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Summary A Rapid Village Survey (RVS) was planned to estimate the extent of the leprosy problem in two well documented endemic districts of East Java, Indonesia. Furthermore, the aim was to investigate the efficacy of the routine programme in detecting new and early cases, as well as the feasibility of RVS in detecting disabled people affected by leprosy in the community. A random sample survey (RVS: a simple method compared to a Population Sample) was used to determine the extent of the leprosy problem. In addition, a Leprosy Elimination Campaign (LEC), was used particularly to detect new and backlog cases in the community. Both RVS and LEC involve a health education campaign followed by the examination of persons voluntarily reporting. Routine programme case finding, involving passive case finding and contact examinations, was also carried out. The RVS prevalence rate of 12 per 10,000 was more than twice the known prevalence rate of 5 per 10,000. The LEC prevalence rate was less than the rate found by RVS, but was within the RVS confidence interval. During the RVS, many children with leprosy were detected, and 10% of all RVS new cases already had disability grade II. The population disability grade II rate due to leprosy was 9 per 10,000. Despite the fact that an active leprosy control programme had been carried out in the surveyed endemic area over a period of many years, the actual prevalence rate found was more than twice the known prevalence. Many children were found during the RVS, thus indicating continuing widespread transmission. In general, it seems that there is still a serious delay in

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detecting new cases under the routine programme. Consequently, there are substantial numbers of persons affected by leprosy in those districts in need of rehabilitation.

Introduction

The two neighbouring districts of Gresik and Lamongan in the northern part of East Java, bordering the Java Sea, are known for their leprosy endemicity. In 1936, the National Leprosy Research Centre, Semarang, Central Java, implemented surveys and started control measures (including home care) in both districts.\(^2\) In 1958, a population survey was organized by the World Health Organization (WHO), followed by a pilot project of leprosy control, integrated in the basic health services.\(^3\) In 1989/1990 the WHO Multiple Drug Treatment (MDT) regimen was introduced in the area.

In 1958, in certain areas of the Gresik district, prevalence rates as high as 5 per 1,000 were found.\(^5\) After the start of the integrated programme, which included treatment with dapsone and, at a later stage, MDT, prevalence rates declined to 5 per 10,000 population in 1996/1997. In addition to the routine leprosy control activities and regular chase surveys (health education to a village population, followed by the examination of suspects),\(^4\) a community health education campaign was organized in 1996/1997. This was carried out in co-operation with the local women’s association, which had representatives in each village.

In 1998, after completion of the Rapid Village Survey (RVS) and before the start of the Leprosy Elimination Campaign (LEC), the new WHO MDT regimen was introduced. This involved a reduction in the number of doses for multi-bacillary (MB) cases from 24 doses within 36 months to 12 doses in 18 months.

In 1997/1998 a number of RVSSs\(^5\) were conducted, and the following research questions were asked:

- What is presently the extent of the leprosy problem?
- How do active case finding methods compare to routine programme case finding performance?
- What is the population disability rate due to leprosy in this area?

The districts Gresik and Lamongan were selected for the following reasons:

- Both districts are well known for their leprosy endemicity, and leprosy control activities have been going on for many years.
- Both districts are logistically suitable as they are situated in the vicinity of Surabaya (1–2 h by road), where the Provincial Leprosy Control Office East Java is located.
- The districts are very similar in many ways, not least given that the majority of the population in both districts is Javanese. Furthermore, Gresik has a sizeable Madurese minority and an extended industrial area.

In the period 1998–2000, after completion of the RVS, a number of LEC surveys\(^6\) were held throughout the two districts, including all villages except those already surveyed by the RVS. The LEC was implemented from October 1998 to March 1999, and a few sub-districts of Gresik were completed in March 2000. In 1998, the total population of both districts combined was 2.03 million with a land area of 2986 km\(^2\).

Materials and methods

An RVS can be used to determine the magnitude of the leprosy problem in a certain area. If previous surveys have been conducted, the trend of leprosy prevalence over the years can be
determined and it will provide information on the effectiveness of early case finding by the health service. RVS is a valid, simple and inexpensive method compared to a total population sample survey; it can give reasonable estimates of the true leprosy situation and it can be carried out by trained general health staff under the guidance of an experienced leprosy supervisor. In an RVS, no detailed census has to be made, as is the case with a total population survey. The first step of an RVS is an intensive health education campaign focused on determining who should present themselves for examination. Thereafter, the group of people to be examined will include all registered leprosy patients and their household contacts, those new cases who voluntarily report with skin problems or disabilities, and those suspects identified by village leaders as possibly suffering from leprosy.

