REVIEW

Promoting early detection in leprosy – a literature review to identify proven and potential interventions addressing patient-related delay

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Summary

Objectives The objective of the literature review was to identify proven and potential interventions to promote early diagnosis and start of treatment in leprosy, specifically, forms of intervention addressing needs at the local or primary level.

Design Using a structured search procedure, we identified recent leprosy-related publications describing proven interventions. To identify potential interventions the search was extended to publications assessing knowledge and attitudes towards leprosy and extended again to identify publications relating to patient-related delay in the context of other infectious diseases.

Results The review identified just 19 publications reporting leprosy-related interventions that included a form of evaluation of which only 10 directly addressed patient-related delay. These included health education interventions focussed on people directly affected by leprosy, their family members and other key individuals or groups within the local community. We identified no reports of interventions focussed specifically on the needs of women.

Conclusions Our conclusion is that the evidence base available to inform the choice of small-scale interventions to promote early detection at the primary level is extremely limited. There is an urgent need to develop and extend the range of proven interventions, specifically those that address the needs of women, those that explore and develop the health promotion potential of people previously affected by leprosy and those that exploit the potential of individuals with leadership roles within the community. This will require careful attention to planning, implementation, evaluation and reporting of interventions.

Introduction, definitions and background

The present paper describes a review of literature describing interventions intended to promote early detection in leprosy, focussing on interventions addressing patient-related delay in diagnosis and start of treatment at the primary level. The review identified proven interventions...
and potential interventions which are the evidence base that informs the choice of interventions to promote early detection.

Delay in diagnosis and start of treatment in leprosy is a recognized risk factor for nerve function impairment at the time of diagnosis and start of treatment. However, the impact of delay is highly variable. The great majority of people exposed to the disease never develop symptoms. Others develop symptoms only slowly. Only some of those affected go on to experience active forms of disease leading to nerve impairments with the possibility of secondary disabilities. While delay increases the risk of nerve impairment, early diagnosis and start of treatment minimizes the impact of the disease.

However, while delay may contribute to impairment, it can also be considered as an outcome, the result of complex cultural, social and economic beliefs and practices relating to disease in general and to leprosy in particular. Typically, these beliefs attach little significance to the early symptoms of leprosy and associate the disease with visible disabilities and deformities. The same belief systems may prescribe and limit options for help-seeking with the effect that decisions to seek medical diagnosis and treatment are delayed. The high visibility of poor treatment outcomes reinforces traditional beliefs and stigmatizing attitudes while good outcomes with no disability remain hidden.

Continuing reliance on systems of alternative and traditional medicine further complicates decisions to seek help. While there is a great variety and variability, the role of alternative practitioners is culturally defined, accepted and accessible. Since they deal with the symptoms of disease in their cultural setting, the services offered continue to be the recognized and preferred source of help in many communities. In contrast, Angel and Thoits draw attention to the difficulties people experience in their contacts with health services, identifying issues of language, behavioural norms and communication that may prevent effective diagnosis and treatment. After presenting to the health services delay may accumulate as health service professionals take time to eliminate other diagnoses and confirm the possibility of leprosy.

Once leprosy is suspected or diagnosed, people may conceal or deny their disease or seek second or third opinions before committing themselves to treatment.

It is apparent, therefore, that delay in diagnosis and start of treatment accumulates as the result of a series of help-seeking actions that reflect local beliefs and practices. The present review has therefore focussed on small-scale interventions intended to address such beliefs and practices, in turn promoting appropriate help-seeking that will lead to early diagnosis and start of treatment.

