

A study of community attitudes and knowledge in relation to leprosy

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SUMMARY — A study of community attitudes and knowledge in relation to leprosy was undertaken in the Bauru Region of the Brazilian State of Silo Paulo as preparation for an integration project in the region. A representative sample of approximately 500 persons was interviewed in 7 municipalities by 15 psychology students. The results of the study showed that the level of knowledge about leprosy in the region is very low with the mean score on a basic knowledge test being 37.5% correct. While results showed the existence of a "leprosy stigma" in the region, they also demonstrated a considerable degree of acceptance on the part of the general population to maintaining close work and friendship relationships with patients under treatment. Other answers to questions in the study indicated that the roots of the "leprosy stigma" lie more in the fear of "contagion" and the disease's effect on social relationships than in the fear of physical problems such as pain and deformities. The author is left with a feeling of cautious optimism as to the success of integration efforts when these are accompanied by health education activities with those with whom the patient is to maintain close contacts.

Termos índice: Lepra — Estigma. Hanseníase. Integração. Educação Sanitária. Reabilitação social.
Key words: Leprosy — Stigma. Hanseniasis. Integration. Health education. Social rehabilitation.

INTRODUCTION

The success of any program designed to promote the integration of the han-senian in society depends strongly on the degree of that society's acceptance and understanding of the patient and his disease. This awareness led to the undertaking of the following study in the Bauru Region, a pilot area for such

an integration program. The study had two goals: the first was to gain a more objective understanding of the "leprosy stigma" in the region. The second was to measure the population's level of knowledge about the disease, an important variable to understanding the strength of the stigma.

STUDY METHODOLOGY

A stratified random sample based on size was taken of the region's 38 municipalities. In the seven municipalities

thus selected, quota samples were taken so that persons interviewed would represent in age, sex, and educational

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levels the region's population over 15 years of age. Approximately 500 persons were interviewed by 15 psychology students in their fifth year of studies. The questionnaire was pre-tested and the interviewers went through several hours of training in the use of the questionnaire. In multiple choice answers, the order of these answers was constantly altered in order to avoid influencing the respondent.

After the data was gathered, it was tested with the chi square significance test (at 0.05 level) to ascertain if significant differences existed between the responses of persons living in a community where there was a dermatology hospital and those where there was none ; between persons under 40 and those 40 and over ; and between persons who had completed the "primary" level of their education and those who had not.

ATTITUDES TO LEPROSY AND THE LEPROSY PATIENT

Since stigma is a relative concept, we needed to get an idea of how the general population rated leprosy in comparison with other diseases and disabling conditions. Would this rating be as bad as often feared? In order to get this information, leprosy was compared with five other conditions having some attribute in common such as contagion, deformation, disability and mysteriousness. At this point in the questionnaire, the respondent was unaware that we were mainly interested in leprosy. After the list of leprosy and the other conditions was shown and read to the respondent, he was asked to choose that condition which he would most fear to have happen to him. When a particular condition was mentioned, it received a (-1). Next, the respondent was asked to choose from the same list the condition he would most prefer to have happen to him if one of them was unavoidable. Conditions thus selected received a (+ 1). Combining the results of the two questions, we feel that we have a fair estimate of the relative rankings of the six conditions in the mind of the general population. Beginning with the condition most feared, we found the following order:

<i>Condition</i>	<i>Score</i>
1. Total blindness	(- 209)
2. Leprosy	(- 42)
3. Mental illness	(- 26)
4. Loss of arm and leg ..	(- 3)
5. Deep facial scars	(+ 8)
6. Tuberculosis	(+ 114)

There was no significant difference in the ranking of leprosy in second place when results were compared by place of interview, age and educational level.

Another area which we wanted to examine was just what was it about leprosy that causes it to be feared. Delving deeply into the roots of the "leprosy stigma" however was well beyond the scope of the questionnaire. Our more modest aim was to see if the fear that the general population has of the disease is more related to its "physical threat" (such as pain or deformities) or of its "social threat" (the jeopardizing of social relationships). To obtain this information, we asked each person in our sample what would be his primary fear if he contracted the disease. Five possible answers were given to choose from two

of them dealing with physical problems and three of them with social problems. The results were the following:

Respondents Major Fear If He Contracted Leprosy

<i>Fear</i>	F.	%
1. Contaminate others .	208	47.3
2. Become deformed ...	35	8.0
3. Pain	15	3.4
4. Loss of job	36	8.2
5. Rejection by others .	137	31.1
6. Other response or no response	9	2.0

There were no significant differences in the basic rankings when comparisons were made by place of interview, age and educational level.

The two preceding situations dealt with the respondent's reaction to leprosy, the disease. The two situations which follow sought to learn more about the respondent's reaction to maintaining close relationships with leprosy patients.