A LEC is a method of active case finding comparable to an RVS. It comprises a health education campaign followed by voluntary reporting and examination of those with skin lesions or other relevant complaints. The objectives of the LEC are to find new and backlog cases, to increase awareness and skills regarding leprosy among general health staff, and to increase awareness among the general population. During the LEC a whole area can be surveyed, and not only a sample of villages, as is the case with RVS.

In East Java, the LEC was conducted by two or three leprosy field workers (staff from health centres in the area), with the most experienced worker in charge and assisted by general staff from the health centre (sometimes including the medical officer). In contrast to the RVS, supervision by district and provincial staff was not regular.

Routine programme case finding activities include voluntary reporting at all health facilities and the examination of contacts of new patients. Once in a while chase surveys are organized. Since 1995, the diagnosis has been made mainly on clinical grounds and no smears are taken routinely. The leprosy worker screens suspects and is responsible for the routine programme activities. This person is usually a general health worker of the health centre (often a nurse or an auxiliary) who has received specific leprosy training and who is usually also involved in other disease control or health programmes. The medical officer confirms the diagnosis and is involved in the treatment of complications. In East Java, the population of a health centre area is on average 30,000–40,000. The health centre is the basic health unit, usually staffed by one or two medical officers and several nurses and auxiliaries. A system of (trained) village midwives is being introduced, some of whom also participate in leprosy control programme activities.

During the RVS, school children were examined at school, and the remainder of the population at a central place in the village or hamlet. A village (average population of 4200 in East Java) mostly consists of several hamlets, and the survey team was thus divided into several smaller teams (consisting of male and female nurses and a leprosy worker) to examine the different hamlets and schools. All suspects and new patients were seen and re-examined by the provincial staff.

RVS school surveys mainly included primary schools, a few nurseries, several junior high schools and one senior high school. It was decided to include all schools and school children in the sample, even if some children (especially high school children) may have come from villages not included in the sample. Alternatively, some children from the sample villages attended school at a place not included in the sample.

Patients were diagnosed and classified by clinical criteria only. No skin smears or biopsies were taken. Paucibacillary leprosy patients (PB) were differentiated between those with a single lesion (PB1) and those having more than one, but less than six, lesions (PB2–5). A leprosy patient with six or more skin lesions was classified as having MB leprosy. Other
definitions used were the child rate, i.e. the proportion of children (<15 years of age) among all new patients, and the disability grade II rate, i.e. the proportion of new patients with WHO disability grade II among all new patients.  

During the RVS, an additional effort was made to determine population disability grade II, or disability prevalence due to leprosy. Together with staff from the health centres and village leaders, lists of disabled patients (i.e. patients with visible impairments) were compiled and these persons were subsequently visited and examined at home.

The following assumptions were made regarding calculation of the sample size:  
- In an area where leprosy control activities have been implemented for several years the estimated prevalence is taken as twice the known prevalence.  
- A 95% confidence interval of 0.5 times (precision) the observed (survey) prevalence is considered acceptable.  
- An estimated cluster correction factor or design effect of 4.  
- The number of clusters of 30, as in the WHO Expanded Programme Immunization.  
- The total sample population is used to calculate the prevalence rate and not only the population actually examined.

The prevalence rate in the two districts combined was 5 per 10,000 on 31 March 1997, with an estimated prevalence rate of 10 per 10,000. In this study, a village was defined as a ‘cluster’ and all inhabitants of the village were part of the cluster. The total sample size became 60,000, with 30 clusters of at least 2000 people. Two-stage sampling was carried out. The first stage consisted of a random sampling of sub-districts (30 out of 54 were selected) and the second stage involved the sampling of villages. Both sub-districts and villages were selected by population proportionate sampling. If the village turned out to be less than 2000, the village next on the sample list was joined to make up the required minimal cluster size. The two district capitals of Gresik and Lamongan were excluded from the study (but included in the LEC), as implementing an RVS in a town would be rather difficult (it was considered to be more difficult to motivate and get maximal co-operation from town people). Additionally, Gresik town in particular has many immigrants from outside the area.

For statistical calculations of the findings from the RVS, the formulae for standard error and estimation of cluster correction factor (design effect), as described in A Simplified General Method for Cluster-Sample Surveys of Health in Developing Countries, were used.

The sample size calculation of the random sample RVS was based on the original prevalence rate, before the reduction of MDT MB from 24 months to 12 months. Throughout the period of the RVS, the duration of the MDT MB regimen was 24 months.

