

## HANSEN'S DISEASE—A MODERN APPROACH<sup>1</sup>

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“When man shall have in the skin of his flesh a rising, a scab, or bright spot, and it be in the skin of his flesh like the plague of leprosy . . . then he shall be brought unto Aaron the priest . . . and the priest shall look on him and pronounce him unclean . . . all the days wherein the plague shall be in him he shall be defiled; he is unclean; he shall dwell alone; without the camp shall his habitation be.”<sup>3</sup>

How far have we come since biblical times in our attitudes toward Hansen's disease? To what degree do present-day understanding and acceptance of the disease reflect the influence of biblical references? What is a modern approach to the control of Hansen's disease?

Historically since biblical times, patient management and attitudes toward this disease have gone through changes that reflect increased medical knowledge. Segregation, isolation, and quarantine still exist, but are designed to accommodate the needs of the patient, family, and community. In May, 1955, at a meeting of the California Medical Association, Dr. Paul Fasal, consultant in Hansen's disease to the California State Department of Public Health “recommended a practical public health Hansen's Disease program,” stating that, “Patients with Hansen's Disease should be able to remain in California, and whenever possible continue to be gainfully employed.” He posed “three requisites for the control of this disease,” early diagnosis, adequate treatment under medical supervision, and public health supervision. He commented, “In singling out this one disease from all other communicable diseases, we do, in my opinion, show fundamentally the same attitude which prevailed in the Middle Ages. This creates untold hardships, disrupts families, and is responsible for many tragedies.”<sup>4</sup>

The fact must be recognized that the unknowns of epidemiological and medical knowledge are complicating factors in the care and management of this illness, but these gaps in knowledge do not account for

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<sup>2</sup> When this paper was written Miss Hoodwin was a member of the staff of Social Service, California State Department of Public Health.

<sup>3</sup> *Leviticus* XIII, Verses 2, 3, 46.

<sup>4</sup> *The Star*, Carville, Louisiana, 14(8):1, May 1955.

the lag between what is known and what is done about this condition medically and socially. The existence of this lag between knowledge and action is illustrated in the case recently found and lost by a local health department. The patient, a man with a wife and three children, who had been under medical care and treatment for a neurological condition without improvement, was eventually diagnosed as having Hansen's disease. Immediate arrangements were made for the patient's admission to Carville, the United States Public Health Service hospital in Louisiana. Though he asked for time to arrange his personal affairs, so much emphasis was placed on his need for immediate hospitalization that he left before business commitments were completed, personal papers organized and family planning accomplished. Within a few weeks after his arrival at Carville, he received an anxious letter from his wife telling him that the family had been found ineligible for public assistance, and that she did not know how they were going to manage. After several similar letters, the patient left the hospital against medical advice. Consequently, neither the hospitalized patient, separated by thousands of miles from his home, or his dependent family was given the care and guidance needed to insure adequate and satisfactory treatment.

To obtain some indication of current understanding and attitudes toward Hansen's disease, the authors carried out a spot survey in the fall of 1955 among 204 professional and nonprofessional individuals employed in the California Department of Public Health. The fact was recognized that this group might have had more exposure to health information than the general public.

Of the group surveyed, 149 were nonprofessional and 55 were professional workers. In analyzing the data from these two groups the nonprofessional responses seemed to be more closely associated with a general public viewpoint and the professional responses reflected the thinking of a high percentage of medical personnel.

The survey analyzed respondents reactions to the following statements and questions:

1. Leprosy is easily spread from one person to another.
2. All persons with leprosy should be isolated.
3. Did you read the Rex Morgan, M.D., comic strip on leprosy?
4. Should all patients with leprosy be sent to the special hospital for the treatment of leprosy?
5. Patients sent by the Public Health Service to the special hospital are escorted. Would you escort a patient to this hospital?
6. Would you mind working next to a person who had been treated for leprosy?
7. Would you mind working next to a person who had been treated for tuberculosis?
8. Do you think some patients with leprosy can be treated at home?
9. Would you mind waiting in a doctor's waiting room with a patient with leprosy?
10. Can people being treated for leprosy work around other people?
11. Do all people with leprosy have obvious sores?

