

Attitudes Toward Leprosy in the Ryukyu Islands

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BEFORE Airaku-en Hansen's Disease Hospital was constructed at Yagaji in 1938, the existence of persons with Hansen's disease on Okinawa must have been the essence of despair. Unable to find work, often denied medical care by a frightened professional community, and socially ostracized, patients congregated in clusters of poorly constructed huts and subsisted by begging. Crippling and deformities were nearly universal among patients. The grinding poverty in which they existed dictated, for the poorest victims, total nakedness. Today, disfigured, ragged patients with Hansen's disease are unusual, and patients in the community cannot be identified unless they are obviously deformed.

Care of leprosy patients has improved greatly in the Ryukyu Islands since World War II. The prevalence of leprosy is thought to be about 1.5 cases per 1,000 population, and with advances in drug therapy it is increasingly appar-

ent that leprosy is as much a social as a medical problem.

This paper, based on data taken from a survey in July 1966, is not a definitive attitudinal study on leprosy. Limitations of existing demographic data have made it difficult to construct a truly representative sample of the Ryukyuan population. Nevertheless, we believe our observations may serve as a guide to further studies, particularly because little on public attitudes toward leprosy has been published in recent medical literature.

Methods

Six Ryukyuan college students used a standard questionnaire consisting of 19 fixed-alternative items to elicit answers from 1,023 Ryukyuan. The first 10 questions were multiple choice, and the remaining nine were of the "agree-disagree" type. The questionnaire was prepared first in English and translated into Japanese. Pretesting suggested that no significant change occurred in the questionnaire because of the translation.

The population sample was taken from three areas: the capital city of Naha, the rural island community of Kume, and the village of Yagaji, a rural community adjacent to the Airaku-en Hansen's Disease Hospital. No two respondents came from the same family, and patients with leprosy and persons who had had leprosy were excluded. Responses were analyzed by the inter-

At the time of this study, the authors were employed by the U.S. Civil Administration of the Ryukyu Islands. Dr. Marshall was chief of the public health division. Miss Maeshiro was health educator of the division, and Mr. Korper was assistant to Dr. Marshall. Dr. Marshall is now assistant professor of preventive medicine at the University of Kansas Medical School, and Miss Maeshiro and Mr. Korper are at Yale University School of Epidemiology and Public Health.

viewee's age, sex, and type of community in which he lived. Yagaji was not included in the comparison of urban with rural communities because of its proximity to the hospital.

When compared to official census data (934,166 as of October 1965), the study sample (table 1) would appear to under-represent persons less than 31 years old, to over-represent women, and to be somewhat better educated than most Ryukyans. However, the extent of these biases cannot be adequately evaluated because of the inadequacy of existing data.

Results

When asked to choose tuberculosis, cancer, heart disease, or leprosy as the disease they would least like to get, leprosy was reported more frequently than any other alternative except cancer. Respondents over 46 years old feared leprosy slightly more than cancer. Fear of leprosy increased with age in both sexes and was significantly greater in rural Kume than in urban Naha ($P < 0.05$). Leprosy was feared least in Yagaji, the location of a leprosy hospital.

Despite widespread fear of Hansen's disease, only 32.6 percent of the respondents in the two younger age groups (10-30 years old) believed they had ever seen a patient with leprosy compared with 72.9 percent in the two older groups (31 years old and over). A significantly larger percentage of rural than urban residents reported they had "seen" patients ($P < 0.05$). No differences in observations were noted by sex. Although less than a third of the younger respondents felt that they had ever seen a patient with Hansen's disease, 84.2 percent claimed knowledge of the appearance of such persons; this number rose to 94 percent in the older age groups. Regardless of age, sex, or community, the overwhelming picture of leprosy was one of deformity. Of the 2.7 percent of the respondents who believed a patient with leprosy might look like an ordinary person, more than half were 10-15 years old.

