A Review of Health Education in Leprosy

Leprosy or Hansen’s disease is an age-old problem that has yet to be completely controlled. It is estimated that there are between 10–12 million leprosy cases in the world. However, only half the number of world leprosy cases were registered as of 1985. Leprosy may be viewed as a risk in areas where the prevalence of cases is over 1 per 1000. Therefore, 56 countries in the world may be thought of as at risk for leprosy. Health education is an integral part of leprosy control. Unfortunately, health education is often underrated in value and misunderstood as to its proper place in leprosy disease control. Joshi says “the present day leprosy control programme is based on three activities namely survey, education (regarding health) and treatment.” Joshi further states that “treatment is emphasized equally by all, but regarding survey and health education it is observed that most of the workers emphasize only on survey and practically neglect health education work.”

Health education's role in leprosy control. It is important to understand the purpose of health education in leprosy. Health education encompasses more than educational methodologies or the dissemination of new health ideas to people. One leprosy worker expressed his misunderstanding of health education in Subbiah in this statement: “I have worked for 16 years as a leprosy worker. When I came to this training, I thought I will learn how to display posters on occasions like Anti-Leprosy Day and how to place slides in a cinema or display leprosy films. But in this training, I learnt that, if health education was added to our work, we would have gotten better results. ...We did not know how to contact people. We now think that there is a better way of approach to people.”

At the Post-Congress Workshop on Health Education in 1984 of the Gandhi Memorial Leprosy Foundation, the following policy statement was reached concerning health education in leprosy. They stated: “Health education refers to the process of assimilation of scientific health knowledge, attitudes and behavior in the health culture of the people. Health education in leprosy aims at ensuring community participation in leprosy control programs. Health education therefore addresses itself to the patients, their families, the community, and to all components of health services.”

The International Federation of Anti-Leprosy Associations (ILEP) set forth their aims of health education as: “a) To correct, by dissemination of the truth in simple terms, popular conceptions about leprosy and the stigma that these engender. b) To increase the index of suspicion about leprosy in first, the patient himself, so that he seeks advice early, and second, in all medical workers, so that they consider the possibility of leprosy at an early stage in the disease. c) To create public support for leprosy patients in their efforts to obtain treatment for their disease. d) To ensure that leprosy patients maintain their place within their family and community. e) To show a realistic appreciation of the benefits of antileprosy treatment in preventing progress of the disease and deformity, so that patients will continue their treatment as long as necessary.”

ILEP states that effective treatment and care is necessary for health education to be effective. Understanding leprosy health behavior, society’s attitudes, the simple instruction of the signs and symptoms of leprosy, and community participation are all necessary for the success of leprosy health education aims. Health education should produce behavioral change in overcoming the sociocultural aspects of leprosy stigma, identification and recognition of the disease, continuation of antileprosy therapy, and

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promotion of rehabilitation (both social and physical).5

Participants at a 1978 meeting entitled “Strategy on Leprosy Control” in India were given questionnaires which included the topic of health education. Of the 106 participants all said that health education has not achieved much progress in the area of leprosy control. The obstacles in health education in leprosy control as listed by the participants included: stigma, disease duration, lack of funds, and disease complexity which included disease transmission. Health education was listed as the third of the five main problems that the Indian government had neglected in funding and management.6

According to Sandler, “health education becomes a high priority need in programmes against diseases whose victims have become a prey to social prejudices as in the case of patients of leprosy.” Such age-old attitudes are well engrained in our culture. Such stigmas, when attached to misconceptions such as “leprosy is hereditary,” thus stigmatize whole families and communities. Therefore, the health education program must be sustained indefinitely to be effective. Health educators should utilize the help of community leaders such as doctors, traditional healers, teachers, and religious leaders. These individuals can be of great help in leprosy health education, especially among illiterate populations such as in India.7 Giri refers to the leprosy health educator as an organizer, a planner and, in a way, a social reformer. Leprosy health educators should have a personal motivation for their work. Giri says that “none can do health education just because he has been told to do it.” Giri feels that of the three health education approaches the group approach is more effective than the mass or individual approach.8