12. Do you consider your knowledge of leprosy to be: good, fair, poor?

13. From which source(s) have you learned about leprosy? Newspaper, radio, or TV, school classes, church sermons or gatherings, Bible, other, specify:

14. The accepted name for leprosy is: Hodgkins' Disease, Hansen's Disease, Berger's Disease, Espundia, don't know.

Included in this discussion are the factual responses which illustrated what people did or did not know about leprosy. In general those who were well informed about this disease had correspondingly good attitudes.

Responses of 80-90 percent of the professional group were in accordance with accepted current medical knowledge in all *except the following areas*: When asked whether all persons with leprosy should be isolated, 11 percent responded "yes" and 15 percent said they did not know. Approximately one-half of the respondents felt that all patients should be sent to the special hospital at Carville. Thirteen percent stated that patients could not be treated at home, and 16 percent did not know. Fifteen percent felt that people being treated for leprosy should not work around other people, and 16 percent did not know.

Perhaps nonprofessional health department personnel might be better informed than the average citizen; yet half of them felt leprosy is easily spread from one person to another. Sixty percent thought all persons with leprosy should be isolated. Eighty-two percent believed all patients with leprosy should be sent to the special hospital for treatment of leprosy. One-quarter of them said they would mind working next to an individual who had been treated and would mind waiting in a doctor's waiting room with a patient with leprosy. Forty-six percent thought that all people with this disease have obvious sores, and an equal percentage did not know that Hansen's disease is an accepted name for leprosy.

Two questions pertinent to the content of this paper were those relating to home treatment and to whether people being treated for the disease can work around others. Only 38 percent of the nonprofessional felt that these individuals could be treated at home, 40 percent said "no," and 22 percent did not know. In regard to working around others, 32 percent answered in the affirmative, 40 percent in the negative, and 28 percent did not know.

Although this sample was small, the responses indicate a lack of knowledge about this disease and point to the need for education of the public in general and of those people in particular who will be giving professional assistance to individuals who have Hansen's disease.

In the past, public health programs often have been restrictive in their approach to the control of Hansen's disease. The California State Department of Public Health, however, approved a control program in 1955 which encourages a reasonable and understanding attitude toward this disease, which has been overrated as to its contagiousness

and underrated as to its potential for home treatment. The program states as its objectives:

1. To collect epidemiologic data which will provide the basis for control measures and evaluate their effectiveness.
2. To establish control measures, including medical supervision of cases, which are applicable in California.
3. To co-ordinate the leprosy control activities of international, national, state, local health departments and other agencies in California and to increase the efficiency of these various activities.
4. To sponsor educational activities which will alleviate the unrealistic traditional attitude toward leprosy.
5. To assist leprosy patients and their families in social and economic adjustments.<sup>5</sup>

The general management of the program is centered around the individual and family. Even though there are relatively few cases of Hansen's disease<sup>6</sup> in California (an average of 13 to 15 a year) the program must be administratively feasible, epidemiologically sound, and acceptable to the medical profession and the public. Concern regarding treatment and followup is based on the impact of the disease on the individual, his family, and the community. To handle the program efficiently the local health department needs to be aware of methods for case finding, case management and surveillance, contact surveillance, and medical and public education.

In Hansen's disease, as in many other diseases, the necessity for early diagnosis and treatment to prevent sequelae is of prime importance. Early recognition of Hansen's disease is a major problem, and persons may spend many months before a diagnosis is actually made. Adequate treatment may mean a prolonged period or a lifetime of medical care and public health supervision. The individual who acquires Hansen's disease can learn to live with the problems inherent in the disease but often is prevented from doing so because of the attitude and fear of this illness by the general public.

In some respects the problems of the individual with Hansen's disease are similar to those encountered by others who experience chronic, communicable, or disfiguring illnesses. Physical and psychological separation from family and community, economic dependency, uncertainty about the course of the illness and degree of disability, and availability and cost of adequate care are anxiety-provoking aspects of most long-term illnesses. Although the patient with Hansen's disease faces all of these, his problems are more severe and intense.

Hansen's disease, more so than most illnesses, is unfamiliar to many physicians. Adequate diagnosis and treatment are consequently more difficult to obtain. Much valuable time may be lost before proper diagnosis is made and treatment begun. Because of this the individual may

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<sup>5</sup> California State Department of Public Health Leprosy Control Program for California, 1955. California State Department of Public Health, Berkeley, California.

