

LEPROSY, SOCIETY, AND HANSEN'S DISEASE¹

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There is in existence today a substantial body of thought that the problems of leprosy would be dealt with better if certain of the traditions relating to it were dispelled. To promote the dissolution of those traditions, the name "Hansen's disease" has been proposed as a substitute for "leprosy."

The proponents of this practical suggestion are outspoken in its favor. Hansen's disease has gained a good deal of ground. Those who take exception to the usefulness or aptness of this title offer no substitute for it. They may remark that the disease was known ahead of Hansen, who discovered the causative organism, or that Hansen could not have made that discovery unless the disease had preceded him! Or they may wonder just how the use of the eponym can become genuinely accepted without a rewriting of the Old Testament; and they find it difficult to imagine *zaraath* rendered the "plague of the Hansen's disease."

At the same time it must be acknowledged that the degree of success of Hansen's disease has reached an order too great to permit of its being dismissed as a vogue, an ism, or a *tour de force*. This success has not been achieved by the medical profession. Indeed, those especially interested in leprosy medically are inclined (1) to be amused by it, (2) to decry it as obstructive to furtherance of medical advances, or (3) to ignore it.

The successes of Hansen's disease have been something of a surprise to many leprologists, a surprise that leaves them puzzled as to what has really happened. Perhaps some of the success has surprised its champions, too. What *is* happening? Is it of importance? Can it be disregarded? Is the importance entirely secondary?

The thesis is presented that this movement toward Hansen's disease is a natural development in a strongly socialized mid-twentieth century, and that, in one form or another, it was inevitable. One has only to regard the strong social influences in every profession, every business, every walk of life, every government in the world, to realize that this social tendency was bound to find expression in leprosy. If this concept be valid, then arguments of the merits of the term Hansen's disease are not of the first importance. It is not the name itself that is important, but the sociologic influences in leprosy. It is not difficult to believe that the champions of this name would employ another one were it more suitable. Those who started the ball rolling are as much carried along by it

¹ This note was submitted for a Letter to the Editor, but as it would be out of place in that department it is used, with the author's agreement, as an article.—EDITOR.

as any. The social forces in leprosy are more powerful than the individuals or agencies involved. The real strength of the usage of Hansen's disease lies not in its being a peculiarly fitting title, which it probably is not, but in its symbolic representation of the flow of the tide.

Those interested in the problems of leprosy are inclined to label them as peculiar to the disease. In actuality it would appear that leprosy enjoys no absolute peculiarities. It is a chronic infectious disease with many features common to other chronic infections. The stigmata possess a force derived from biblical references, which force is absent from other diseases; but other infections have been as much or more deeply stigmatized in practice in the course of history, and stigmatization as a disease is by no means peculiar to leprosy. Man's inhumanity to man has, in the course of time, afforded many examples of cruelties in social treatment of other diseases as well as leprosy, some of them bizarre and all of them absurd.

At the same time leprosy is a disease ideally suited to the hypnotisms of black magic, and offers many opportunities to the modern sorcerer. Both in and out of the medical profession there has been a steady stream of wand-wavers, and incantations of mystical ideas designed to explain the evil, to protect against it—and to extract funds from the innocent and the religiously inclined toward doing good for the afflicted. Not a few of the speculators about leprosy select their facts about the disease to fit their ideas, ignoring those that do not agree. The many claims of having artificially grown the *lepra bacillus* in the test tube are a somewhat shocking evidence of human weaknesses involved in scientific endeavors. It is also somewhat shocking that the leaders in "socialized leprosy" have been equally casual in their regard for the facts of the disease.

Yet it would be as grave an error to condemn the modern wave of social interest in leprosy for its overstatements, or its unwonted zeals, as it would be to condemn modern medicine for its failure to produce all the answers. The social character of the wave motion is shown quite clearly by the nature of some of the organizations which take an interest in it—such as the American Legion and the Knights of Malta, both of which make substantial contributions in the field. At the worst it might be claimed that the activating spirit within such agencies is that of the self-appointed do-gooder, yet the actions and contributions are clearly social rather than medical or religious in character. Political outgrowths from the social beginnings are a natural pathway, and on occasion an effective means of advancement of the social development.

The physician genuinely interested in leprosy, and actively engaged in treating it, is often perplexed as to his position within the leprosy society. Although he may be wearied and bored by the monotonous arguments, he will find it impossible to remain wholly aloof and yet retain his full effectiveness as a physician. He is like a man in a skiff circling

'round and 'round the whirlpool, not wishing to be drawn in yet ceasing to be a party to the proceedings if he paddles away. What should his position be? The delicate jugglery required for maintaining the intermediate position is not likely to appeal to him.

Perhaps no single feature of sociologic leprosy becomes more tedious to the student of leprosy more quickly than *leprophobia*, the moralized complaints made about it, and the holier-than-thou remedies offered. Leprophobia is something more than a thorn in the flesh to the individual with the disease; it is a real and serious obstacle to his equitable social existence. The social movement in leprosy makes substantial capital of it. I wish to cite some examples to illustrate that leprophobia is not always what it seems.

