**Original Research Article**

Effectiveness of special awareness campaigns in sustaining leprosy awareness through community participation in rural areas of Maharashtra

Vasudev K. Rokade¹*, A. B. Prabhavalkar²

¹Department of Community Medicine, Gujarat Adani Institute of Medical Science, Bhuj, Gujarat, India
²ALERT-INDIA, Mumbai, Maharashtra, India

Received: 10 December 2018
Revised: 30 January 2019
Accepted: 02 February 2019

*Correspondence:
Dr. Vasudev K. Rokade,
E-mail: researchguide86@gmail.com

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**ABSTRACT**

Background: ALERT-INDIA had launched a strategic programme, leprosy elimination action programme (LEAP) involving all stakeholders, in support of integration of leprosy into general health system. Present study was performed with objectives to understand the effect of focused IEC in transfer of basic knowledge about leprosy, to assess the impact on the level of knowledge about leprosy in the community and to measure the sustainability of knowledge about leprosy over a period of time.

Methods: Community level IEC campaigns under SSD and house to house leprosy IPC were carried out by trained staff of NGOs who partnered with LEAP and by trained community volunteers (CVs) from the villages respectively. The questionnaire assessment for IEC effectiveness through SSD strategy implemented is studied. The questionnaire was administered with the interval of 1 month, 3 months and 9 months after SSD to assess the knowledge retention, perspective and sustainability of leprosy awareness.

Results: The lowest in SSD area was the knowledge about early signs followed by perception about deformity, spread, and cause. In non-SSD area lowest correct responses was in regard with early sign of infectious leprosy followed by spread, infectivity, cause, perception about deformity, patch as early sign and perception about social acceptance.

Conclusions: Focused IEC as a part of selective special drive (SSD) with involvement of CVs properly inducted can increase the level of knowledge and help sustain the leprosy awareness.

Keywords: Awareness, Knowledge, Leprosy, NGO

**INTRODUCTION**

Leprosy, also known as Hansen’s disease, is a chronic infectious disease caused by *Mycobacterium leprae*, a microorganism that has a predilection for the skin and nerves. Though nonfatal, leprosy is one of the most common causes of nontraumatic peripheral neuropathy worldwide. The disease has been known to man since time immemorial. DNA taken from the shrouded remains of a man discovered in a tomb next to the old city of Jerusalem shows him to be the earliest human proven to have suffered from leprosy. The remains were dated by radiocarbon methods to 1–50 A.D.¹ The disease probably originated in Egypt and other Middle Eastern countries as early as 2400 BCE. An apparent lack of knowledge about its treatment facilitated its spread throughout the world. *Mycobacterium leprae*, the causative agent of leprosy, was discovered by G. H. Armauer Hansen in Norway in
1873, making it the first bacterium to be identified as causing disease in humans.\textsuperscript{2,3} ALERT-INDIA had launched a strategic programme, Leprosy Elimination Action Programme (LEAP) involving all stakeholders, in support of integration of leprosy into general health system. Selective Special Drive (SSD) is one of the four components of LEAP.\textsuperscript{4,4} Its primary thrust is to create a chain of leprosy spokespersons in the community. The emphasis is on house to house IEC campaign with the involvement of the community, in partnership with NGOs. This community based strategic intervention is aimed to sustain leprosy awareness and improve the treatment seeking behaviour in the community. LEAP was launched in four backward districts: Gondia, Gadchiroli, Bhandara (tribal districts) and Wardha of Vidarbha region of Maharashtra in 2006-07. The effectiveness of SSD in the rural communities is studied. Present study was performed with objectives to understand the effect of focused IEC in transfer of basic knowledge about leprosy, to assess the impact on the level of knowledge about leprosy in the community and to measure the sustainability of knowledge about leprosy over a period of time.

**METHODS**

Present retrospective study was conducted from June 2006 to April 2007. Community level IEC campaigns under SSD and house to house leprosy IPC were carried out by trained staff of NGOs who partnered with LEAP and by trained community volunteers (CVs) from the villages respectively. The questionnaire assessment for IEC effectiveness through SSD strategy implemented is studied.

**Inclusion criteria**

Inclusion criteria were natives belonging to that area/community; those who were willing to participate.

**Exclusion criteria**

Exclusion criteria were those who were not willing to participate; those who had systemic diseases.

The aspects of knowledge and perceptions examined in all the three rounds were early signs and symptoms; cause; mode of transmission; infectivity and curability. Results of SSD intervention studied over a period of 9 months are presented in this paper. The villages (with 1500-2500 population) from tribal and non tribal districts where SSD was undertaken and the non-SSD areas in the same districts were selected by lottery method for the study. 65 trained staff from four non-leprosy NGOs were involved in community level IEC campaign. 718 trained CVs were inducted and involved in house to house leprosy campaign.

The questionnaire was administered with the interval of 1 month, 3 months and 9 months after SSD to assess the knowledge retention, perspective and sustainability of leprosy awareness. The respondent and the interviewer were constant in all three rounds in order to minimize individual variations and perceptions.

**Statistical analysis**

The data was coded and entered into Microsoft Excel spreadsheet. Analysis was done using SPSS version 15 (SPSS Inc. Chicago, IL, USA) Windows software program. The variables were assessed for normality using the Kolmogorov-Smirnov test. Descriptive statistics were calculated.

