

Stakeholders perspectives on perceived needs and priorities for leprosy control and care, Tamil Nadu, India

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Although leprosy has been declared as eliminated in India, treated patients with persisting disabilities still require care. With the shift from vertical to integrated services, questions remain about case detection and maintaining the quality of patient care. We conducted a qualitative study to clarify the perceived status of elimination, patient care and other aspects of leprosy control from the perspective of various stakeholders. We interviewed leprosy programme managers, Non-governmental organization directors, healthcare providers, patients and community leaders from Kanchipuram district, Tamil Nadu. Consensus endorsed the current approach to integration of leprosy in primary healthcare, but healthcare personnel acknowledged problems from shortage of medicines and failure to fill key positions. Patients were concerned about limited clinic hours, long waits and delayed treatment. Disabled patients indicated how they were troubled by stigmatization of their condition. Programme managers mentioned limited support for needed research and some emphasized the potential threat of emerging drug resistance. Although consensus supports an integrated approach for leprosy services in primary care, the relative priority of different aspects of leprosy control vary among stakeholders. Perspectivist approaches to methodologically sound operational research could guide planning for effective case detection and patient care during the post-elimination era.

Keywords : Leprosy elimination, stakeholder analysis, qualitative study, Tamil Nadu

Introduction

WHO defined leprosy elimination as prevalence less than 1 case per 10,000 population and initiated the campaign in 1991. In 2001, WHO declared that the historic target of global leprosy elimination was attained (WHO 2001). By 2010, all the countries achieved the elimination target

except a few (WHO 2010). The elimination slogan contributed to develop. However, the experts have suggested that reductions in prevalence may be an artefact of elimination campaign strategies instead of a real reduction in the number of cases (Fine 2007, Penna et al 2011), and effective interventions to truly achieve elimination require

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additional epidemiologic and microbiologic investigations (Richardus and Habbema 2007).

The current strategy aims at sustainable control in the primary health care set up. In WHO's global strategy for further reducing the leprosy burden and sustaining leprosy control activities for 2006-2010, prevalence has been replaced by new case detection rate (WHO 2006). The strategy emphasized timely detection of new cases and effective chemotherapy with multi-drug therapy (MDT). A third consideration concerns provision of high-quality patient care, its availability, affordability and other aspects of equity in access.

India's National Leprosy Eradication Programme (NLEP) announced leprosy elimination in 2005 (Special correspondent 2006). Within India, various research strategies have documented the existence of endemic areas despite the achievement of elimination status (Gupte et al 2004, Shetty et al 2009). Effective case detection and the quality of care for both new cases and treated cases with persisting disabilities therefore remain needs of the leprosy control programme. In this regard, inputs from various stakeholders in leprosy control could contribute to understanding priorities.

Qualitative methods are required to assess the quality of patient-centred care. Social and cultural factors, especially stigmatization and the lack of awareness in the community of the medical basis and effectiveness of treatment for leprosy, are major contributors to the persisting burden of leprosy. The complexity of leprosy morbidity cannot be appreciated adequately solely from the number of leprosy patients, because it is not clear from the numbers alone what is required to meet complex needs. Furthermore, priorities for leprosy control may vary according to the vantage point of different stakeholders. Each is concerned with issues that relate to their particular interest - symptoms and treatment for patients, a well - functioning health system with capacity for

case detection and treatment for healthcare personnel and programme managers, and epidemiologic trends and potential pitfalls (such as emerging drug resistance) at higher levels of planning. Assessing the various priorities of different stakeholders benefits from qualitative methods and contributes to the planning process. Leprosy endemic areas of the state of Tamil Nadu in Southern India are appropriate settings for such research. In 1997, Tamil Nadu became the first Indian state to successfully integrate leprosy services in the general health system. The focus shifted from case detection to accessibility of leprosy services in rural areas and promoting awareness in communities. With such a fundamental shift in the orientation of the control strategy, one might expect different views to proliferate.

In this context, we conducted an explorative study with the objectives to (1) identify and explain the perceived status and priority of key aspects of leprosy control among various stakeholders and (2) clarify the level of awareness of leprosy, the influence of social and cultural concepts of leprosy on popular ideas about the disease, and locally perceived prospects for treating it.