There was a physician who worked for two years in a leprosarium, willingly and with industry, although he had not taken the post through forces wholly of his own election. He was a conscientious man. While at his work he practiced the isolation-ward technique to a maximum degree. The shoes worn to the hospital were kept outside his doorstep, never to enter his home, and he never failed to wash his hands after touching anything touched by a patient or possibly contaminated by a *lepra bacillus*. His colleagues were mildly amused by his extreme precautions. He had a wholesome respect for leprosy; his experience with it lessened his fears not in the slightest—if anything they enhanced them.

The sociologists in leprosy voice the claim that education will destroy leprophobia. Yet here was a man well educated in every way, a personable and likeable gentleman essentially devoid of eccentricities, who remained untouched in his fears in spite of a thorough education in the disease and in spite of the fact that he readily acknowledged the infinitesimal likelihood of his acquiring the infection. Was there something wrong with the man? Was he a coward, beset by fears generally? Did he possess a pathologic personality?

The answer to all these questions is, "No." He was simply a *hesitant* man, one who liked to take a long look before he leaped. His whole life was built upon this quality of his personality. His hesitancies had kept him apart from many futilities and vanities, and had led him into lines of action valuable to him. He went into leprosy work hesitantly, and no amount of education and assurance of its harmlessness to him took that hesitancy away. He was a hesitant man in his personality, and a destruction of that hesitancy would have meant the destruction of a part of him that was of much value to him. The point is simply this: that education as a cure for leprophobia has its definite limitations.

A realistic approach to sociology and leprosy must take arms for this man in some measure. The sociologist must not, above all, make the error of condemning him for a fool, a coward, or an immoral person. Yet there is in the social movement in leprosy a strong element of condemnation

of the leprophobe, which can only be seen as a pathetic unsocial act within a socialistic trend.

The extreme opposite of this case is that of another physician, also a worker at leprosy, who exhibits an apparent contempt for its infectiousness. He will shake hands with any patient and not bother to wash afterwards unless he knows the patient's hands to have been soiled by something other than lepra bacilli. His colleagues consider him to be unnecessarily careless. He once spent several weeks in a hospital because of an occupationally acquired infection, yet he appears to have gained no lesson thereby and remains callous toward leprosy. While he does not show off vaingloriously, as has been observed in some others, an inquiry would reveal that he has lived through exposures to tuberculosis, typhus, several virus diseases and some others, all of them much more devastating to health than leprosy.

Now the point to be made here is that leprophobia, or its absence, has nothing to do with this case. The contempt, if that is what it is, is general, and a *specific* disregard for leprosy out of the question. He is a negative leprophobe.

Our third leprophobe was the Brakeman of the Sunset Limited. As a brakeman, one of his duties was to guard the rear of the train, with flag, lamp, or fuse, whenever it stopped en route between Los Angeles and New Orleans. He kept his equipment at the rear of the last car of the train, which on one occasion had as its passengers a physician, a nurse, and five persons with leprosy. The Brakeman knew in advance of these patients, and had had the opportunity to be relieved had he wished, which he declined. He was a genial and loquacious gentleman, "Churchy, but not too churchy, if you know what I mean." He was most curious about "his" patients, and spent several of his quiet hours inquiring of the physician about the disease. His tour of duty took him only a part of the trip, and his last official act was to carry his equipment, unnecessarily, through the patients' car.

He was replaced by a Second Brakeman, who kept his equipment at the rear of the second car from the end. This man also knew of the passengers ahead of time, and he never entered the last car. He had only a bare greeting in passing for the physician, whom he avoided, and usually was not to be seen. There was still a Third Brakeman for the last leg of the trip. Where he kept his equipment is unknown, but he was seen several times to drop off the train as it approached a stop, several cars from the rear.

What happened? The First Brakeman was a man of uncontrollable curiosity. He had almost surely contributed his version of leprosy to the Second Brakeman, creating a state of leprophobia which had probably not previously existed. Apparently the Second Brakeman put the fear of God Himself into the third.

Although this story may appear to have a flavor of levity distasteful in connection with a serious matter, it none the less serves to illustrate how leprophobia may, and frequently does, develop with great rapidity. It also illustrates a basic feature of leprophobia: *It does not exist, except as occasion for it may arise.* But the background for it, the biblical references, the use or general understanding of "leprous" to mean generally odious or loathsome rather than to refer to a specific process, is probably in some degree already present with most people.

The creation of a hospital specifically for the treatment of leprosy will thus, necessarily, create a leprophobia among the nearby residents of the area. Personal observations among the residents in the neighborhood of the hospital at Carville, Louisiana, indicate that these people are as reasonably well informed about leprosy as educational means could be expected to provide. They are complacent about their neighborhood hospital. Are they rid of leprophobia? Emphatically not, nor do they expect to lose it. It cannot be said that they *suffer* from it, or worry about it. They just have it, and that is the fact. I find it difficult to believe that a broad educational plan in leprosy would not create several times the general amount of leprophobia it dispelled. The assumptions that educational procedures would eliminate leprophobia are inadequately founded; that they would have an ameliorating effect among many men is true, but when one examines what has happened with respect to other educational effects in other diseases the grave doubt is aggravated.

