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## NEW APPROACH ABOUT THE CURRENT PARADIGM OF THE SELF CARE IN LEPROSY

The selfcare paradigm in public health departments is essentially a matter of cooperation between the activities of health professionals and patients self aptitude which is supported by "Bioethic" and recognition of patient's autonomy<sup>1</sup>. In past, this cooperation was of a paternal type. Since the fifties, with scientific advancements, the morbidity and mortality profiles changed, as result, the period of survival for patients with chronic diseases has increased considerably. Due to this important change there is a necessity of teaching these patients self responsibility and SELF CARE. It is known that the effective multidrug therapy scheme for leprosy, does not necessarily prevent nerve damage because the diagnosis, in most cases, is made too late to prevent such consequences<sup>2</sup>. In other words, prevention measures for disabilities are not associated to the diagnosis and treatment<sup>2-3</sup>. In 2006, 46,535 new leprosy cases were diagnosed in Brazil, and 94.4% of these were examined, 17.7% already presented with a grade I of disabilities and 5.5% grade II at the moment of the diagnosis. In reality, it can be concluded that the number of individuals with disabilities could still increase when one assumes that the reactions can occur during or after the treatment and these individuals will have a similar life span as any healthy individual<sup>4</sup>. It is indicative that these disabled patients will develop the necessary autonomy towards selfcare his/her entire their life. The question arises: "WHAT ACTIONS ARE BEING TAKEN TOWARDS PATIENTS IN RELATION TO SELF CARE IN LEPROSY?"

In leprosy Reference Institutions we should study and analyze the practices of care taught to health care professionals. For example, in an ongoing experimental study on the use of silicone insoles of to prevent foot ulcers or relapses<sup>5</sup>, we could observe that the product

provides a greater lubrication of the skin and comfort, reduces hyperkeratosis, increases the ability to walk and theoretically, it should reduce the frequency of visits of patients to the health center for check-ups when compared with those using "EVA" insoles. In this context, silicone insoles are indeed better than that technology, however, did not dispense the selfcare activities, since, the patients returned frequently because of other problems such as those of hands and eyes. Consequently, we needed to concentrate on the attention and behavior of patients living far away from health care center, thus, we started another study, through domiciliary survey, so that we could evaluate the patients registered within the Leprosy Program (in the city of Jaú/SP) and practicing selfcare<sup>6</sup>. We observed that the selfcare practice was either absent or inadequate, even among those 100% who received practical training about selfcare from professionals. However, this knowledge was not incorporated into their daily routine. Further questions arise: "IS THERE A DIFFERENCE BETWEEN GUIDANCE AND EDUCATION? IS THERE AN UNIFORMITY OF INFORMATION BETWEEN PROFESSIONALS AND PATIENTS?"

Following such questions we tried to identify the factors interfering in the practice of selfcare in leprosy, taking into consideration the knowledge, ability and related support. We assessed patients' concepts about the disease and how they receive and apply the instructions given by professionals<sup>7</sup>. Among 30 interviewed patients, only 56% of them were informed about the risks they would be faced with, 93% of these patients clearly showed the lack of knowledge about selfcare, characterized by wrong interpretation of information and cognitive limitation. These indicated

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that most of the patients didn't really understand the causes of injuries and were dependent on the interpretations based on simple beliefs and myths. The 100% of the interviewed patients gave evidence of deficient ability for selfcare characterized by incapacity to perceive one part of their body, muscle skeletal injury and pain, suggesting the necessity of a caretaker in order to perform prevention of disabilities activities. 54 % of the answers showed evidence that they receive support in order to perform selfcare, and this, did neither hamper the interaction with the community, nor there is inadequacy of the health system or lack of resources. Next question arise then: i) does this support characterize a dependent management for selfcare? ii) how have leprosy professionals being educated to execute their functions optimally?

Therefore in another study we checked if the content of the courses for the health professionals provided them enough knowledge to introduce actions or to implement leprosy control measures in each health unit<sup>8</sup>. We found out that 61% of them already worked in the leprosy program after finishing the courses, and the practical, theoretical and didactic education contributed effectively in their works. However, 39% informed that they no longer worked in the leprosy program, and the most frequent causes for discontinuation were dismissal from the job or transfer to other health sectors (66%). This trend suggests an

administrative and political lack of commitment with the leprosy program coupled with training scheme. According to the experience of two nursing trainees from Instituto Lauro de Souza Lima<sup>9</sup>, they observed a specialized, systematically humanized and wholesome assistance, with high degree of satisfaction by the patient. In that content a patients reaction to such assistance was: "I am well looked after and the nurses take good care of me".

Finally one can ask the following questions: What is the role of the nurse? What is the role of the team? Should we help or teach the patient what to do? What type of relation between professional and patients are we building? Is it paternalist or a bondage based "autonomy"? Which model of assistance has been used to deal with leprosy chronicity? Are we far away from the paradigm of the Bioethics which supports selfcare? It is hoped that all these above mentioned answers can be found in future.

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