The prevalence of the LEC was calculated as the ratio of the total of patients found (those newly detected and those already on treatment) divided by the total population of the villages surveyed. No effort was made to calculate confidence intervals of the prevalence rate found by the LEC. The result of the LEC was compared with the result of the RVS after a new prevalence rate for the RVS was calculated, based on the new MDT MB regimen of 12 months (only considering those patients who had received 12 doses or less).

**Results**

**RAPID VILLAGE SURVEY**

The RVS prevalence rate (MDT 24 doses) was found to be 12 per 10,000 (95% confidence intervals of 8.2–15.8), as shown in Table 1. There was a wide range in prevalence rates
between the different clusters. The cluster correction factor was retrospectively calculated to have been 4.2. If we would consider in the RVS only those MB patients having received 12 doses or less, the prevalence according to the RVS would have been 9.5 per 10,000, with 95% confidence intervals of 4.7–14.

Of the 58 children found during the RVS, 22 were diagnosed as single lesion PB leprosy (PB1), 15 as PB leprosy with between two and five lesions (PB2–5), and 21 as MB leprosy. A total of 54 out of the 58 children were found by school survey. Of the new patients found during the RVS, one was a relapse from monotherapy, three were undergoing a reactivation of the disease after defaulting from previous treatment, and one patient was actually diagnosed 4 months earlier but never started treatment. Three months after completion of the RVS, two new patients with single lesion PB and one with PB2–5 reported to the health centre from the sample villages and were included in the survey totals. One child with single lesion PB leprosy was examined by the staff during the survey, but was not diagnosed with leprosy. In the afternoon of the same day, the grandmother brought the child for examination to the provincial staff. One MB patient was examined during the survey, but was not diagnosed as having leprosy. One year later she reported to the health centre and was put on treatment. This last patient was not included in the survey totals. The numbers of new patients found by RVS, LEC and routine programme are compared, and child rates and disability grade II rates calculated, as shown in Table 2.

Thirty five percent of the total population was examined during the RVS, of which almost two-thirds were school children. In total, 29,739 school children were seen, among whom 54 were detected as having leprosy. The detection rate of the school survey was therefore 182 per 100,000 children examined. Of the adult population, 15,403 were examined (13% of the adult group), among whom 42 confirmed cases of leprosy were found (not including the three adult patients who reported at a later stage), and a case detection rate of 273 per 100,000 persons examined. If one takes as the denominator the total sample population (and not only the population examined) then the RVS detection rate was 79 per 100,000.

During the RVS a total of 112 disabled persons (due to leprosy) were found: 78 males and 34 females. This represents a population disability grade II due to leprosy of almost 9 per 10,000. Several disabled persons (possibly due to leprosy) could not be seen (were not at home) during the survey or refused to be examined, and are hence not included in the totals. Most of the persons affected by leprosy were living with their family (parents, brothers,
sisters, children, cousins). Only four, two men and two women, were living independently, without any support.

The HF score, which consists of the WHO grading of hands (H) and both feet (F) (but not the eyes), with a maximum of 2 points per extremity, was used to assess the severity of the disability. The average HF rate was 5.6 out of a maximum of 8. Only 7% had eye problems as well. Of these 112 disabled persons, both hands and feet were involved in 56% (mostly paralysis and clawing, absorption and bone loss, ulceration). In a few cases only one extremity was involved (paralysis, ulceration).

**LEPROSY ELIMINATION CAMPAIGN**

The LEC prevalence rate (MDT 12 doses) was 6.4 per 10,000 (Table 1). In total, 553 new patients were detected, corresponding to a detection rate of 30 per 100,000 population (total population minus RVS population in denominator).

**ROUTINE PROGRAMME**

The known prevalence rate in the Gresik and Lamongan Districts on 31 March 1997 was 5.0 per 10,000, and the known prevalence rate among the population where the RVS were conducted was 4.1 per 10,000 (MDT MB 24 doses). On 30 September 1998, the known prevalence rate among the population where the LEC was performed was 3.6 per 10,000 (after change to MDT MB 12 doses). The detection rate of the routine programme was 28 per 100,000 population in the year 1997.