During the past decade enormous amounts of publicity, much of it with educational slants, have been delivered to the general public in two outstanding examples—cancer and poliomyelitis. The extent and degree of the public demonstrations and writings about these two diseases is of such magnitude that no owner of a radio or television set can have avoided them. No one in the country who can read has been permitted to escape the perpetual assaults upon his intellect of the hundreds and thousands of statements coming all the way from the Presidents of the country down to every cross-roads expert.

Has the *fear* of cancer or infantile paralysis been in any degree lessened thereby? I should say that our public consciousness of these two diseases results in fears unparalleled in the past, and that the publicity campaigns have with deliberate calculation capitalized upon those fears, using them forcefully to enlarge and enhance the values of vaccination against poliomyelitis and of early treatment of cancer.

Let us assume that these public campaigns about them have been genuinely effective in lessening the risks of these diseases and thus valuable, a point which will find a large general agreement. We may then ask whether the similar social trend in leprosy is different in its general results, and is in the same sense valuable. I believe that it is valuable, and will continue to be valuable, and that the leprologist who scorns the value thereof is not being realistic.

At the same time it is necessary to take exception to some of the exploited concepts, and it seems particularly important to take exception to the thought that education in leprosy eliminates leprophobia, or that the value of the socialistic trends in leprosy lies in that direction.

When the poliomyelitis and cancer campaigns are thoughtfully considered, their most significant feature would seem to be that both have something with solid medical background to offer, vastly improved treatments for early cancer, improved treatment of and now vaccination against poliomyelitis. May we, with polite irony, suggest that a *sine qua non* of the value of the current socialism in leprosy is not the thought symbolized in "Hansen's disease" or the cure of leprophobia, but the introduction of the sulfones into the treatment of leprosy by Guy Faget in 1941?

What's in a name? A logical application of Shakespeare's poetic "rose by any other name" to leprosy must read that leprosy by any other name were likewise just as sweet. There being nothing sweet about the original, will changing the name make it so? Shakespeare does not say so—he says just the opposite.

The use of personal names in science has, without plan, steadily given way in the twentieth century, largely due to the fact that increasing knowledge of a phenomenon, a law, or a disease, so enlarges the perspective that the concept of the original description is left far behind. As an example, "Bright's disease" for chronic nephritis has become a useless phrase, too general and vague in its concept. In bacteriology person names, latinized, are used for generic classifications, and there are examples in which the person name is incorporated into an accepted and useful title. The organism of undulant fever is now *Brucella* (for Howard Bruce), and brucellosis is in common usage. It is conceivable (and reasonable) that a future classification of the mycobacteria might group the lepra-type organisms together under *Hansenella*, which could lead to "hansenellosis." It would seem that, for this to occur, it must take place naturally, necessarily following a standard formal classification. Meanwhile, "hansenosis" must rank as a pure invention, badly wanting a basis for its employment.

The trend away from person names has often followed a pattern. We have seen the "consumption" of a hundred years ago turn into the somewhat artificial but wholly accepted tuberculosis, with Koch's disease enjoying only a transient usage. One can only postulate that the simple and general usefulness of the title tuberculosis has been the determinant factor. The nature and pathology of the disease were well known before Koch, who proved its infectiousness and its bacterial agent. Application of the history of the usage of Koch's disease to the present case:

Consumption Koch's disease Tuberculosis
Leprosy Hansen's disease ? ? ?

leads to the inevitable thought that Hansen's disease cannot serve as more

than a temporary expedient. Is it a wonder that leprologists find the name awkward and unsatisfactory? Is it good planning for the sociologist in leprosy to expect that the physician should submit to an awkward name as an expedient?

What's in a name? Bernard Shaw, using the phrase, "The Unsocial Socialist," emphasized the fact that something of what is passed out as the furtherance of society often becomes the attempted aggrandizement of one society as against another. The historical examples are many, and the weaknesses of their social claims are illuminated by their occasional slogans. The "Down with the Infidel" of the idealized adventures known as the Crusades was a valued, but false, inspiration to the zealots who were thus taught to disregard the basic teaching of Jesus, "Love thine enemies." There is said to be in existence today a strong social-political movement whose slogan is, "Down with the Capitalist!" There is a strong flavor of "Down with the physician who denies us" in the socialistic trend in leprosy, as though he were the obstacle in the path.

It is suggested that the major strengths of the socialistic forces in leprosy derive directly from medical contributions to leprosy, and that the physician may wisely and well maintain this truth. He will serve his patients and his profession best by adherence to the immediate problem of leprosy, the chronic infectious disease, without permitting himself to be diverted into leprosy, the social question mark. This has been his behavior of the past, and there is sound reason why it should continue.