Materials and Methods

Study setting

We conducted the study in the Kanchipuram district of Tamil Nadu in South India. Kanchipuram district has 59 health facilities, 11 urban health posts and 48 primary health centres (PHC), health sub-centres (HSC) and dispensaries. There are three leprosy hospitals (Tambaram, Tirumani and Polambakkam) in the district and a NGO leprosy hospital (Gremaltes) in Chennai which provides reconstructive surgery. The district was part of the South India Leprosy Vaccine Trial conducted by the Indian Council of Medical Research (ICMR) (Gupte et al 1998).

Study design

We conducted a qualitative study among respondents representing a range of interests in leprosy control, including patients, healthcare providers, policymakers and community leaders. Qualitative in-depth interviews were developed, covering perceived epidemiologic trends, the status of control and the quality of patient care. These interests were represented with an appropriate level of emphasis in interviews with particular categories of respondents. For instance among patients the emphasis was more on care and among health staff it was more on control and care.

The in-depth interviews were guided by an agenda, and interviewers were trained to engage respondents in conversation as they covered these points, making them comfortable so they could speak freely. The interview questions were developed in English, translated into Tamil and back-translated by a second field staff member, to minimize distortion in the meaning of translated questions. The interviews were conducted in English or Tamil depending on the preference of respondents. We tape recorded the interviews, transcribed and translated them from Tamil into English.

Study participants and sample size

Respondents were selected to represent a range of interests and various levels of knowledge, position and experience of different stakeholders. From the NLEP operating in Kanchipuram district, six leprosy patients were asked to participate, a man and a woman in each of the three groups - two with a recent diagnosis, two who were no longer in treatment and two with disabilities. To assess the views within the NLEP, four experts were selected, including program managers and the deputy director of NGO leprosy hospital); five health workers at a primary health centre, including a medical officer, health inspector,

pharmacist and two village health nurses; and two local community leaders. Of these 17 respondents, all but two resided in the Kanchipuram district. Two of the four experts, however, were chosen to represent a broader range of experience at the state and global levels.

Approach to analysis

A descriptive overview account of responses with reference to the study aims was prepared for each stakeholder group from a review of the transcripts. MAXQDA computer software was used to manage and analyze the qualitative data set (Kuckartz 2001). The data set included translated interviews, which were imported and coded in MAXQDA. Coding facilitated access to interview content on perceived epidemiologic trends, leprosy control, and leprosy care-each with appropriate sub codes. Codes and sub codes were attached to text segments for retrieval to facilitate comparison within and between stakeholder groups.

Human subject protection

The study was reviewed and approved by the Institutional Ethics Committee of the National Institute of Epidemiology (ICMR). The purpose of the research was explained to all respondents, and they signed an informed consent form before the interview was started.

Results

Qualitative interviews were conducted from May to June 2007. The following is an account of the key points, relative priority and status of leprosy epidemiology, control and care from the in-depth stakeholder interviews. Patients' accounts were primarily concerned with access to services, and healthcare providers focussed on health system support (personnel, surgical backup, and availability of supplies and medicines). Policymakers focused on programme operations and trends concerning epidemiology and the

status of elimination and tools for control. Compared with other stakeholders, responses of community leaders were relatively superficial, suggesting this was not a high priority in their leadership activities.

Leprosy epidemiology

All the expert respondents agreed that prevalence has declined at all levels, whereas, a comparable reduction in incidence was less clear. The healthcare personnel of the PHC felt there had been a reduction in the multi-bacillary (MB) leprosy caseload, but policy makers described an increase in MB leprosy in Tamil Nadu. The policy makers also described a reduction in childhood cases and deformities.

Leprosy control

The team leader of the WHO global leprosy programme explained the principles of WHO's current strategy for leprosy control: equity, quality, sustainability, and collaboration. Healthcare personnel elaborated their approach and activities for leprosy control, focusing on information, education and communication. After the integration of leprosy services in primary health care, active case finding was ceased, and cases are detected from diagnosis based on clinical symptomatology during regular health programme operations. Healthcare personnel and expert policymakers agreed that continuing with the current approach to integration, rather than the defunct vertical programme, was crucial for maintaining sustainable leprosy services.