**Discussion**

An advantage of the RVS is that no detailed census has to be made (as is the case with a Total Population Survey). Furthermore, only a minority of the population (voluntarily reporting with specific complaints) will have to be examined, and absentees do not have to be traced. In contrast to a Total Population Survey an RVS can be applied in relatively low-endemic conditions. The outcome of this RVS showed that the real prevalence was more than twice the known prevalence. The confidence intervals are within the criteria set at the start. There is a

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Table 2. New patients found during RVS, LEC and routine programme

<table>
<thead>
<tr>
<th></th>
<th>RVS</th>
<th>LEC</th>
<th>Sample villages before RVS 96/97</th>
<th>Routine programme 96/97a</th>
<th>Routine programme 97/98a</th>
</tr>
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<tr>
<td>New patients found</td>
<td>100</td>
<td>553</td>
<td>59</td>
<td>701</td>
<td>567</td>
</tr>
<tr>
<td>% MB</td>
<td>46</td>
<td>67</td>
<td>75</td>
<td>76</td>
<td>70</td>
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<tr>
<td>% children</td>
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<td>8</td>
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<tr>
<td>% disabled grade 2</td>
<td>10</td>
<td>8</td>
<td>15</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Case detection rateb</td>
<td>79</td>
<td>30</td>
<td>20</td>
<td>26</td>
<td>28</td>
</tr>
<tr>
<td>MB detection rateb</td>
<td>36</td>
<td>19</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Data on disability incomplete/

b Per 100,000 population.
wide variation in prevalence between the different clusters. The cluster correction factor was found to be 4.2. A similar figure (factor 4) was used for the calculation of sample and cluster size. A precision of 50% (0.5 times the survey prevalence) was considered acceptable, with the probability of achieving statistical significance at 5% (in effect, a precision of 32% was achieved).

The known prevalence was 5 per 10,000, the estimated prevalence rate 10 per 10,000 and the found prevalence was 12 per 10,000. Even if two-thirds of the single lesion PB cases were excluded (supposedly self-healing), the prevalence rate for the RVS would still be 10 per 10,000. A correction factor of 2 to estimate the real prevalence seems to be realistic, even in an area where leprosy control has been established for many years.5,7

The RVS is actually a ‘quick and dirty’ method. The RVS (and also the LEC) depends on suspects reporting voluntarily. Even under the most favourable circumstances not all cases of leprosy will be detected by this method. Most schoolchildren were seen (and most children of school age attend school in the area studied). However, not all adults with skin lesions will report for examination, and not all adults will be in the village during the survey (due to working in the fields or factories, visiting school or markets, or being otherwise absent from the village). Some patients do not want to be known as suffering from leprosy and some of them receive treatment from clinics outside the area (and as such are not known by the health centre as suffering from leprosy). The actual turnout was satisfactory, with more than 10% of the general population seen (excluding school children). Four patients reported within 3 months after the survey to the health centre.

In the original scheme, the intention was to interview all new patients in order to determine delays in detection (patient delay and doctor delay). However, the many ‘don’t knows’ (especially in case of children) did not allow analysis of the questionnaires. It was calculated in Gresik and Lamongan that the cost of a case found by RVS was twice the cost of a case found by LEC (details not shown here).

The main methodological differences between RVS and LEC, as conducted in the study area, were:

- The objective of an RVS is to determine the extent of the leprosy problem, whereas one of the main objectives of the LEC is to trace backlog cases. During the RVS only a sample of villages are examined, whereas during the LEC most, if not all, villages are surveyed in an endemic area. The two district capitals were excluded in the RVS, but included in the LEC.
- All schools in the sample villages were examined in the RVS. As it turned out, only a few schools were examined during the LEC.
- The rigour of the sample survey methodology was maintained by the constant presence of senior provincial staff during the RVS. The LEC was only sporadically supervised by district and provincial staff.
- Health centre staff, including the health centre doctor, were actively involved in the RVS. During the LEC, in some cases only the leprosy workers participated.

The LEC (MDT MB 12 doses) prevalence rate of 6-4 per 10,000 was less than that of the RVS (9.5 in case of MDT MB 12 doses), but fell within the 95% confidence intervals of the RVS. This holds true, even if we take into account an estimated level of 10% over-diagnosis (false positives) during the LEC.

The main difference in outcome between the two methods (RVS and LEC) has been the number of children diagnosed with leprosy: many during the RVS, and only a few during the
LEC. Even the routine programme reports annual child rates of 24%. The majority (62%) of children found during the RVS had either MB leprosy or PB with between two and five lesions. Even less experienced general staff should not miss such cases. Doubts can be raised about the awareness of the general population and health staff about the early signs of leprosy during this LEC. Increased awareness should translate into early detection and reduced disability rates among new patients. The detection rate of MB patients found by the LEC was only half the detection rate found by the RVS (Table 2). It is not clear if and how many backlog cases were missed by the LEC. One additional reason for the lower numbers found in the LEC could be the inclusion of the towns which are acknowledged to be much less easy to survey.