No significant differences by age or sex were observed among the 50.4 percent of the respondents who believed that a person who casually touches a patient with leprosy probably risks developing the disease. However, this belief was significantly greater in rural than urban areas

Table 1. Respondents to questionnaire about leprosy, by age, sex, and community, Ryukyu Islands, July 1966

Age (years) and sex	Community			Total
	Yagaji	Kume	Naha	
All ages.....	151	264	608	1,023
Male.....	56	111	212	379
Female.....	95	153	396	644
10-15.....	38	49	68	155
Male.....	13	22	30	65
Female.....	25	27	38	90
16-30.....	31	55	203	289
Male.....	11	27	91	129
Female.....	20	28	112	160
31-45.....	43	68	203	314
Male.....	18	26	38	82
Female.....	25	42	165	232
46 and over.....	39	92	134	265
Male.....	14	36	53	103
Female.....	25	56	81	162

($P < 0.05$). More respondents, 40.6 percent, believed leprosy is transmitted by bodily contact than by any other route although 34.5 percent felt that rats or insects, or both, were also important sources of infection. The rats-insects belief was common in both rural and urban areas, and no significant differences were observed by age or sex. Though rats and insects were regarded as a major mode of transmission, only 14.9 percent of the persons queried felt that control of these creatures could control leprosy.

The belief that early diagnosis and prompt treatment are the best measures for controlling leprosy was most prevalent in the youngest age group and declined steadily in the older groups, who tended to favor permanent isolation in a hospital (fig. 1). These feelings did not vary by sex or region.

Among the respondents 13.2 percent regarded leprosy as a hereditary disease, and this belief was significantly more common among women ($P < 0.01$) and among those over 45 years old ($P < 0.01$). Another 25 percent of the interviewees regarded leprosy as both hereditary and communicable, and 54.2 percent felt that the disease is communicable only. Although 5.8 percent denied any knowledge of how leprosy is transmitted, only 1.8 percent regarded leprosy as a kind of punishment.

Knowledge that leprosy is moderately com-

municable was most common in Yagaji and least well known in Kume. Between urban and rural populations (Naha and Kume), differences in opinion about the communicability of leprosy were highly significant ($P < 0.001$).

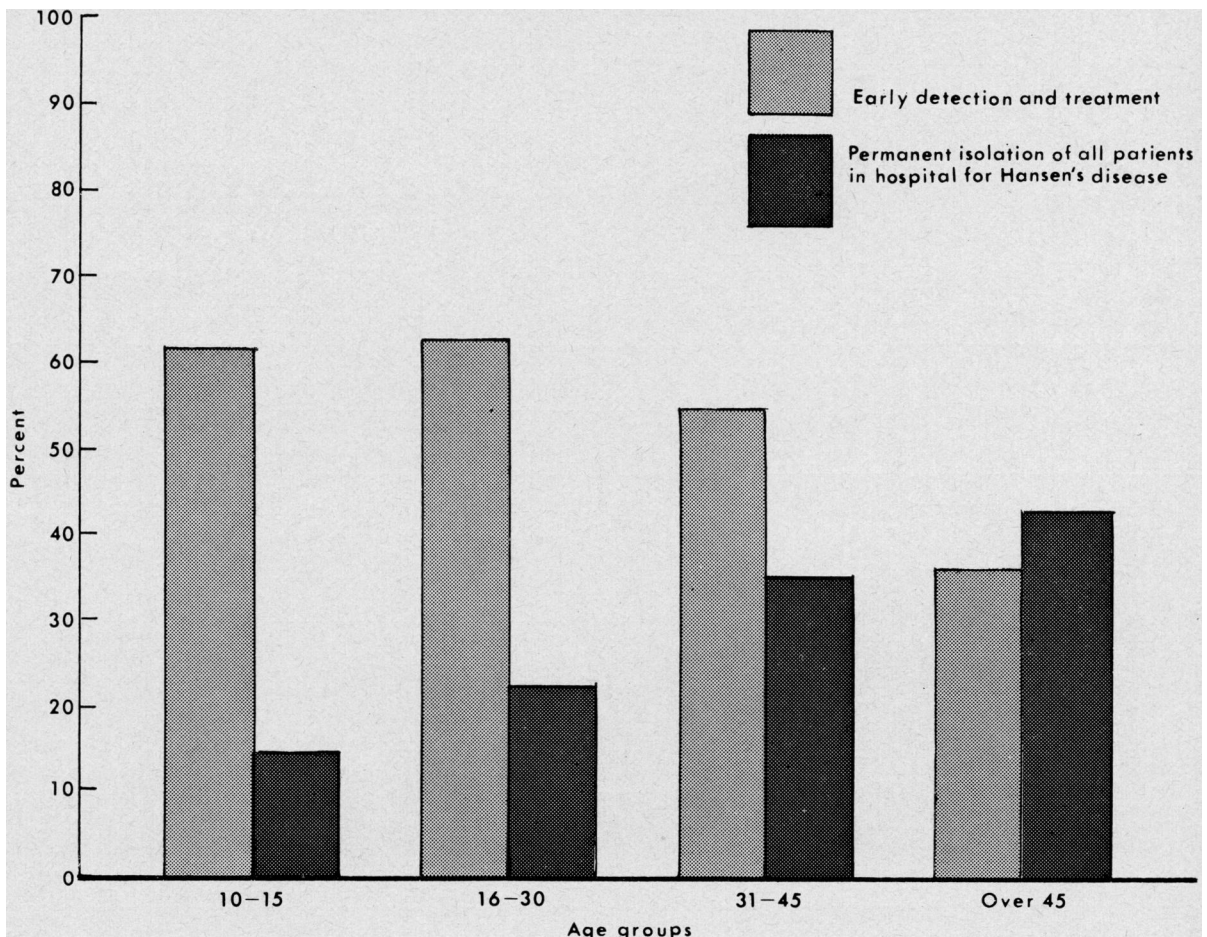
When asked to identify "the worst thing about leprosy," 64.1 percent of all respondents chose social separation or scorn. In the older age groups fear of infecting others was also an important factor. No differences in responses to this question were noted by sex or region. Very few persons associated leprosy with severe pain or death.