**Objective**

Our interest was in the effectiveness of interventions addressing local attitudes and practice through the motivation and participation of community leaders, teachers, religious leaders, people currently or previously affected by leprosy or other groups and individuals within the local community. The objective was to identify local, small-scale interventions proven to be effective in encouraging people developing the early signs of leprosy to seek timely diagnosis and start of treatment.
Methodology for the literature search

We adopted a systematic approach to the literature review that ensured that we identified and synthesized all the relevant literature. We identified keywords and constructed a formal search procedure which was replicated across nine publication databases (see Figure 1). This allowed us to identify small-scale, local interventions addressing local needs and focussed on the needs of people currently or previously affected by leprosy, their family members or friends, neighbours or members of the local community, including local schools, teachers and religious or community leaders. Publications describing interventions addressing the attitudes and skills of health service workers were also identified but are not reported here. Interventions including an evaluation were identified as primary sources, those lacking

Figure 1. Elements of the literature search strategy.
validation as secondary sources. Excluded were publications prior to 1990 and large-scale interventions organized at a national or state level, for example, National Leprosy Elimination Campaigns. Also excluded were publications relating to treatment compliance. Though not reported in here, we applied the same search procedure to other disease, including Buruli ulcer, TB and HIV/AIDS.

The search procedures were developed and applied during the months April to August 2004.

For publications recognized as primary sources we tabulated details of authorship, country, type of intervention, target population, method of evaluation, a summary of findings and comments.

Results of the literature search

The search procedure identified a total of 75 publications describing interventions or assessing knowledge or attitudes towards leprosy. Nineteen of these described a form of evaluation and were recognized as primary sources. These are grouped in the five types of intervention following.

- Health education activities focussing on community groups (4 primary sources).
- Educational or counselling activities among affected people (2 primary sources).
- Educational activities in schools, focussing on teachers, children or children’s ability to influence the knowledge and attitudes of their parents (2 primary sources).
- Educational activities among students, including medical students (1 primary source).
- Training of traditional healers or practitioners in alternative medicines (1 primary source).

The nine remaining primary sources included interventions in the form of educational activities with health service staff (2), active case finding (2) and diagnostic testing (5). No primary sources were found describing interventions addressing problems encountered by women or addressing stigmatizing religious beliefs and practices. The next five sections follow the five headings above, reporting primary and secondary sources and summarizing the potential for such interventions. The final three sections present items of discussion, followed by conclusions.

Health education activities focussing on community groups

The review identified four primary sources describing validated health education activities in local communities. Two other publications described the preparation of culture-specific health education materials but did not evaluate their impact. A further 18 publications reported the results of surveys of knowledge, attitude and practice towards leprosy.

Van den Broek et al. reported the 7-year evaluation of a health education campaign in a region of Tanzania. For their evaluation, the authors used structured and semi-structured interviews to collect information from children, medical staff and local people in the project area and found evidence that the programme had increased knowledge and decreased the tendency to stigmatize among school children. Factors associated with persistent stigmatizing attitudes included low level of education, rural residence, older age, female gender and Moslem religion. To induce behavioural change the authors recognized the need for sustained campaigns covering a broad sector of the community. They recommended a focus on rural
Croft and Croft\textsuperscript{12} explored knowledge and attitudes towards TB and leprosy, comparing areas with high and low levels of health education input. In the low input area, they found that knowledge of the two diseases remained low and was worse for leprosy than TB. In the higher input area they found increased levels of knowledge and indications of changed behaviour, but concluded that changes in attitude lagged behind changes in knowledge.

Krishnatray \textit{et al.}\textsuperscript{13} assessed the relative effectiveness of alternative health education approaches among different caste groups in three rural communities in India. Data were analysed using a factorial design and multivariate analysis of variance. Participants were randomly assigned to alternative “treatment” groups. The intervention for the participation group involved shared dialogue and care activities with staff and patients over 3 days. The diffusion group heard talks on leprosy. The control group were interviewed. In assessing post-test differences, baseline assessments were used as covariates. The authors found no differences between castes but significant differences in knowledge of spread and in behavioural involvement. Variables found to account for differences were knowledge of cause and perception of risk. The participation group had the highest scores for knowledge of cause and the lowest scores for perception of risk. Individuals who spent time learning from those directly affected were found to be much more receptive to the health education message. Involving key individuals from the community in such a programme may be an effective way to influence an entire community.