One situation involved an hypothetical work relationship. The respondent was told that one day his boss introduces a leprosy patient as a new member of the respondent's work group, explaining that the new employee is both physically and medically able to do the work for which he was hired. The respondent was then asked what would be his reaction to working closely with this patient. He was given three possible choices as responses. The results were the following:

Attitude To Working Closely With Leprosy Patient

<i>Answer</i>	F.	%
1. Very against working with patient	88	20.0

2. Somewhat against working with patient 97 22.0
3. Not against working with patient 248 56.4
4. Other response or no response 7 1.6

An application of the chi square significance test showed a significantly greater degree of acceptance of a close working relationship with patients by persons with higher educations. Comparisons by place interviewed and age showed no significant differences.

Persons who indicated reluctance to working with the patient were then asked to give their reason for this in a follow-up question. The results were that 154 persons (82.3%) gave responses classified as "contagion fears", 12 persons (6.4%) gave answers classified under "the disease would interfere in the work". The remaining 21 persons (11.3%) either failed to give a response or their responses were so diverse to be adequately classified.

Another hypothetical situation presented to the respondent involved a friendly relationship with a person of his own sex. The person interviewed was asked to imagine a situation in which he is told by one of his close friends that the friend has recently discovered that he has contracted leprosy and is now under treatment. The respondent was then asked to choose from a list of four possible actions the one which most closely approximated the one he would take in such a situation. The results were:

Probable Reaction On Discovery That Close Friend Had Leprosy

<i>Reaction</i>	F.	%
1. Stop all activities together	57	12.9

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| 2. Stop some but not all activities together | 182 41.4 | 5. Other response or no response | 3 0.7 |
| 3. Continue activities together as before | 154 35.0 | There were no significant differences when comparisons were made by place interviewed, age or educational level. | |
| 4. Increase activities together | 44 10.0 | | |

KNOWLEDGE OF LEPROSY

In theory, the dissemination of present scientific knowledge about the disease should have a positive effect on reducing the "leprosy stigma". How then do the concepts which the public holds about leprosy reflect this present scientific knowledge? How does the public score on a basic knowledge test about leprosy?

Unfortunately, the answer to this question is "very poorly." Especially so when one considers the fact that most of the questions involved "yes" or "no" answers. The mean score for the sample was 37.5% correct. Comparisons between groups showed that higher educated persons scored approximately seven percentage points higher than those with less education. The differences in the scores of groups separated by place of interview and by age however, were less than one percentage point. Let us look at some of the responses.

1. *Cause of leprosy* — Only 11.2% correctly identified the cause of leprosy as being a "bacillus", "bacteria", or "germ". Another 12.5% gave "contagion" as the cause and for the purposes of the questionnaire, were given partial credit. While most persons (59.3%) said that they didn't know the cause, others ventured guesses. In order of their frequency, the top ten guesses were:

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| 1. Lack of hygiene (27) | 3. Virus (8) |
| 2. Blood (15) | 4. Rapid changes of hot and cold (7) |

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2. *First signs of leprosy* — Full credit was given to persons mentioning "insensibility and lesions" (3.4%). Partial credit was granted for mentioning "lesions" by itself (26.4%), "insensibility" by itself (6.4%) and pain (1.8%). Other first signs mentioned in order of their frequency were:

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| 1. Wounds or cuts (37) | 6. Changes of skin color (3) |
| 2. Itching (21) | 7. Blisters (3) |
| 3. Deformities (11) | 8. Fever (3) |
| 4. Loss of hair (8) | 9. Loss of eyebrows (3) |
| 5. Peeling skin (5) | 10. Paleness, swollen ears, swelling, skin irritation |

3. Is leprosy inheritable? — A total of 46.1% felt that it was not inheritable. The rest either thought it was (41.4%) or did not know (12.5%).

4. *Do only humans have leprosy?* — In response to this question, 36.3% thought that only humans could have leprosy, 52.3% thought that other animals could have it also, while 11.4% said they didn't know. Those who thought that other animals or things besides humans could have leprosy were asked to identify some. The ten

most frequently mentioned were the following:

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| 1. Dogs (137) | 6. Rats (9) |
| 2. Horses or burros (58) | 7. Pigs (6) |
| 3. Cats (57) | 8. Chickens (4) |
| 4. Cattle (28) | 9. Sheep (3) |
| 5. All animals (18) | 10. Monkeys (3) |

5. *Contagion* — A series of questions were asked about contagion. First we wanted to know if the respondent thought leprosy to be contagious or not. The results were that 75.7% thought it was contagious, 19.8% thought it wasn't, and 4.5% said they didn't know.

Those who had stated that they thought leprosy was contagious were then asked to give their opinion as to whether it was "very" contagious or only "slightly" contagious. Sixty-three percent gave the first response while 33.6% thought it only slightly contagious. Another 3.2% said they didn't know.

Another *follow-up* question asked to those who felt leprosy was contagious was if they believed that all leprosy

patients were contagious. We found that 66.7% thought that all were, 24.9% thought that only some were, and 8.4% said that they didn't know.

