Suggestions for the restructuring of hanseniasis institutions in Brazil

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SUMMARY — After seeking to establish the fact that the structures of institutions for the treatment of Hansen's disease are normally obsolete, archaic, and foster paternalism and sentimentality, the author proposes a restructuring of these institutions with the end of transforming them into modern hospitals. Basically, the author proposes a division of these institutions into three areas:

1. Hospital proper
2. Residential area
3. Asylum area

He then gives a definition for each of these and describes its principal activities.

Termos índice: Hanseníase. Hospital. Asilo.
Key weedy: Hanseniasis. Hospital. Asylum.

INTRODUCTION

Since its earliest days, the specialized hospital for the treatment of Hansen's disease in our country has evolved very little in its basic structure. The three-way division of these institutions into "sick zone", "intermediate zone" and "healthy zone" is a characteristic which has largely remained without alteration in almost all of the 28 sanatoria of the country.

In some states, like that of São Paulo, attempts have been made to modify this system by changing the names of these institutions so that they better correspond to heir primary purposes. Relatively little success however has been attained in modifying their basic structures up until now. In their general frameworks, the asylum-colony, the sanatorium, and the dermatology hospital practically remain unaltered.

Without doubt, here in the state of São Paulo, the administrative reform undertaken by the Secretary of Health,

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has brought about qualitative and quantitative changes in all of the department's units in terms of personnel and material, and has, in some degree made us more aware of the need to solve the problem. Nevertheless, in the rest of the country, the concepts of asylum-colony and leprosaria yet remain.

This state of affairs is the result of the fear society, and to some degree, the medical profession, have had of the disease. Such fear has led to the compulsory isolation of the patient, his marginalization and stigmatization. At the same time, paternalism as well has contributed to the formation of "professional patients".

It is obvious that Hansen's disease should be viewed as a disease to be treated within the concept and -with the technical resources of a public health program. A health team headed by a "Hansenologist" is fundamental to the success of any program geared to combat the disease. Such a specialist should be technically prepared and aware of the importance of his role within the health profession. Likewise the health profession should grant the Hansenologist the support and respect he deserves.

The general consensus is that rarely has there existed within asylum-colonies or leprosaria, technical and scientific attitudes towards the treatment of the disease. Because of this, these institutions have obviously failed as basic elements in the treatment of Hansen's disease. Furthermore, experience has taught us that in reality, the patient has little need of hospitalization if outpatient centers fulfill their functions in the control and treatment of the disease.

Therefore, it is concluded that there is really no adequate reason for the continued existence of hospitals specialized only in the treatment of Hansen's disease. Those which continue to exist should either be closed or should widen their definitions of service to include other dermatological problems or other medical specialties.

Meanwhile, no matter what decision is made, the hospital should strive to achieve medical excellence and to eliminate past mistakes and thus become more than only a dim imitation of a real hospital. In the following, we propose a method for restructuring these outdated institutions in a logical manner within the limits of public resources. In such a reform, we hope to eliminate the emotional and paternalistic factors which have long characterized the treatment of this disease,

1. THE HOSPITAL PROPER

A hospital in its physical structure should follow the norms dictated by modern construction techniques for hospital building.

It is correct to say that the present structure of dermatological hospitals, because of their pavilion type buildings and the ends for which they were built, do not offer an ideal situation for a modern hospital. An attempt was made, therefore, to study the possibility of transforming these sanatoria buildings into hospitals which would con- form to modern theories about what hospitals should be. This process was begun in the specific case of Hospital Lauro de Souza Lima in 1969 in line with the administrative reforms advocated by the Coordinator of state hospital services and the state Secretary of health.

According to our understanding, we define a hospital as an institution that takes in patients who are in need of hospital beds where they will receive medical and nursing attention on a 24-hour basis. To furnish this attention, a hospital needs equipment, auxiliary personnel, adequate facilities, and a progressive spirit determined to overcome all obstacles so that medical treatment, based principally on the work of doctors and nurses, is provided.

This has been the desire and the goal of the staff which for many years has worked in this institution. It is based on the fundamental premise that Hansen's disease is a disease like any other, and that in any program undertaken for the control of the disease, the initial aim should be the patient's treatment and cure.

In a specialized dermatological hospital it is basic that there be a clinical staff that is highly motivated and responsible. This groups should be composed of all the medical specialties necessary to solve the problem and should work as a team if it is to achieve the above mentioned objectives.

Attaining these goals is the crucial problem that all dermatological hospitals are facing, not only in this state but in the rest of Brazil as well. Hospital Lauro de Souza Lima, while still a long way from reaching these objectives, is nevertheless taking firm steps toward them.