Sociocultural aspects of leprosy in health education. Overcoming stigma should be the first step in leprosy health education programs. Fear and misconceptions are barriers that need to be overcome in the leprosy stigma. Early in health education programs there should be an emphasis on the identification and recognition of leprosy. However, if the stigma problem has not been addressed previous to the leprosy identification phase of the program then the results could be disastrous. People will often avoid detection until their leprosy has developed into a more advanced stage. This makes the prospects for treatment and cure more difficult. Without addressing the concepts of stigma before the identification phase the result may be ostracism. Philips tells the story of a young school boy in Uganda who was dismissed from school and later made to leave home after his leprosy was detected. One Ugandan chief tried to close down a shop when it was discovered that the owner had leprosy.9 Moffat Bwanali, a former leprosy worker in Malawi, told of the unfortunate situation that developed when hundreds of villagers were forced out of their home villages after the identification phase of a leprosy control program. These leprosy-identified individuals had to create a new village at the expense of the control program.10

Valencia mentioned that the stigma in Indonesia could result in loss of job and family. In India females suffering from leprosy often are unable to get married.11 In North Sulawesi, Indonesia, as in other places, leprosy is viewed as a curse from God. It is interesting that Bijleveld points out in his survey in North Sulawesi that “no one ever cited a passage from the Bible or Koran to us to support this notion of leprosy as a curse.” Actually, teachings in the Koran and the Bible may be an aid, especially with the aid of local spiritual leaders, to overcome health notions that are unsupported by the respective faiths. Black magic is also believed in North Sulawesi as a cause of leprosy. Such a curse may have been the result

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9 Bwanali, M., personal communication, July 1986.
of martial problems, land questions, or jealousy. In The Philippines, according to Jalardoni, "a great majority of them (leprosy patients) believed that the disease is brought about by the Fatigue-Heat-Cold triad." This is locally called "pasma." The pasma concept does not necessarily result in leprosy stigma directly. However, health education needs to be applied to correct this misconception of disease transmission.

**Health education and leprosy knowledge.**

Shetty, et al., utilized the leprosy knowledge, attitudes and practices in Mangalore, India, as the basis for a health education program. Correct responses to the question of the "cause of the disease [leprosy]" for the community (non-patients) and for leprosy patients were 8% and 22%, respectively. For the question of "symptoms of the disease," correct answers for the non-patients and leprosy patients were 15% and 42%, respectively. For the question concerning the "spread of disease to others," the community responded favorably by 54% while the leprosy patients responded at 41%. The "mode of spread—due to close proximity to a case" was answered correctly by the community at 19% and by leprosy patients at 12%. This study demonstrated an overall lack of knowledge in the basic areas of leprosy. The health education program was then designed to address these points. Also, the authors emphasized the need for health education for the leprosy clinic patients.

The Indian National Leprosy Control Programme (NLCP) in 1983 surveyed the community awareness of leprosy in nine villages and six urban slums in Tamil Nadu State, India. These surveys were done as part of an evaluation of the health education section of the leprosy control program. The results indicated a high lack of knowledge of leprosy causation. The percentages of leprosy patients and community (non-patients) that had insignificant-to-little awareness of disease causation were 75% and 81%, respectively. Further studies by the NLCP indicated that the majority of survey participants had poor overall understanding of the causation and prevention of leprosy deformities. The majority of people surveyed (73%) were against casual social contact with leprosy patients. When questioned on possible community suggestions and contributions to the leprosy control program, 79%-84% of the community did not respond to this question. Only 24% of the community responded with the suggestion of the need for health education and rehabilitation. Kumar, et al. responds that "it is surprising to note that our NLCP infrastructure and mass media have not fulfilled their responsibilities of educating the communities." The study concluded that community leaders should be utilized more effectively. Also, they concluded that there needs to be better evaluation of the leprosy health educators.

A study in Agra, India, indicated that only 8.5% of uneducated leprosy patients and 20.7% of educated leprosy patients (with an eighth-grade education or above) understood the cause of leprosy. Pal and Girdhar indicated that "the rest (of the patients) considered that the disease was due to past sin, fate, curse of God and other causes." The authors emphasized the essential need for health education in the control of leprosy. In this study it seems evident that if the leprosy patients have little understanding about the disease then the community around them may have even less.