More or less similar numbers of new patients were found during the LEC as compared with the total number of new patients found by the routine programme in the previous year. Based on experience with LECs in other areas, this seems to be an acceptable outcome. If the total number of new cases found during the LEC is considerably less than the annual number of new patients found by the routine programme, then serious questions can be raised about the way in which the LEC was conducted.

The proportion of children among the cases detected by the RVS is very high. What is obvious is that leprosy is still very prevalent among this group of school children, pointing to an infection early in life. Transmission is still widespread in both districts (but keep in mind that leprosy happens in clusters), even after many years of MDT. Child prevalence may be an indicator of the magnitude of the leprosy problem in an area. The high correlation between child prevalence rates and total prevalence rates for leprosy has been noticed in the past.\textsuperscript{10} Results from a study in Indonesia indicate that seropositivity rates (seroprevalence of antibodies to phenolic glycolipid-I) among school children may reflect the leprosy incidence.\textsuperscript{11} A consistent decline in the proportion of children amongst the total new cases detected over the years may indicate a declining leprosy problem in that area. In a leprosy endemic area, school surveys can still be a valuable tool to monitor the leprosy problem. It seems worthwhile at least in endemic areas, to include school surveys when conducting a LEC.

During the RVS, many PB cases were found, particularly PB single lesion cases. It seems that single lesion PB cases do occur in considerable numbers, but either do not come to the attention of the health services, or are not diagnosed correctly. Many of those will be self-healing and are only found during special activities. From the few examples given, it is clear that during the RVS the health centre staff missed some cases. The only indicator for the delay in detection is the disability grade II rate among new patients. Data from the routine programme are often incomplete and unreliable. From field visits to endemic areas in East Java province, it is estimated that the proportion of new patients with disabilities is at least 15%. A similar figure was found in the sample villages by the routine programme in 1996/1997. Ten percent of new cases found during the RVS (even though there were many children and many PB cases) and 15% by the routine programme, point to late detection, which may be considered a serious problem.

In the literature, there are few reliable estimates of the disability burden from leprosy.\textsuperscript{12} According to Jacques van den Broek, the number of leprosy patients in need of care can be estimated by: \textsuperscript{12} 1) population surveys (RVS, LEC) of persons disabled due to leprosy and extrapolation of the findings to the whole population; 2) inviting all leprosy patients in a catchment area to come forward, simultaneous with for example a LEC; 3) demographic modeling, as was done in Tanzania; and 4) capture-recapture techniques, as was shown in Nigeria.
It has been estimated that 3–4.5% of the population in developing countries is disabled from any cause, including leprosy.\(^1\) The WHO estimates that at present the global prevalence of patients with disability due to leprosy (disability grade II) ranges between 1.3 and 1.5 million.\(^2\) If the population of the developing world is estimated to be 4 billion, than around 1% of the estimated moderately to severely disabled persons in the developing world is due to leprosy. In Gresik and Lamongan this would translate in 600–900 disabled persons due to leprosy. These two districts being endemic, the actual figures may be much higher.

With a total population of 2.03 million in Gresik and Lamongan as per 1998, and a population disability rate due to leprosy of 9 per 10,000, the estimated number of persons disabled by leprosy in both districts will be around 1800. The data regarding the age distribution of new patients found, patients on treatment, and persons affected by leprosy, are incomplete. As such, the expected number of disabled cases cannot be estimated and compared with the number of disabled cases found. The public, especially in the case of minimal (visible) disabilities, will not recognize all cases with disabilities due to leprosy. During the survey, a few known cases with disabilities due to leprosy refused to be examined or even interviewed. These cases were not on MDT, nor registered anywhere. This precluded the possibility of estimating their number by capture-recapture techniques.

The total number of new patients over the past 10 years in Lamongan and Gresik has been 5,600. An estimated 15–25% among them may have had, or developed, a disability due to leprosy during and after treatment. In total an estimated 840–1400 disabled persons due to leprosy. Additionally, many patients who previously (before 1989) received monotherapy may still be alive. In the three well-known leprosy villages in East Java, many persons affected by leprosy originate from Lamongan and Gresik.

In summary, 600–900 disabled persons due to leprosy in Gresik and Lamongan based on extrapolation from WHO figures, 1800 from the RVS results and 840–1400 from the new case disability rate. The outcome of this small study suggests that there is a substantial need for care and socio-economic rehabilitation in those leprosy endemic districts in East Java. Fewer patients would profit from surgical interventions as well.

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