Briefly, what is being attempted on a practical' basis in our institution is to offer the Hansen's disease patient a high level of hospital medical assistance modeled on the delivery systems of hospitals that treat other diseases in the country. According to this pro- gram the patient would be interned the minimum length of time necessary and returned to his home community after being released by the hospital. An attempt would be made to establish the best norms for appraising an assistance program. This, naturally, would result in an excellent condition for study, research, and teaching; as well as in an effective and permanent opportunity for rehabilitation, and health education, at least as much as is possible during the patient's hospital stay.

It is also important to mention the great difficulty that occurs when we try to plan for the number of hospital beds needed for the treatment of Hansen's disease patients. Because of the nature of the disease, normally the patient will not need to stay in bed. Occasionally, however, he will need to be bedridden for the care of acute reaction crisis, ulcers of the extremities, or other illnesses.

In order to plan, it is necessary to have at hand accurate statistical data. Unfortunately, we know this data does not exist. Realistically speaking, this is because we lack conscientious, responsible, effective, full-time and well-paid doctors in both the dispensaries and hospitals of the state who would provide such accurate data. This fact makes global planning for hospital beds difficult.

Hospital Lauro de Souza Lima has therefore used as a basis for reference in determining the number of hospital beds to plan for, the utilization of its present buildings. Our planning begins from the fact that almost all infirmary beds are used 100% of the time.

It is possible that with an effective dispensary program using special methods such as plaster casting, boots, adequate shoes for the patients, along with an effective rehabilitation sector now being developed within the hospi-

tal, we will run the risk of being left with a reasonable number of unoccupied beds, for upon completion of the current remodeling and expansion, the hospital will have almost 300 beds.

If this should occur, there is the possibility of offering these unoccupied beds to patients needing hospital treatment coming from other similar institutions within the state, or of giving greater attention to other dermatologic- al problems besides Hansen's disease by treating a larger number of patients with problems such as pemphigus, blastomycosis, leishmaniasis, etc.

Along with the assistance program itself, the hospital would undertake teaching, research and health education. Also it would emphasize its rehabilitation section, focusing primarily on medical or physical rehabilitation. Such rehabilitation work would be closely related to similar work being carried out by the dispensary and by other institutions outside the hospital such as the health centers.

2. RESIDENTIAL AREA

The years of being an asylum and sanatorium have left the dermatological hospital with a colony made up of "carvilles" and married couples' houses. These buildings were built primarily because of the large numbers of patients who were interned who did not need hospitalization (this being a chief characteristic of patients interned in hospitals specialized for Hansen's disease).

Generally speaking, this type of internee could get along with just a periodical visit to a dispensary for diagnostic, therapeutic follow-up or social service assistance. In the process of reforming dermatological hospitals, we forsee the time when this type of patient will not be admitted for hospitalization. It is generally accepted, that aside from rare exceptions, these patients should be treated in their home communities.

The basis for this opinion stems from the conclusions of medical authorities who have worked toward understanding the problems involved in the control of Hansen's disease. Meanwhile, the reality of the matter is that our institutions are filled for the most part with patients of this type. Of course I realize that there are also many reasons for why this is so.

Though it is common knowledge and beyond discussion, nevertheless as clarification it shoold be stated that a dermatological hospital as a suppletive organization to the health centers needs to collaborate with the latter by receiving and treating their patients.

Along with these patients who come unnecessarily from dispensaries and at times from other sources, we also can find a large number of internees who live within the hospital, but with the physical ability to be self-sufficient These are victims of the old system of treatment and have completely lost ties with their home communities. We believe that these are candidates for a rehabilitation program which would eventually result in their leaving the hospital.

From now on, these patients, called residents, will be treated in such a way as to aid their return to society by method of an extensive program of rehabilitation and health education which will use both the hospital resources as well as those of the community.

These patients, whose maintenance is inappropriately a burden to the hospital's budget, will be requested to fulfill a variety of obligations. The state, in accordance with its guidelines for hospitals, does not have the responsibility of supporting these patients even thought it continues to accept them.

By obligations we mean that these patients will be required to be responsible for the up-keep of the buildings in which they live as well as maintaining the cleanliness of the areas in front of them without receiving any pay from the state. Also, it would be required that these patients participate in structured medical, health education, and rehabilitation programs.

As has been emphasized, these patients should be in treatment at the dispensaries in their home communities, but instead they are interned in the hospital. Logically, the hospital should be especially concerned with the control of this group so that when they are dismissed from the hospital, they not be carriers of the disease. Though this be an obvious fact, it has not been conscientiously carried out in an organized way during internment. We believe however that it would be the best contribution that a dermatological hospital could give to the control of Hansen's Disease.