**RESULTS**

Table 1 describes the demographic information of the study participants.

| Table 1: Demographic information. |
|----------------------------------|
| **Variable** | **Number** | **Percentage (%)** |
| **Age in years** | | |
| 15-35 | 537 | 44.7 |
| 36-55 | 663 | 55.5 |
| **Gender** | | |
| Male | 665 | 55.5 |
| Female | 535 | 44.5 |
| **Level of education in SSD area** | | |
| Educated | 544 | 90.7 |
| Un-educated | 56 | 9.2 |
| **Level of education in non- SSD area** | | |
| Educated | 365 | 60.8 |
| Un-educated | 235 | 39.1 |

**The silent characteristic of the respondents**

Age, sex, education: 36.7% respondents were between 15 to 35 yrs and 44.7% were between 36 to 55 yrs age group. 55.5% respondents were male and 44.5% are female respondents. Most of respondents were educated (76%). Level of education among respondents from SSD area is higher than respondents from non-SSD area being 90.7% and 60.8% respectively.

**Occupation and income:** Proportion of farmers was higher in SSD area (62.7%) than in non-SSD area (39.8%). Proportion of labourer was higher in non- SSD area (32.5%) than in SSD area (13.7%). Most of respondents were from BPL (below Poverty Line) category (71.2%). In non-SSD area 81.6% fall in income group below Rs.1000/- per month.

It is noticed that in pre-SSD test 4 questions of 10 in SSD area and 3 questions in non-SSD area received correct responses between 25-50%. The four areas were regarding infectivity, curability and social acceptance. The lowest in SSD area was the knowledge about early signs followed by perception about deformity, spread,
and cause. In non-SSD area lowest correct responses was in regard with early sign of infectious leprosy followed by spread, infectivity, cause, perception about deformity, patch as early sign and perception about social acceptance. Post-SSD analysis in SSD areas reveals that correct responses were significantly higher than in the non-SSD areas. Questions attracted over 80% correct responses (7 out of 10), 2 questions attracted 50 to 75% correct responses in contrast with the responses in non-SSD area. The responses in non-SSD areas where 4 questions each got less than 50% and between 50-75% correct responses. The other responses were not correct. Highest correct response was about knowledge about curability being 87.5% in SSD and 75.7% in non-SSD areas. The overall comparative analysis indicates influence of SSD intervention in transferring knowledge of leprosy in the community to a greater level over a period of time. The marginal increase in the knowledge and perceptions were observed in non-SSD areas, which was due to the fact that at the end of the interview in each round, wrong information and perceptions were corrected and correct information was given to the respondents.

Figure 1 (A and B): Various leprosy IEC programmes conducted by trained NGO staff and CVs after pre-test in SSD areas.

DISCUSSION

Fewer than 1 in 20 people (5%) exposed to M. leprae develop clinical disease. Host cell-mediated resistance determines whether an individual will develop paucibacillary (PB, high resistance) or multibacillary (MB, low resistance) disease. For PB disease, the incubation period is up to 5 years, and for MB disease it is 20 years or longer.\(^7\) The global registered prevalence of leprosy cases at the beginning of 2011 stood at 192,246 cases, which is less than the 228,474 new cases detected in 2010.\(^8\) The reason for the disparity is that some new cases complete their treatment within the year and get removed from the registry, finding of present study were similar to study done by Arun et al 2013.\(^9\)

A definite increase in correct responses in SSD areas is observed at the end of 3rd round - 9 months post-SSD. This is confirmation of the fact that the observations in the first two rounds were real in terms of imbibing the knowledge and perceptions about leprosy.\(^10,11\) Similarly the question pertaining to the early sign (SOS) of infectious leprosy (LL) got 49.3% correct response in 3rd round against just 16% in pre-Test in SSD areas with almost a 3 fold increase. The same was merely 5.5% in non-SSD area. These observations were in agreement with studies done by Skolnik.\(^1,2\) This huge difference can be attributed to the fact that IEC during SSD was higher focused on non-patch oriented approach. This resulted in increased awareness and voluntary reporting of significant number of untreated lepromatous cases identification during SSD. The marginal increase in knowledge and perceptions observed in non-SSD areas was due to the facts that at the end of the interview in each round wrong information and perceptions were corrected. Correct information was given to the respondents. Knowledge about the availability of effective leprosy treatment is raised from 39% to 87.2% in SSD areas against 59.2% to 66.5% in non-SSD areas. As regards social attitude and relations analyzed: Initial 40% correct responses in SSD areas about perception in view of isolation of leprosy patient increased by two folds (from 40% in pre-test to 82.2% in 3rd round). In non-SSD area during pre-Test. This changed marginally at the end of 9 months in SSD areas. Level of perception about marriage of leprosy patient was higher at the end of 9 months. The increase was much higher in SSD areas (81.7%) than in non-SSD areas (54%). As regards the health seeking behaviour analyzed: Preference to seeking leprosy advice from GHCS was significantly appreciable in SSD area (85.2%) than in non-SSD area (68.7%) at the 3rd round. Willingness to take MDT from local health centre was 22% higher in non-SSD area (80.8%) in pre-test than in SSD area (66.2%). This has considerably changed in SSD areas (84.3%) at the end of 9 months.

CONCLUSION

Focused IEC as a part of Selective Special Drive (SSD) with involvement of CVs properly inducted can increase the level of knowledge and help sustain the leprosy
awareness. Our study in the rural community confirms this. Non leprosy NGOs and community level volunteers can play crucial role in mobilizing community support through leprosy IEC campaigns and can be trained & involved effectively to transfer the basic scientific facts about leprosy to create awareness in the rural community. Such an involvement of NGOs and CVs from villages widens the scope of new case detection, as they continue to be spokespersons for leprosy in their village communities even after SSDs.

ACKNOWLEDGEMENTS

We thank the team of investigators who collected data from Wardha and Gondia district of Maharashtra. We also thank the LEAP Support Team for the guidance and assistance in data analysis for this study.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Rokade VK, Prabhavalkar AB. Effectiveness of special awareness campaigns in sustaining leprosy awareness through community participation in rural areas of Maharashtra. Int J Community Med Public Health 2019;6:1139-42.