The results of the second portion of the questionnaire appear in table 2. Respondents generally agreed that leprosy is caused by germs, that it does not necessarily imply crippling, that

early treatment is an effective way to prevent crippling, and that leprosy is curable. However, about 40 percent believed that all patients spread the disease, less than half believed that a crippled person might be free of disease, and 42 percent believed that all patients will eventually become crippled. Isolation of all patients was favored by 87 percent of the interviewees, and 32 percent felt that this isolation should be permanent.

If the beliefs pertaining to isolation reflect a fearful, punitive, or hostile attitude toward patients with leprosy, data in the table suggest that such views are significantly more prevalent in the older age groups. Differences of opinion by sex are relatively slight. Females more often regard leprosy as hereditary and so tend to re-

Figure 1. Ryukyuan's answers to "the best method to control leprosy," by age group of respondents, in percent ¹



¹The figures do not add up to 100 percent because the question could prompt 5 possible answers.

ject the fact that Hansen's disease is caused by germs as well as the concept of universal risk. The beliefs of urban and rural populations were not strikingly different either. Surprisingly, the etiology of leprosy was better known in Kume than in Naha, but less surprising was the observation that rural respondents more than their urban counterparts tended to favor permanent isolation of patients with Hansen's disease.

Discussion

The concept of leprosy in the Ryukyu Islands was quite uniform. Comparisons of urban with rural respondents revealed attitudes differing more in degree than in kind. Residents of Kume harbored more fear of leprosy, believed they saw patients more often, and were more convinced that touching patients is dangerous. The village of Yagaji reported greater knowledge of leprosy than either Kume or Naha, but this difference did not affect the villagers' opinions regarding isolation of patients. The only significant difference of opinion by sex was that more women than men regarded leprosy as a hereditary disease; more fundamental differences were related to age.

Attitudes were less punitive and factual knowledge of the disease greater among the younger groups. Younger people were less afraid of the disease and more committed to belief in the effectiveness of early diagnosis and prompt treatment, probably because their personal experience with patients was related less to a stereotyped picture.

Of the very small number of respondents who believed that patients with leprosy might look ordinary, almost 60 percent came from the two younger groups although they comprised less than half of the sample population. The image of the person with leprosy has not changed among older persons because they have not been exposed to anything which might eradicate the fear of deformed patients they have seen.