If by a program of assistance, complete ambulatory treatment and continual health education the control of this group were achieved, we believe that in a short period of time we would have excellent results. The same methods that have been used in Venezuela could be used here.

3. THE ASYLUM

The last topic that we will deal with is the future of the patient in the dermatological hospital, or better yet, the ex-patient who has theoretically been cured but who, because of his age, deformities, insensibility, or psychological stigmatization caused by the disease, continues to live at the hospital and depends completely on the state for his welfare. These are people who have cut all ties with their home communities and normal lives as a result of the passing of time, the disease, and treatment methods of the past. They are not candidates for a rehabilitation program. They are truely incapacitated. They do not need, at least primarily, the specialized medical assistance of a hospitaL

Even though in some cases they might still need ambulatory care, in reality, they lack the ability to care for themselves. Help for these patients such as a special place to live, clothes, tools especially made for them, as well as humane care and special nursing, would be given to them in an effort to provide comfort and to prevent the worsening of their physical condition. An area within the hospital limits would be set aside to provide them a comfortable place to live. At Hospital Lauro de Souza Lima, the buildings called "carvilles" which are still in good condition and grouped in blocks (see map) would be the ideal location for these patients.

It should be stated that in principle, this group of ex-patients should live out the rest of their lives in this area. On the other hand though, there is the possibility that these patients be transferred to community asylums, thus

relieving the dermatology hospitals of this burden. This could be done only after careful stuay and most probably, only by using state resources such as those of the Secretary of Social Welfare.

THE ROLE OF THE DISPENSARY

As was said in the beginning, the dispensary as the center for the three divisions (namely the hospital proper, the residences, and the asylum) should establish close and direct ties with these entities as well as with the dermatology departments of the state community health centers. In this way, the dispensary would take on the characteristics of a polyvalent clinic which would treat outpatients, focusing primarily on general medical needs and also on problems specific to the disease.

All of the technical staff of the hospital would participate in the work of the dispensary, from doctors of all specializations, to nurses and other auxiliaries as well as those involved in the rehabilitation and health education program, working not only as assistants- but also as trainers and teachers.

In developing this dispensary, a model situation would be sought. The dispensary should have all of the technical resources necessary to the treatment of the disease in an integrated situation. As has already been said, it is planned that this model dispensary would emphasize rehabilitation and health education, along with its general assistance program. It could also serve as a training center for the state and eventually perhaps for other parts of the country.

RESUMO

Após esclarecer que as estruturas hospitalares para a hanseníase são obsoletas, arcaicas e sofrem de mal permanente da paternização, fundamentadas por conceitos emocionais, o autor propõe a reformulação destas estruturas, isto 15, dos antigos Asilos-Colónias e Sanatórios, para adequação dentro da técnica hospitalar moderna, aproveitando o que está construído até o presentes momento.

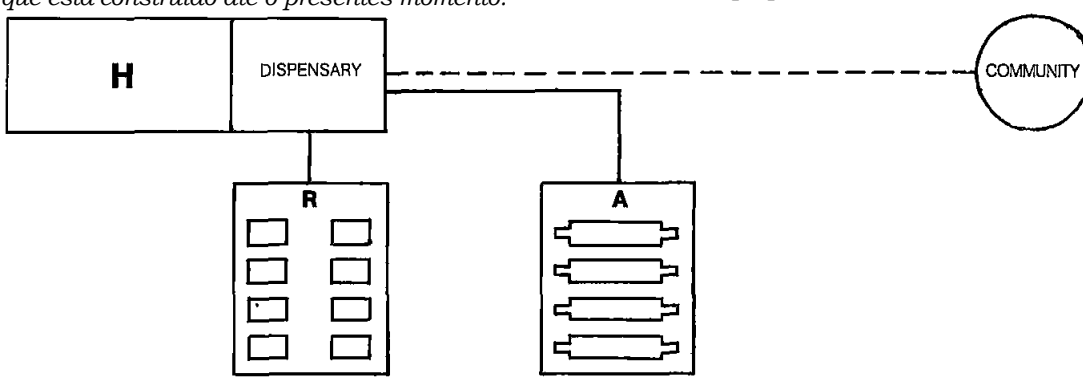
Basicamente, propõe a divisão de 3 áreas com finalidades especificas:

a) 0 hospital propriamente dito,

b) A área residencial e

c) A área asilar.

Estabelecendo para cada uma a definição e as atividades próprias.



H: Hospital — R: Residences — A: Asylum

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