Crook \textit{et al.}\textsuperscript{14} compared knowledge, attitude and practice towards leprosy in two different areas of Bombay. In the trial zone, the intervention involved 12 months of systematic and carefully planned health education activities. In the control zone, a shorter term mass education campaign was conducted. Independent evaluation found continuing ignorance of disease and treatment in both zones, though there was greater knowledge in the trial zone. There was continuing ignorance of the early signs of leprosy. Women were generally less aware than men. This study design would have been improved by including an assessment of knowledge at baseline in each zone. However, it does draw attention to the difficulties faced in spreading knowledge about a subject that may not be seen as a priority. The findings in relation to women are of interest, given the key role played by women in identifying the early symptoms of disease among children.

In two early publications, Chen\textsuperscript{15,16} applied procedures of human behavioural research to develop health education materials tailored to specific communities and cultures. It appears no formal evaluation of their impact has been published. The review identified a further 18 publications describing surveys and anthropological studies in 11 countries that assessed knowledge and attitudes towards leprosy or contrasted knowledge and attitudes in selected community groups.\textsuperscript{6,17–31} Attention is also drawn to the impact of culture on the cognitive structure of illness and the need for health education messages and materials tailored to local cultures.\textsuperscript{5,32}

While there is a limited evidence base for effective interventions, we identify the following as important issues arising from the reported interventions:

- The need to identify problem groups within the community who persist in traditional beliefs and attitudes.
- The need for a long-term view in presenting health education.
The need for culturally sensitive educational materials.
The potential for people affected by leprosy to influence and change the attitudes of others in the community.

Educational activities among affected people

The review identified only two primary sources reporting interventions focused on people directly affected by leprosy. Working in Nepal, Floyd-Richard and Gurung used group counseling among individuals receiving MDT to encourage unity, to address shared concerns, to develop a caring attitude towards others, to develop an understanding of stigma and to overcome its harmful effects. Participatory evaluation was achieved by asking those involved to assess the changes they had experienced as a result of the counseling. In Brazil, Pennini et al. found that a simple education program with new patients was as effective as contact survey in locating new cases.

Fourteen secondary sources covering seven different countries reported knowledge and attitudes among people affected by leprosy or the impact of the leprosy diagnosis. In Ethiopia, Bekri et al. identified factors contributing to delay in diagnosis and start of treatment, including delay resulting from referrals and late diagnosis within the health services. Other publications were concerned with routes to diagnosis and start of treatment, the impact of the leprosy diagnosis and patients’ satisfaction with health services.

Again, the review has drawn attention to the limited evidence base for effective interventions. Further research is needed to validate the findings of Pennini et al. in Brazil and Floyd-Richard and Gurung in Nepal. Their findings suggest that individuals directly affected by leprosy can be encouraged to come to terms with their disease. With growing self-confidence they have the potential to share their experiences with others and in turn promote early detection.

Educational activities in schools

Two publications describe validated interventions in schools. One other explored the knowledge and attitudes of school teachers.

Jacob et al. made baseline assessments, conducted school lessons and then set a homework project in which children involved their parents. The authors then assessed changes in attitudes towards leprosy among both children and parents. They found children improved in knowledge but not in attitude while parents had only modest improvement in knowledge and unchanged or worsened attitudes. They concluded that, although there had been some transfer of information from the children to their parents, the homework assignment had not proved effective. Since there was an increase in negative attitudes among some parents, the authors concluded that one educational session was not enough. There was a need for on-going, continuous health education. They also called for further studies to field test alternative forms of intervention. Similar work by Bhore et al. found that the approach was effective in communicating knowledge but had no direct impact on attitudes.

These negative findings relating to attitudes suggest this approach is too complex. Questions arise about children’s ability to communicate health education messages that challenge social norms. Incomplete or inadequate communication may have the opposite
effect to that intended. An alternative approach may be to research interventions focussed on
combined groups including children, their parents and their teachers.

Survey results reported by Rajaratnam et al. suggest that action is needed to improve the
knowledge of leprosy among school teachers. Once they become aware, teachers are in a
position to influence opinion in their communities and among those they teach. Similar
interventions might address the knowledge and attitudes of individuals leading women’s
groups, religious groups or development groups, encouraging them to influence the attitudes
of others.

Educational activities among students, including medical students

One publication reported a validated intervention with medical students in India. Another
described knowledge and attitude towards leprosy among university students in Brazil.

