may run away, but if you take care and say you will be cured then people will accept. If you tell it like a bomb then you will have an explosion."

Principle causes of delay. In the second series of interviews we asked patients to identify the main cause of their delay. Staff and some community representatives reinforced patient responses, which are presented in the five groupings that follow.

Five individuals attributed their delay to lack of awareness, using comments such as: "I have never seen or heard details of leprosy," and "I didn't recognize the disease," or "I only decided to do something when I got pain." The leprosy clinic staff, pastors, and teachers identified the main contributors to delay as ignorance, the absence of pain, and being unconcerned, the word "mañana," acknowledging people's willingness to delay action for another day.

Four individuals believed natural healers had misled or failed them. Comments from some of these individuals included, "I believed his [the natural healer's] explanation and followed his advice and treatment," and "I was living in darkness. I didn't understand. I simply trusted the people I saw." Staff, teachers, and pastors agreed that the preference for herbal remedies was a major contributor to delay.

Four individuals reported frustration with the health services. Comments included: "I didn't know a doctor that could make a difference," and "No one knew (recognized) the disease. I looked for help, but there was no answer," and "Always, always, always, doctors are not specialists in leprosy, so they don't diagnose correctly." Staff, pastors, and teachers added points about cost, fear of the diagnosis, and uncertainty about the treatment. They acknowledged that many people don't know where to go for help and don't know that the treatment is free. One woman who had made extensive use of natural healers and the health services said, "I had been pursuing two parallel sources for help. Both failed me."

Three individuals attributed their delay to denial. Four people admitted they had rejected an early diagnosis. Pastors and teachers said people fear the consequences of the disease. They fear what people may say and they fear rejection, so they conceal their symptoms or deny the diagnosis.

Three individuals commented that lay referral had been late. One man said, "My friend only told me that he too had been treated after I had started treatment." Others said, "It would have been nice if my neighbor had given his advice earlier," and "It was good that my neighbor (helped), but it could have been earlier." Staff reported that on occasion, people had recognized symptoms in others, but felt unable to give direct

advice. Instead, they maintained their anonymity by coming to the hospital and asking staff to make a home visit.

DISCUSSION

Our fieldwork in Paraguay provided evidence that many different factors contribute to delay in presentation. These include: a lack of awareness of early symptoms, traditional beliefs, interactions with natural healers, and interactions with the health services.

Traditional beliefs and lack of awareness. Belief that significant disease must involve pain means that the early signs of leprosy are considered insignificant. We also heard a great variety of attributed causes reflecting traditional beliefs. None of these encourage people to seek treatment. Rather, they attach insufficient meaning or significance to the early signs of leprosy, fail to recognize the route of transmission, and lead to a lack of urgency in response. All of these contribute to delay in presentation and start of treatment.

Stigma. From staff, we heard that to inform neighbors of the leprosy diagnosis was equivalent to a death sentence. Evidence from patients indicated that this should not be interpreted literally. Rather the threat was to the status and continued normal functioning of the individual or their family within the community. Informants told us the situation is changing. The positive reports of some of those interviewed reinforce this view. Nevertheless, we heard evidence that people do continue to be stigmatized and the leprosy diagnosis continues to bring a significant psychological impact, including fear, concealment, rejection, spoiled relationships, and a threat to the ability to work. Those most at risk of stigmatization live in isolated areas with poor communications, limited access to health services, and continuing reference for traditional medicines. Late lay referral, denied diagnoses, and non-compliance with treatment are evidence that stigma has an impact on delay in presentation.

Interviews with teachers and pastors suggest that health education about leprosy in Paraguay has been limited and has had little impact. The local mayor emphasised how difficult it will be to change established attitudes within society. As elsewhere, information about early signs and the free avail-

ability of MDT as an effective cure has been central to the health education message. The present findings suggest that if traditional attitudes and beliefs are to be addressed, there is need for more effective messages and methods of communication.

The role of traditional medicine. We found evidence that natural healers continue to play an important role in society. The services offered are well established, locally accessible, non-threatening, and relatively affordable. The majority of patients we interviewed continued to make use of natural healers, in some cases persisting with treatments for several years. Most people using natural healers did so in parallel with seeking help from private or general health services. People were ready to try two or three different treatments before moving on to another healer or to the health services.

We heard evidence that at least some natural healers are aware of leprosy and recognize the limitations of their treatment. Only one had made a referral, and another spoke of a "big" disease he was unable to treat. The healer we interviewed had bought miscellaneous medicines from pharmacies and said he would be happy to screen for leprosy and refer people with suspect symptoms. There may be a possibility here for some innovative arrangement with local healers for referral or even for distribution of MDT blister packs. As well as channelling treatment through trusted and accepted individuals within the community, involving natural healers would open up other possibilities for disseminating information and educational materials and creating a first point of contact in the event of reactions or problems with selfcare.