**Research studies in health education in leprosy.**

Matthews and Jesudasan evaluated a leprosy health education project in South India. Knowledge, attitude and prac-

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lice (KAP) surveys were administered to the community before and after the project core. The health education core included information, motivation, and action stages. In response to the question “What is the first sign you can see?” only 16% of the public and 46% of the leprosy patients were able to recognize the sign of the patch. A greater percentage however recognized a patch with anesthesia as a sign of leprosy. A majority of survey participants, however, said they would seek medical attention if their skin showed signs of the patch. A majority of both the public and leprosy patients gave incorrect answers or did not know the cause of leprosy. Various erroneous answers included God’s will, fate, karma, sin, hereditary causes, sexual immorality, spoiled blood, and bad water. In response to the question “How do you prevent leprosy from spreading in the community?” 34% of the public and 30% of the leprosy patients answered allopathic medical services and checkup. The responses of “don’t know” for method of prevention for the public and for the leprosy patients were 24% and 37%, respectively. An unusual answer to the method of prevention by 1% of both public and leprosy patients was that “patients should be put to death.”

With regard to rehabilitation of treated leprosy patients without deformities, the majority of the public and of the leprosy patients believed that these treated patients could work at hard labor or without restriction. About two thirds of both the public and leprosy patient respondents felt that treated leprosy patients with deformities should be restricted from major forms of work. Responses to the question “Why did you not go for treatment earlier?” included lack of leprosy recognition, thought patches were insect bites, thought leprosy was incurable, thought it would just disappear, did not know where to go for treatment, the treatment location was too far, and some (3%) hoped to be cured by traditional medicine. Therapy compliance was also found to be a problem in the study population. Of those questioned, 43% ceased treatment; only 5% of the patients finished the therapy course. No single reason predominated. While half of the leprosy patients questioned have anesthesia sites, 42% of the respondents indicated that they took no precautions for foot and hand damage. This study demonstrated the need for health education in all phases of leprosy health promotion and disease control.

The evaluation of the project by Matthews and Jesudasan showed a favorable attitude change after the program in both the general public and the leprosy patient groups. The attitude mean score percentages for the general public before and after were 12 and 43, respectively. The attitude mean score percentages for the leprosy patients before and after were 3 and 50, respectively. The KAP showed improvements in the areas of knowledge, attitude, and practice. Matthews, et al. stated “an intermediate objective of the leprosy project was to improve the knowledge of and attitude towards leprosy of patients and general public so as to achieve the required change in behavior.” The article also mentioned the behavior change theory of Matthews. This theory states: “that an action will be taken depends on the product of three factors: 1. The perceived probability that the action will lead to the goal (p), 2. The perceived importance of the goal (i), 3. The perceived effort required (e).” A low figure for the formula ip(i–e) results in little action or behavioral change according to Matthews. Unfortunately, these calculations were not analyzed as to their relationship to information, motivation and action in Matthews’ South Indian study. For effective health education in this area of 200,000 people, Matthews, et al. concluded that five workers would be needed for at least 2 years.

A KAP study in Tamil Nadu, South India, was conducted by leprosy health education workers and trainees from the Ghandigram Institute of Rural Health. One questionnaire was given to new leprosy cases; the other was given to defaulters. The majority of new cases had not reported for treatment because of perceived “lack of susceptibility.” Transmission of leprosy by heredity was the response of 73.7% of new patients. The response of patches for signs and symptoms of the disease was answered by 18.4% of new patients. Defaulting among

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the majority of the moderate cases was the result of misunderstood severity and insufficient progress. The majority of severe cases defaulted because of no improvement. Social stigma, withdrawal, and fear accounted for 43% of the rest of the severe defaulters. Dharmalingam and Shanmugan concluded that "the KAP study revealed severe deterrents to prompt treatment: lack of awareness of the seriousness of the problem; escape mechanism; and the fear of being labelled a leprosy case with the stigma of the disease." They further state that the community fails to support and give sympathy to the person with advanced leprosy. The authors conclude, "these findings point to the fact that health education alone is inadequate. Strong group support is a major asset in the control of leprosy."