Conversely, younger people must derive their concept of the appearance of patients from second or thirdhand information; there is no experience to contradict their theoretical knowledge of the disease. Consequently, they tend not only to "know" the facts—they are also more likely to believe them. Whether these young people represent a more enlightened cohort which will retain its views with increasing age is not known. However, responses of the younger in-

Table 2. Responses to nine statements about leprosy, by interviewees' age, sex, and place of residence (urban or rural)

Statement	Percent agreeing	Comparative distribution of agreement		
		By age	By sex	By community
Leprosy is caused by germs.....	75.9	Young > old ¹	Male > female ¹	Kume > Naha. ¹
All patients with leprosy spread the disease.	39.4	Old > young ¹	No difference.....	No difference.
All patients with leprosy eventually will become crippled and ugly.	41.6	-----do-----	-----do-----	Do.
All patients with leprosy should be isolated.	86.9	-----do-----	-----do-----	Do.
With early treatment, patients with leprosy can escape crippling and ugliness.	90.7	No difference.....	-----do-----	Do.
Leprosy is curable.....	86.0	-----do-----	-----do-----	Do.
Many persons crippled by leprosy no longer have the disease.	44.3	-----do-----	-----do-----	Do.
Everyone has a possibility of getting leprosy.	68.2	-----do-----	Male > female ¹	Do.
Once it is known that a person has leprosy, he should spend the rest of his life in a leprosarium.	32.0	Old > young ¹	No difference.....	Kume > Naha. ¹

¹ $P < 0.001$.

NOTE: Young, below 31 years old; old, 31 years old and over. Kume is a rural, island community; Naha is capital of the Ryukyu Islands and the largest urban center.