Interactions with health service providers. Although a minority of patients had delayed a long time in diagnosis or referral from within the health services, our evidence was that at least some doctors were effective in recognizing the possibility of leprosy and in making referrals. The senior staff of Hospital Mennonita are involved in teaching programs in medical schools and encouraged by a trend of increasing numbers of referrals, though the cost of consultations is an issue.

We found evidence that people moved quickly from one doctor to another. In some

cases, this was because they did not like the doctor's diagnosis and sought an acceptable alternative. Others simply ignored the doctor's referral. People tended to make fewer visits to individual doctors than they did to natural healers. People expressed disappointment in the inability of the doctor to make a diagnosis. Others had expected a straightforward cure. For some, cost was an issue. Others thought they had tried the doctor's cure and now there was no need of further action.

These findings suggest an analysis that associated delay with the doctor's failure to diagnose or refer would be simplistic. While improved diagnostic skills are important, patients need help if they are to make effective use of the services available to them. Such help might come through education programs or from within the health services. Even so, where the individual's financial resources are limited, the cost involved may prohibit effective use of the health services.

Age and gender. The initial series of interviews suggested delay in presentation was a particular problem among men and individuals aged above 45 yrs. We have insufficient information from the second series of interviews to explore this finding in greater detail. All 3 older women interviewed had concealed the diagnosis from neighbors and expressed concerns for the impact on family members. Among the 6 older men, the emphasis was more on the continuing ability to work and to support their families.

We have insufficient evidence to draw any conclusions about differential impact of the diagnosis between young men and young women. The 2 young men interviewed gave no indication of a significant impact from the leprosy diagnosis. Three young women interviewed each had a parent or grandparent previously affected by leprosy and each experienced significant social or psychological impact. One had discontinued treatment and left to work in Brazil. Another had been excluded from school. The third had denied the diagnosis, married and left for Buenos Aires; only after 9 yrs did she return with more advanced symptoms to restart treatment. In our observation of 2 women newly diagnosed, we witnessed the draining away of

self-confidence and the shocked reaction to the diagnosis. The experiences of these 5 young women suggests that stigma may have a greater impact on women, but a further round of field work would be needed to explore this area in more detail.

Review of methodology. Our report demonstrates that the chosen field methods provided a great richness of data. The participation of community representatives and local staff, as well as patients, allowed us to draw on a wide range of knowledge and experience. The variety of methods and sources allowed us to validate findings. Relying on local skills and knowledge proved effective in collecting data.

The first series of interviews produced limited data but was useful in validating information from other sources. Further information might have been gathered from a review of patient records. The second series of interviews provided a wealth of information, though it involved travelling many hundreds of kilometers. In contrast, the free-listing exercise proved to be a straightforward exercise producing a lot of information in a very short time. This approach might also have been used with groups of patients.

Success in the use of qualitative methods depends on identifying or developing the necessary skills in the field. Interviewing skills are common among field staff, but are generally restricted to closed questions and clinic forms. The methods used here required an open-ended approach, listening and analytical skills, and were dependent on a good rapport with patients. Many project staff members established sympathetic and understanding relationships with patients. Some basic training procedures would prepare them for an effective role in data collection as described here.

For the purposes of the present report, we completed a detailed and time-consuming analysis of our data. For the purposes of local problem-solving, it would suffice to complete a more basic analysis, drawing attention to help-seeking actions contributing to delay, to people who delay, and to locations where people delay.

CONCLUSIONS

Our qualitative fieldwork in Paraguay linked delay in presentation to lack of

awareness, traditional beliefs, stigma, seeking help from natural healers, and to interactions with the health services. Traditional beliefs diminish the importance of the early symptoms of leprosy, so people remain unaware of their need for help. Stigma continues to impact people affected by leprosy. Many people prefer the treatments offered by natural healers. Only after these have failed, do people present to the health services. While some individuals spend much time and money within the health services before leprosy is suspected and a referral made, there is evidence that the number of referrals is increasing. Further research might explore a potential role for natural healers in screening for the early signs of leprosy and distributing MDT blister packs.

Our findings suggest it would be all too easy to underestimate the task of addressing traditional attitudes and behavior towards leprosy in Paraguayan society. Health education must play a central role in disseminating knowledge and addressing attitudes in the community at large, among the medical profession, and among people affected by leprosy. To achieve more substantial inroads into the traditional attitudes and behaviors will require more extensive and innovative approaches than those used to date. There can be no doubt that this will be a challenging task.

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