Hogerzeil and Reddy studied the integrated Community Health Project (CHP) as it relates to leprosy health education in Diclpalli, India. They compared CHP to the survey, education, treatment (SET) method which had been the basis of the Indian government's leprosy control program. SET relies on educated paramedical workers. CHP, however, relies on illiterate village health workers (VHW). The ratio of CHP to SET workers is 20:1. The study's results demonstrated better case-finding among the SET. However, the number of new cases in the CHP increased by nearly 150%. The number of new cases in the CHP remained at a steady level. Leprosy case-holding had a better increase in the CHP than in the SET. Hogerzeil and Reddy state, "in our opinion there is no doubt that intensive, continuous health education should be the highest priority in any leprosy control programme." The authors further emphasized the importance of the integration of leprosy into the general health education program.

A study in Gujarat, India, compared health education with slum and school surveys. The detection rates per 1000 during the period of 1972 to 1982 for primary school survey, slum survey and integrated survey were 0.29, 1.90 and 7.38, respectively. The integrated survey included the cooperation of skin camps of such organizations as the Lions Clubs, Rotary Clubs, and Jaycees. From 1981 to 1982 the percentages of detection from slum survey, health education and rapid survey were 41.76, 40.66 and 3.30, respectively. The article demonstrated the usefulness of health education in the detection of new leprosy cases. However, the specifics of their health education methodology was not mentioned in the article.

Hari refers to a school survey that was part of a health education leprosy scheme in the state of Andhra Pradesh in India. From the period of February to December 1977 the case detection rate was 43 per 1000. This included the examination of 46,237 children. As part of the school survey, Hari stated that "all the healthy children must be given health education in regard to clinical, therapeutic, and social aspects of leprosy." This study did not state what form of health education was given, if any, during the survey. If health education were given during this project, it would be important to assess its impact.

The Anthropology Department of the University of Poona, Poona, India, evaluated the leprosy health education programs in two Indian cities, Poona and Jalgaon. Groups interviewed in the survey included: doctors, volunteers, lay persons (male), housewives, factory workers, institution heads, employees, teachers and teacher trainees. The phrase "Leprosy is curable" was answered positively by 87% of the Poona and 78% of the Jalgaon non-doctor survey populations. The Poona and Jalgaon responses that "contact with leprosy patients as cause of leprosy" were 59% and 27%, respectively. Leprosy as a hereditary disease was the response of 36% of Poona and 47% of the non-doctor survey respondents. Mutatkar states "our social system which is based on the principle of hereditary in-

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equality amongst the various castes seem to have become a cultural value which would not be easy to change." Among the respondents who indicated that leprosy was curable, at least 10% of these groups in both Poona and Jalgaon believed leprosy was caused by immorality. The statement that disease would spread to other patients if treated in their clinics was agreed to by 4% of the Poona doctors and 25% of the Jalgaon doctors. The article by Mutatkar did not indicate how leprosy health education was done or by whom (other than perhaps the doctors). Mutatkar emphasized the need for continual contact by health educators to have an impact on the deep-rooted health beliefs and attitudes.

The health education component of a leprosy program in three regions of Tanzania was evaluated in 1972. Health education activities included the use of auxiliaries for leprosy public health programs, a campaign using home visit health workers, health education sessions for the general public during community meetings, and leprosy health education lectures for school children. The results showed that the majority of school children stated the current view of leprosy transmission. There was, however, a higher percent of adults who answered incorrectly. Adultery, heredity, and witchcraft were common answers among the adults. Almost all respondents believed leprosy could be cured. Between 80%–85% stated they would use traditional medical treatment. The community leaders generally supported modern medical treatment. In the areas of the study there was rarely segregation of those suffering from leprosy from their families or villages. The leprosy campaigns also discouraged divorce on the grounds of leprosy. The study results indicated some moderate discrimination against the marital partner with leprosy in some domestic areas within the home. The study in Tanzania emphasized continued health education and not irregular programs.

Mass media in leprosy health education. An evaluation on the use of billboards on leprosy was done in India in 1984. Twenty-five hundred billboards with the phrase “Leprosy is Curable” were placed on all of the Madras City bus fleet. This study wished to examine awareness and find out public reactions and attitudes toward leprosy. Questionnaires were given to 500 people at the bus stands, terminals, or intersections. The composition of the respondents were 30% college students, 30% office workers, 20% factory workers, 15% businessmen, and 5% housewives. All respondents answered yes to the question “Have you seen and cared to read the billboard about leprosy displayed in the city buses?” All but 2% of the respondents were able to give the billboard message. Further comments were listed by 41.2% of the respondents. Of those who gave comments, 43.5% felt the wording should be different. However, 11.5% felt the message “Leprosy is Curable” was powerful. Twenty-two percent of the respondents said that leprosy should be further explained on the poster; an equal number felt that the message should be put in slums and trains. A majority (52.8%) of the respondents stated that they “would like to know more about leprosy through the same media.” Of the respondents who answered “any other” on the last question 68.5% felt that mass media should be used in leprosy campaigns. The study definitely showed the effectiveness of the use of billboards for awareness. This method is unlikely to cause behavioral change. The cost effectiveness of such a program needs to be examined.