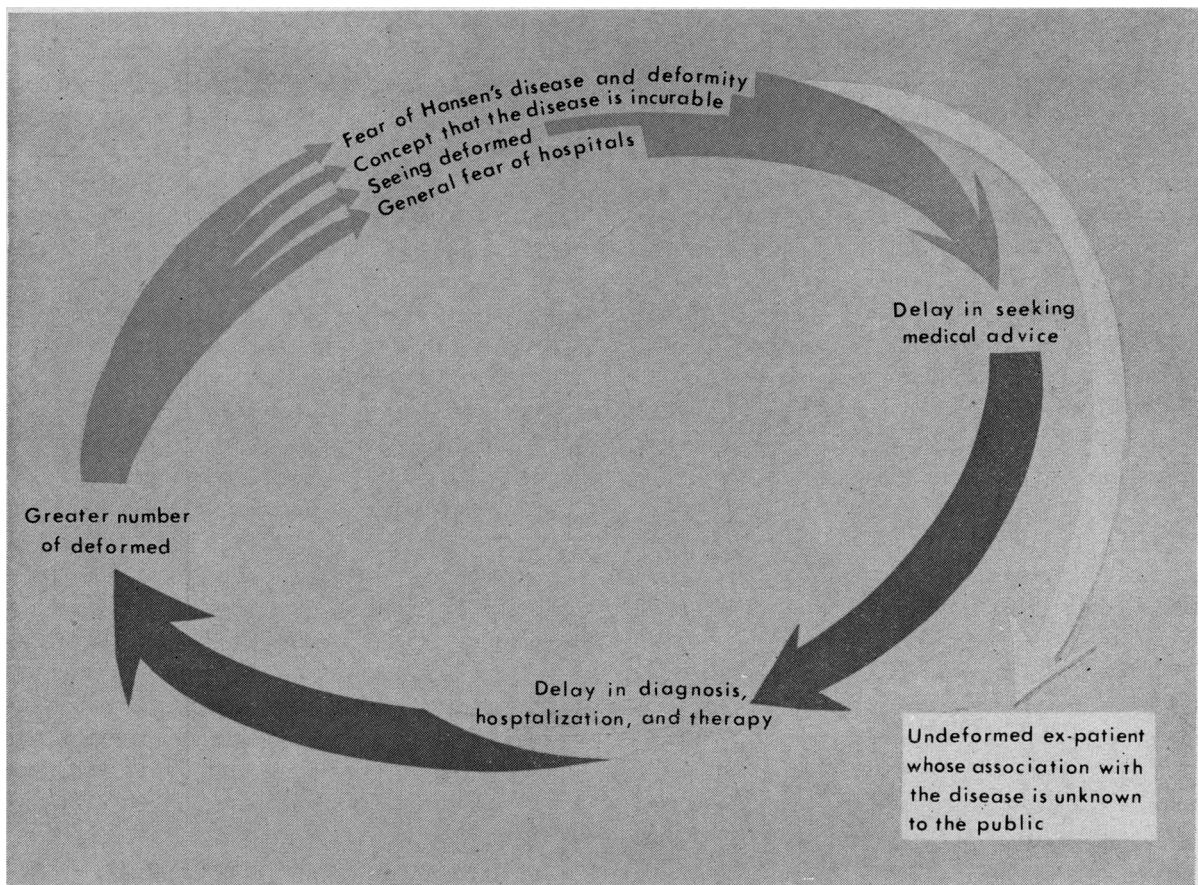


Figure 2. Factors influencing the social epidemiology of leprosy in the Ryukyus

interviewees suggest that the more fearful and punitive attitudes will pass away with the older segments of the population.

Unfavorable popular beliefs and attitudes toward leprosy are almost invariably ascribed to "ignorance," a word usually used to describe a dearth of factual knowledge about leprosy among the lay public. The literature is replete with appeals to enlighten the public and thereby remove the aura of fear and despair associated with Hansen's disease. Results of this study suggest that lack of factual information may not be the main problem and that public knowledge of facts is not sufficient to alter traditional attitudes.

Cochrane (1) recommends emphasizing 10 points about leprosy when conducting educational campaigns directed at the public, and six of these points were subjects of questions asked of interviewees in this study. Recognition of four of the six points by a majority of the

sample population and knowledge of the other two by approximately 40 percent of the respondents imply that many educational campaigns may have fallen short of their goals because they reemphasized what was already known.

The basic problem is to ascertain why knowing the facts is ineffective and to determine how to use facts to alter traditional beliefs. In this study more than 75 percent of the respondents agreed that crippling could be avoided by early treatment; yet 42 percent also agreed with the statement that all patients with leprosy will eventually become crippled and deformed. Apparently using the same rationale, 86 percent identified leprosy as a curable disease, but 32 percent stated that all patients should be permanently isolated.

For many people, factual information seemingly remains separate from the process by which public beliefs about leprosy are formu-

lated. We propose that the key to this dilemma is a conflict between factual (theoretical) knowledge and the results of direct observation: people in the Ryukyus "know" the facts, but theoretical knowledge does not dispel attitudes based on conflicting experience.

Obvious deformity is the only characteristic by which a patient with leprosy can be identified by the lay public, and usually to them deformity *is* leprosy. Unless patients are deformed or crippled, they are not recognized as persons with leprosy and pass unnoticed. Identification of leprosy with deformity subverts the potentially enlightening impact of factual information. Apparently the situation is similar in India (2).

In the public mind, which equates leprosy with deformity, to be "cured" implies correction of deformity and uncorrected deformities, therefore, are not evidence of cured patients. Consequently, the vast majority of respondents know leprosy is curable because they have acquired theoretical knowledge of the disease. However, a deeper conviction that leprosy is not curable exists in many of these same persons, particularly those in older age groups, because they personally have observed the crippled extremities and mutilated faces of its victims.

Our impression is that factual knowledge either is ignored or molded to conform with the reality of direct observation. These deductions perhaps explain the paradox of Yagaji, where knowledge is relatively great but attitudes remain unchanged, and the differences in attitude between the young and the old. We do not intend to imply that factual knowledge of leprosy is irrelevant. Indeed, we believe that possession of this knowledge offers hope for a more enlightened future.

The desire to isolate patients with Hansen's disease also deserves comment. From this study we could not determine whether the popular endorsement of isolation as a control measure is based on fear of leprosy and its spread or if it is a reflection of public familiarity with tradition. This distinction is critically important because it may indicate how former patients will be received in their home communities and how the populace might react to changes in the present system of medical care, such as the development of an extensive home care program.

We know of several persons suspected of having leprosy who fled into remote mountain areas to live as recluses rather than submit to hospitalization. In other instances, the families of patients have been obliged to relocate because of social pressure. Such situations suggest that fear of leprosy and dread of isolation are somehow interdependent and that perhaps it is isolation which leads to social ostracism of patients' families and stigmatizes the patient.