Integration of leprosy treatment in primary care was a welcome development for most of the patients we interviewed. They described advantages it brought, such as improved access to outpatient treatment and home care for the rural population. They found it less costly for services and less time was required to obtain needed treatment. Patients also reported disadvantages,

however, from integrated services, referring to longer waiting times at the PHC. Some also found home care less available, and they were disappointed because this expectation was unfulfilled. The following account of a leprosy patient whose diagnosis had been made a year earlier, but who had not yet started treatment illustrates this frustration:

“Doctors came to my house for a check up. They told me that I am having a patch, and that it needs treatment for 6 months. So far I have not taken any treatment for this, because I don't think this is a disease. I am waiting for the treatment at my house. I went to Poonnamalle hospital, but it was so crowded, I left and went to work”

Healthcare personnel described the need for the appointment of leaders responsible for leprosy services in the health centre to ensure the quality of care and effective leprosy control.

Leprosy policymakers agreed that the political commitment to control leprosy has lessened over the years, a result of publicity emphasizing the success of leprosy control and its elimination as a public health problem. When asked about changes in leprosy control over the last years, the former leprosy inspector who is now the health inspector said:

“Priorities have definitely changed. When the MDT regimen was implemented, we were fully concentrated on the leprosy treatment only. Nowadays, sometimes the drugs are not even available. If you want to treat an MB patient, then you have to go to a deputy director of leprosy. And sometimes he as well has no drugs. That is the difficulty of the treatment”.

Although other experts did not emphasize this concern, the WHO team leader was particularly concerned about potential for emerging rifampicin drug resistance. This is the main drug on which MDT relies, and sporadic resistance has been reported. WHO has begun to develop

alternatives to the current drugs, but this is an increasingly more difficult task as the market for drugs to treat leprosy becomes smaller with perceived success of the programme. Experts did not foresee a role for a vaccine.

Community awareness requires dissemination of information about leprosy through different media, such as television, pamphlets or health personnel. The respondents felt that this has been effective in Tamil Nadu, where there is greater awareness of leprosy than in other parts of the country.

Leprosy care

Health personnel described problems they encountered in treating people with leprosy. Some patients do not return to the PHC for treatment, and for those who do come, delays receiving drugs are also a problem. Patients with disabilities reported having sought help only after noticing symptoms more troubling than signs of hypo-pigmented skin patches.

With regard to care, healthcare personnel advised that they routinely instruct leprosy patients with a nerve injury about preventing further injuries. Such advice has been appreciated, and patients we interviewed said they followed that advice. The PHC staff reported that for surgical treatment of disabilities they refer patients to an NGO leprosy hospital in Chennai. NGOs have taken over responsibility for preventing impairment and disability. Problems with this outsourcing of surgical interventions were noted; a medical officer expressed the following concerns about the quality of surgical care:

“It is not very encouraging. The patients come back to us saying, they were asked to come on another day. But I don't know if these patients refused surgery. I have not seen one patient who has come back with perfect surgery. I have also heard that some patients want to keep their disabilities for begging, because without that, how else will they get money?”

All respondents agreed that leprosy is still a stigmatized disease. Two female patients with a disability elaborated on the problems. One spoke of how not only she but also her family were ostracized: “They are avoiding all my relatives and also me. We will not go anywhere.” Another woman with a clawed hand said that her mother-in-law always refers to her as “the deformed-hand woman (Nondik-kai)”

The patients said that most of their information about leprosy came from hospitals, “doctors” visiting their house (i.e., field investigators from ICMR), friends, television or films.

They referred to their condition in various ways, such as leprosy disease (thozhu noi), infectious disease (Thottru noi), skin disease (thembal), patch (padai) or the big disease (Peria viyadhi). The last of these terms was mentioned by a patient who referred to a Tamil film, in which the lead actor portrays a leprosy patient with physical deformities [a film called Blood Tears (Rathakanneer: <http://en.wikipedia.org/wiki/Rathakanneer>)]

Discussion

This study examined the experience, perceived needs and priorities for leprosy control from the vantage point of various stakeholders in an endemic area. The patients, health care providers and policymakers indicated substantial concern with distinctive aspects of leprosy control. However, community leaders felt that they were less engaged.