The use of photographs for leprosy health education was discussed by Hatters and Samuel. One project utilized 30 postcard-size prints of Nepali leprosy patients and clinical leprosy conditions. The second study produced health education teaching aids for the care of anesthetic feet. The second project utilized nine 18” x 16” black and white prints. Eighteen out of 25 questionnaires answered by hospital staff said that the prints were valuable teaching aids. The photos were not pretested. However, it was possible that Nepali may have difficulties in depth perception. Also photographs showing only a
foot may be confused with an amputation. A previous study in Nepal concluded that pictures alone could not be used to convey meaning. Pictures, therefore, must be used in Nepal in concert with other media.26

A study in Bombay, India, indicated that mass media forms of health education which included film shows, slide shows with talks, group talks exhibiting photographs, and exhibitions were effective in leprosy detection. The authors concluded that “the results of this study indicate that in a comparable urban situation it should be possible to identify 54% of total leprosy cases by techniques other than surveys.” The percentage of the infective lepromatous type detected by health education (mass media) efforts was 82%. The nonsurvey techniques are, therefore, effective in identifying the most progressive forms of leprosy. Further information is needed to indicate what forms of mass media used in the study were most effective.27

Defaulters and health education. A 1976 Indian study on defaulters (or those who stop initial treatment and therapy) indicated that 72% defaulted because of deficient knowledge about leprosy and its treatment. In the study by Gopal, all readmitted defaulters were given health education before continued treatment. It was not mentioned but intensive health education should take place throughout the therapy.28 Hertroijs studied defaulters in Tanzania. Of the patients he personally met only 3% indicated ignorance as a reason for default. However, for those patients not met personally 27% of the patients defaulted for reasons unknown. Hertroijs stated “more and better health education should be given to the general public with one of its targets being the removal of the stigma attached to the disease.”29 A study in Kanpur, India, indicated that illiteracy and ignorance was the second of 13 factors listed for leprosy default. This group had a percentage of 62.9%.30 A study in Uttar Pradesh State in India, in 1979, on the irregularity of treatment in leprosy patients, gave ignorance 22.9% of the time as one of the reasons for irregularity. These examples give quite strong support for the need of effective health education in leprosy.31

Literature and materials in leprosy health education. Much leprosy educational literature is available. This literature is especially published by the leprosy aid organizations. A fine packet of information of eight items has been produced jointly by the OXFAM Health Unit and LEIPRA.32 The Leprosy Mission International’s literature list or “Teaching and Learning Materials in Leprosy (TLM)” includes such areas as control, diagnosis and management, multidrug therapy, laboratory, primary health care worker material, and deformity prevention.33 The Philippine Ministry of Education and Culture has put out a series of booklets aimed at directing proper attitudes toward leprosy.34 A very simple booklet by P. J. Neville presents the basics of health education in leprosy.35

The gap in leprosy health education. Tare said “that in the methodology of leprosy control programme, based on survey education and treatment (SET), health education remained the weakest component and most neglected in training in field work, in records, in supervision, and in evaluation.” In general there is a great need for research in leprosy health education. Major areas

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where health education in leprosy have been lacking and need strengthening include: the training of health education workers, the understanding that health education encompasses more than "information giving," research in the precise nature of stigma, research in socio-religio-cultural aspects of leprosy, improved leprosy health education material with emphasis on behavioral change and initial aspects of leprosy, communication methodology research, economic aspects of the target groups as they relate to leprosy health education, health planning research, the utilization of non-professional workers and the integration of leprosy health education programs into primary health care, and research into evaluation of health education. Germane to health education is the positive change of health behavior in people. Therefore, all facets of health education in leprosy should relate in some way to this behavioral change.36

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