The 400 patients in the home care program and their families seem to avoid much of the scorn heaped upon families with a member in an institution. Apropos to the desire to avoid being identified with leprosy, our efforts to produce a motion picture emphasizing patients without crippling or deformity were frustrated when patients who were not disfigured refused to be photographed because they were afraid that audiences viewing the movie would remember their faces and condemn them after they left the hospital. Such behavior indicates that unmarked patients plan to join the army of the "unseen" upon discharge and that identification with the hospital is tantamount to a mark of Cain.

Implications of the negative attitude toward hospitalization for treatment of leprosy are complicated by the fact that Ryukyans, regardless of the nature of their illnesses, avoid hospitals. Ryukyans generally still regard the hospital as a place in which to die, and many Ryukyuan physicians have commented on the difficulties involved in treating patients who "just give up" upon admission to a hospital.

The extent to which isolation for leprosy connotes social stigma and perhaps the irrational hope that to avoid the hospital is somehow to avoid disease cannot be determined from this study because of the general fear of all hospitals and related medical care institutions. It is probable that these fears reinforce each other and, unfortunately, result in long delay between the onset of symptoms and the establishment of a diagnosis. The delay, in turn, produces numerous unnecessarily deformed patients. The cycle of fear, delay, and deformity exerts a vast and perhaps preponderant influence on the epidemiology of leprosy. Our concept of this process is presented in figure 2.

To break the cycle most effectively, it ap-

pears necessary to provide the public not with facts alone but with a new mental picture sufficiently impressive to dispel the traditional association of deformity with leprosy. This process of image substitution is especially important for the younger people who can be expected to embrace it sooner and easier than older persons because the new picture will conform with younger persons' knowledge of the disease.

Assuming successful implantation of a new image of leprosy, the known fact that leprosy is a curable disease would take on new meaning and lead, hopefully, to less fear of the disease and prompt persons who might have leprosy to seek early diagnosis and treatment. As early treatment of patients with leprosy becomes more widespread, the number of deformed patients can be expected to decline, serving further to fix the new image.

Casefinding campaigns and mass surveys, however buttressed by efforts to acquaint the public with facts, run the risk of driving victims, both real and imagined, into hiding and perhaps increasing still more the fear of the disease. For Ryukyans at least, the great need seems to be not only education but an image of leprosy which will lend credence to the facts.

Summary

A fixed-alternative questionnaire designed to ascertain public beliefs about leprosy was administered to 1,023 Ryukyans, and the results were analyzed by age, sex, and type of community (urban or rural).

The most striking differences of opinion were related to age. Younger persons were better informed about the nature of Hansen's disease, voiced greater confidence in the effectiveness of early diagnosis and treatment, and held less rejecting attitudes toward persons who have or have had leprosy.

Nevertheless, factual knowledge of leprosy was widespread at all ages, and it cannot be said that on the Ryukyu Islands attitudes toward leprosy are conditioned by ignorance. Although the facts are widely known, leprosy remains equated with crippling, deformity, and, to an unknown extent, isolation. A new image of leprosy is needed to alter traditional attitudes which facts alone do not alter when they conflict with direct observation.

REFERENCES

- (1) Cochrane, R. G., and Davey, T. F., editors: *Leprosy in theory and practice*. John Wright & Son, Ltd., Bristol, England, 1964, p. 584.
- (2) Wardekar, R. V.: *Hints on diagnosis and treatment of leprosy*. Gandhi Memorial Leprosy Foundation, Wardha, India, 1964.

No Smallpox Vaccination Required for Travelers Between Mexico and the United States

A certificate of vaccination against smallpox will no longer be required of persons arriving in the United States from Mexico, provided they have visited only these two countries 14 days before entering the United States. The last reported outbreak of smallpox in Mexico occurred in 1951, and the United States has been free of laboratory-confirmed cases of the disease since 1949.

This change in quarantine procedures was announced in Houston, Tex., last June by Dr. William H. Stewart, Surgeon General of the Public Health Service, at a joint conference with Dr. Rafael Moreno Valle, Secretary of Health and Welfare of Mexico.

This action has been reciprocated by Mexico which has waived the requirement of a valid smallpox vaccination certificate for anyone who has not been elsewhere than Mexico and the United States for the past 15 days.