<sup>6</sup> 550 cases between 1920 and 1955.

go through an unnecessarily long period of knowing that he is ill before finding out what is wrong and what to do about it.

Isolation can separate the patient physically and psychologically from his family and community. The patient may have to live apart from his family for an indeterminate period or he may require hospitalization over a thousand miles from his home in California. Such a distance makes visiting virtually impossible. Family ties that can be maintained in other chronic illnesses through frequent visits are severely strained under these conditions. Even if the type or stage of the disease is such that the patient can remain at home, the fear that the community will ostracize him often leads the person and his family to withdraw from community life or to move elsewhere, so that disruption of family life results.

If temporary hospitalization is necessary, it is equally important that the patient and family be properly oriented to the routine at Carville and provisions made for communication between the patient and the family. This can be as important as patient care in the local community.

Ignorance about Hansen's disease may greatly restrict employment opportunities even for the employable individual. The employer who is willing to hire or to retain a worker with Hansen's disease may be influenced against this decision by fear of losing other employees. Should the patient be able to get a job where he does not have to reveal his condition, the nagging fear that someone will find out may lessen his productivity and threaten his job security.

The foregoing factors, plus the consternation that is created in a community when it becomes known or suspected that a person with Hansen's disease is living in the area, make planning with the patient and his family a difficult task. That a satisfactory solution can be worked out has already been demonstrated in several communities. In one case, when a 40-year-old laborer learned he had Hansen's disease, type undetermined, he resisted all efforts to help him take precautionary measures. A period at Carville was recommended to establish a definitive diagnosis and to institute a treatment regime. He refused to leave, fearing his family would become totally dependent on public assistance. Both the health and welfare departments were concerned about his family of wife and seven children, and together they set out to help evolve a workable plan. The health officer reviewed for the health and welfare staffs the current knowledge about the disease, emphasizing that it is not highly communicable but stressing the need for taking the necessary precautions. The patient was advised that he could safely remain in the community if he could get adequate medical supervision and live apart from his family. The health department arranged for the patient to have further tests and periodic examinations at a nearby medical center. The welfare department agreed to assist in

meeting medical expenses and helped the family locate other housing where the patient could live outside the main house in a converted garage. The patient continued to work on his job, which required only infrequent and casual contact with other people.

This case demonstrates what can be done when there is a real meshing of interagency gears. Without sharing of knowledge and responsibility, this family might have been broken up or the patient might have remained in the home, a constant potential hazard to his children. In this case the activity of only three agencies, the health department, welfare department and medical center made planning easier than in those situations in which there are numerous community agencies involved.

Because Hansen's disease has many social, economic, and psychological ramifications, several agencies might be working with the family concurrently. Effective co-ordination of services is essential to the resolution of the multiple problems which accompany this disease. Because this disease is a public health problem, it is logical that the health department should serve as the catalyst to bring the agencies together, to clear away misconceptions about the disease and to evolve a co-ordinated constructive approach. Such an approach is essential if patient and family are not to be caught in the cross currents of agency activity. This can be done without a breach of confidentiality if the patient participates actively in planning and knows that all of the agencies concerned are working together in his interest.

The role of the local health department is of prime importance in the proper management of Hansen's disease. The objectives as stated by State Health Department policy are equally applicable in the local situation but with these added responsibilities:

1. To provide leadership in co-ordinated planning among community agencies.
2. To interpret medical information and assist in social, emotional, and economic adjustments.

Education by the health officer of his own staff and of other agencies is often the first step in achieving a smoothly functioning community operation mobilized around a problem of Hansen's disease. The health department staff should not be overlooked in the zeal to educate the community; for only if the public health worker is fully cognizant of the implications of the disease and its treatment can he be helpful in imparting a realistic viewpoint to others. The health department's role in clearing away misconceptions about Hansen's disease cannot be overestimated. In each case the health department staff needs to assess the impact of the disease on the patient, his family, and the community. By anticipating with the patient and family the problems to be faced, the health department can set in motion the community machinery needed to help the individual obtain medical care, continue to live as normal a life as possible and retain his place in the family and community without fear or prejudice.