Shah et al. assessed the impact of wall posters intended to communicate information on
leprosy to medical students in colleges in Mumbai, India. Impact was assessed by a survey of
all students taking a relevant course module. Responses were compared between those who
had seen the posters and those who had not. There was a small increase in awareness among
those who had seen the posters. The students themselves asked for posters with more impact.
It is not clear if changes in attitude matched changes in knowledge. Ramirez-Soltero found
lack of awareness and stigmatizing attitudes among university students in Brazil. Students in
general might be considered a strategic focus for health education activities.

Training and potential role for traditional healers

One publication reported a validated intervention with practitioners in traditional or
alternative medicines. Kaur et al. taught a group of traditional healers to identify the early
signs of leprosy. Training was provided through a series of lessons over several months.
Compared to a baseline measure, the authors found an initial increase in knowledge.
Knowledge increased after further training. The training resulted in referral of 12 suspect
cases with only the early signs of disease. The authors draw attention to the potential of
traditional healers in promoting the control of leprosy and other diseases.

The research suggests that where alternative or traditional medicines continue to be
valued, establishing communication and developing awareness among local practitioners is
an area with potential for promoting early detection. This may form part of a wider
programme meeting the health needs of women and children, the treatment of simple skin
diseases, the identification of the early signs of TB and the prevention of HIV/AIDS.

Discussion

WHAT IS EARLY DETECTION?

Early detection in leprosy is defined as diagnosis and start of treatment before the onset of
nerve impairment. This definition gives rise to two areas for concern. Firstly, failure to set a
specific time limit defining persistent symptoms ignores delay that does not result in
impairment. Consequently, it gives insufficient weight to factors contributing to delay and so
leaves individuals with the most active forms of disease at risk of impairment. It follows that
there is an argument for defining “persistent” symptoms that should encourage those affected to take early decisions to seek help. In contrast, there are good reasons to encourage caution. Some individuals develop the early signs of disease but then experience spontaneous recovery. Others present with symptoms relating to more or less common skin conditions. In both these cases it is important to avoid over-diagnosis. Rather than “early detection”, the term that is central to WHO publications relating to the Campaign for the Elimination of Leprosy,53 the focus is now moving towards “timely detection” (draft report of WHO Strategy to Sustain Leprosy Services in Asia and the Pacific), a term that reflects the need for balance between detection that is neither too early nor too late. It is important to note that most published work does not make this distinction.

EVALUATION METHODOLOGY

The review has drawn attention to the small numbers of interventions that have been adequately evaluated. Contributing factors may include limited time and resources, a lack of familiarity with the methodology and difficulty in identifying a specific measure of outcome. A minimum requirement for a quantitative approach to evaluation is the identification of a measurable outcome allowing the comparison of a pre-intervention baseline assessment with an end of follow-up assessment using an appropriate sample size and statistical test. The alternative is to rely on qualitative methods such as semi-structured interviews and focus group discussions to collate information and compare assessments from multiple sources.

More complex designs may assess the impact of alternative high and low input interventions in different areas. Consistent application of these methods would be an important step towards the development of the essential knowledge base.

GENDER-RELATED ISSUES

While we found no primary sources, the review identified ten publications describing women’s experiences in relation to the impact of leprosy and access to health services. Women are more likely to delay and to present with impairment.54 Women experience greater social impact.55–58 They experience more problems in accessing local health services.59 Other publications have described the experience of women affected by leprosy in Nepal, Indonesia, Nigeria and Brazil.60–63 Wide ranging socio-cultural, economic and service factors were found to influence female participation and delay. The authors of these publications identified the need for community and patient education to combat traditional fears and beliefs and called for improved case finding and case holding, where possible with the involvement of people previously affected by leprosy.