Finally, the group which thought that only some patients were able to transmit the disease was asked if deformities were a sign that a person was contagious. To this question, 45.5% answered "yes", 35.7% answered "no", and 18.8% either answered that they didn't know or gave another answer.

6. *Is leprosy curable?* — A positive 74.1% thought that it was. Of the remainder, 14.8% thought it wasn't and 11.1% said they didn't know.

7. *Recognition of "hanseniase" as other name for leprosy* — All throughout the questionnaire, "leprosy" was used instead of "hanseniase" because of our fear that the latter name would not be widely recognized by the general public. In fact this seems true. When asked to choose from a list of five fictional and non-fictional names "another name for leprosy", only 11.1% chose "hanseniase". The majority (60.2%) simply said they didn't know.

DISCUSSION OF THE RESULTS

What do the results which we have presented tell us about the level of leprosy knowledge and the strength of the "leprosy stigma" in the community? What kind of practical applications, if any, do these results have?

Level of leprosy knowledge — In reality, the results of the knowledge test need little comment. Except for the positive *sign* that about 75% of the region's population think that leprosy is curable, the results leave one with a feeling of dismay. Health education about leprosy is just not reaching the community. This is true even in a city

which has one of the better Hanseniase hospitals in Brazil.

Strength of the "leprosy stigma" — It is more difficult to draw clear conclusions from the results of the questions related to attitudes. Certainly, the results indicate that there is a "leprosy stigma". But what do the results tell us about the strength of this stigma? Should the results dismay us or encourage us? The answer to this of course depends a lot on what we were expecting. The fact though that leprosy placed second in our scale of conditions most feared indicates that

the stigma is strong. This is discouraging. On the other hand, the optimist would note that leprosy is in second place and a long way from being the most feared condition that some leprosy workers have preached. An even stronger reason for encouragement is that 84.3% of the people interviewed chose a condition other than leprosy as "the most fearful". Approximately 6% even chose leprosy as the most preferable of them all.

We also feel cautiously optimistic after examining the answers to the two questions dealing with maintaining close relationships with leprosy patients. Relatively few persons assume extremely negative attitudes to such relationships. Although the number expressing some fears is large, the majority of persons do seem ready to maintain some type of work and friendship relationships with patients. Given the knowledge level of the population about the disease, these fears are to be expected. Especially focused health education programs could do away with many of these fears.

This leads us to our next question. Just what are the main fears which maintain the "leprosy stigma"? Our information does not answer this question fully, but it does give us more data to consider. A part of the answer to the question would have to be "contagion". We saw that 82.3% gave this as the reason for their hesitation to working closely with a leprosy patient. Contagion cannot be the whole answer however, because other diseases many times more contagious than leprosy do not cause nearly as much fear. In order to delve a little more deeply into the question, we asked our sample directly what would be their primary fear if one day they contracted leprosy. The results indicate that the primary fears of leprosy revolve more around social

problems caused by the disease such as threats to others or rejection than around physical problems such as pain and deformities. We feel that this observation is collaborated by the fact that such mutilating conditions as double amputation and deep facial scars placed lower in our ranking of the condition most feared than did leprosy and mental illness.

One of the results to our question about the primary fear to having leprosy surprised us. This was the unexpectedly high number of persons who responded that their main fear would be in transmitting the disease to others. Perhaps such an altruistic response can be brushed off as an attempt to "look good" in the eyes of the interviewer. On the other hand, it might be a valid indicator of the sense of guilt that some patients have been observed to have because they feel themselves threats to others. Such a sense of guilt sometimes leads these patients to reject others before they themselves are rejected. At any rate, there is vast room for further research in this search for the roots of the "leprosy stigma".

Practical applications of the results — Although frequently a topic of discussion, organized programs to advance the socio-economic integration of hansenians are relatively few. The lack of strategies and resources partially explains this phenomena. Another probable explanation though, is that many leprosy planners are pessimistic about the success of such programs due to the strength of the "leprosy stigma". Some feel that only cases who can maintain their disease a secret have chances to live truly integrated lives.

Integration efforts based on maintaining the disease a secret have a number of draw-backs however. One of these is the psychological burden that the patient has to bear because of his

fear of being "found-out". Another is the awkward position it causes for the doctor, social worker or placement officer who is responsible for helping the patient in his integration efforts. A third problem is that a policy of secrecy adds to the "leprosy stigma" which we want to do away with, giving emphasis to the disease's differentness and shame. A fourth problem is that opportunities for the education of the patient's contacts about the disease are limited by secrecy.

While one must respect the desires of the patient in such matters, we do not feel that hiding the disease is a

necessary pre-requisite to the acceptance of the patient in integrated situations. Our results show that while a "leprosy stigma" exists, a considerable degree of acceptance to close relationships with patients also exists. This acceptance is even more noteworthy when one considers the erroneous and prejudicial knowledge that the general population has about the disease. We are therefore guardedly optimistic about the success of integration programs which are accompanied by health education activities with those with whom the patient is to maintain close relationships.

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