On the questions of leprosy epidemiology, the respondents produced more diverse accounts of the frequency of occurrence of types of leprosy. The questions about barriers to care and the need for quality services generated responses focusing on different aspects of these problems. There was also consensus about the importance of maintaining an integrated approach to leprosy

services in the context of primary care, even though respondents also acknowledged problems with that approach. No respondents, however, advocated return to a vertical programme.

Respondents referred to problems arising from both health system and behavioral factors. Awareness of early and late manifestations of a single condition is essential for successful control that relies on passive, rather than active, case detection. Delays in initial help-seeking and the start of treatment reflect the low priority patients give to the painless patches typical of early signs of leprosy. It is difficult for them, however, to accept the relationship between relatively insignificant signs at the outset and a disease that is so serious in its later stages. The two seem like different entities altogether. Patients also referred to the importance of basic practical features of health system operations, such as inconvenient hours that complicate access to services in the PHC, and anxiety about being identified there as a patient with a stigmatized disease.

Consideration of the common terms used for leprosy clarified community views about the disease. Names used for leprosy indicate ideas the basis for the disease that may be taken as justification for discrimination, such as the term referring to it as an infectious disease (Thottru noi). In a report about historic profiles and perspectives of leprosy in India, Jacob and Franco-Paredes (2008) highlighted the need towards identification of interventions to dispel stigma of the world's most misunderstood disease (Jacob and Franco-Paredes 2008).

Overall questions about the quality of healthcare indicated a focus among patients on limitations of services provided by the health system, and among healthcare personnel on limitations of patients' commitment to make use of available

services. Competing considerations influence patients' behavior and help seeking, influenced by a balance of perceived quality and effectiveness of disability care and surgery, and the social vulnerability that results from acknowledging the condition. Although the medical officer who explained why patients did not take full advantage of opportunities for disability care attributed it to stigma of receiving services. Others, however, rely on the stigma of leprosy to maintain a livelihood through begging, a point that has been reported from studies in Andhra Pradesh (Staples 2007). Livelihood interests may therefore play a paradoxical role for some in maintaining stigmatization of leprosy, suggesting that social interventions providing skills to earn an income are also an important aspect of quality health services and closely linked to the effectiveness of clinical care.

Respondents at various levels disagreed about some aspects of epidemiological trends and the relative significance of MB and PB types of leprosy. Although healthcare personnel referred to a reduction in both MB and PB leprosy caseload at their PHCs, the policymakers noted an increase of the percentage of MB leprosy cases in Tamil Nadu. This may be an artefact of policy, rather than changes in the epidemiology, resulting from a shorter course of treatment for PB, which makes their prevalence decrease disproportionately compared with MB. Subramanian et al (2006) had documented a relative increase in the percentage of MB cases in the study setting. They suggested that with less active detection in our post-elimination programmes, sub-clinical cases may accrue and transmit the disease. No treatment or inadequate treatment, and a longer period for incubation may also result in progression to MB.

Among expert respondents with various levels of responsibility, emphasis on consideration of the perceived threat of resistance varied according to

the level of responsibility. Appreciation of the potential of emerging rifampicin resistance is expected at higher levels, where priorities are not limited to operational questions of using existing capacity effectively, but include the additional responsibility of developing and maintaining treatment capacity.

Critical accounts of health system operations from patients and patients' behavior from healthcare personnel were complementary. Although questions of policy affecting the epidemiologic data suggested potential artefacts in reporting current trends, the post-elimination focus on integrated services has been accepted at all levels, from patients to health personnel, policymakers and community leaders. Insights from various levels of stakeholders indicate areas of consensus and concerns. While we have demonstrated the relevance of that point for leprosy, but it applies no less for other aspects of health systems planning and public health.

Our study has few limitations. The respondents were fewer in number and were purposively selected. This may limit the external validity (especially the group of patients, healthcare providers and community leaders). However, this may not be applicable to the interview of expert respondents. This study was conducted as part of training requirements in international health and therefore, there were constraints of time and logistics to expand the scope of the study.

On the basis of an exploratory study involving few stakeholders in leprosy control, we conclude that consensus among them supported an integrated approach for leprosy services in primary care and the relative priority of different aspects of leprosy control varied among them. Further in-depth studies with methodological rigor among a representative sample of stakeholders are needed to provide guidance for a more effective approach to treating leprosy patients in primary

care and reducing the burden of this archetypal neglected tropical disease in the population.

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