With such plentiful evidence for the differential impact of leprosy on women, it is remarkable that there are no reports of interventions seeking to address these issues. Awareness of the potential of women as health care providers64 is reflected in the more general role they play in health promotion65 and as lay workers.66

ISSUES-RELATING TO RELIGIOUS BELIEFS AND PRACTICES

While published work includes references to religious beliefs and attitudes towards leprosy there have been no reports of interventions seeking to reassess these in the light of what is now known about the cause. Ahmed Mohamed67 discussed attitudes towards leprosy and
those affected by the disease in the light of teaching in the Koran. Kaplan\textsuperscript{68} suggested that biblical writings concerning leprosy should be interpreted as general skin diseases. In practice, lack of awareness and negative attitudes is found among the adherents to both Muslim and Christian religions.\textsuperscript{21} Where local attitudes pose a threat to early decisions to seek help there is the opportunity for interventions that encourage religious leaders to differentiate between core teachings and any local practices arising from traditional beliefs about the disease.

PHARMACISTS AND VILLAGE DOCTORS

Our review found no papers describing interventions or evaluating the potential role of local pharmacists or the owners of medicine shops as a source of referrals. Van den Weg\textsuperscript{6} reported the use of medicines bought from local pharmacies as a popular first response to skin conditions. There was a similar finding from work in India and Bangladesh.\textsuperscript{69} Unpublished work from Thailand (Nicholls P. G., unpublished report of findings from fieldwork during training sessions with government field staff in Thailand, November 2003) identified local pharmacies and medicine shops as the first choice for medicines to treat skin conditions. Rather than focussing on these preferred sources of help, it appears that the focus for health education has been in clinics and hospitals. Similarly, little has been written about the potential of village doctors in screening and referral.

ACTIVE CASE FINDING

While the review identified primary sources describing approaches to active case-finding in India\textsuperscript{70} and Indonesia\textsuperscript{71} and secondary sources in India\textsuperscript{72} and South Africa\textsuperscript{73} these fall beyond the scope of the present report. In the context of integrated leprosy services such activities may not be a priority. However, community groups and voluntary organizations working to complement local health services have the opportunity to research and develop roles that might include support for newly diagnosed cases and their family members and contact surveys. Mehta \textit{et al.}\textsuperscript{74} have reported on one such intervention.

OPPORTUNITIES FOR FUTURE INTERVENTIONS

The present review identified just 19 published reports of evaluated interventions intended to promote early detection in leprosy. Of these, only 10 sought to address patient-related delay. Much more could be done to develop and assess such interventions. There is an urgent need to develop an evidence base that will support informed decision-making in the promotion of early detection. Conclusions and recommendations arising from the review are summarized as follows.

\textit{Responding to the special needs of women}

Addressing the specific needs of women and equipping them for a general health promotion role within the family should be a priority.

\textit{Educational activities among affected people}

Educational and counselling activities with people directly affected by leprosy may enable them to cope with the impact of their disease and develop a role in health promotion.
Educational activities in schools and among students and their family members

Specific interventions are needed to promote knowledge and attitudes among students, teachers, school children and their family members.

Role of key individuals and community groups

More research is needed to identify how the delivery of leprosy health services may benefit from involving practitioners in traditional or alternative medicines who are a recognized source of help in their communities. This may be extended to include local pharmacists and village doctors and be responsive to a range of diseases.

FOCUS FOR OTHER FORMS OF INTERVENTION

- Aspects of religious teaching or practice that promote or sustain stigma.
- The role of key individuals within the local community, including political leaders and the members of development groups and co-operatives.
- Development of new roles for voluntary organizations seeking to complement the role of local health services.

METHODOLOGICAL ISSUES

- The review identified the need for improved planning of interventions relating to design and evaluation.
- Alternative quantitative or qualitative methods may be used.
- There is a need for materials and messages that are sensitive to the local culture.
- There is a need for a long-term commitment to communicating the message.

Conclusion

The primary conclusion from our literature review is that much more needs to be done to build knowledge about the effectiveness of interventions promoting early detection in leprosy. This requires greater attention to the processes of planning, implementing, evaluating and reporting of interventions. Among the many forms of potential intervention to promote early detection we identify priorities as follows:

- Interventions that address the specific needs of women and develop their role in health promotion in general, including leprosy.
- Interventions that support those directly affected by leprosy and develop their health promotion potential.
- Interventions targeting strategic groups and individuals within the community.

Reporting of interventions with improved planning and evaluation would contribute to the development of the evidence base that is essential for informed decision-making in the future.
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