

ABSTRACT

The proposal of this study was to understand, through phenomenological analysis, the feelings and experiences of the leprosy patients with regard to his/her illness.

The inquiry had the objective to evidence the meaning of leprosy in the life of patients, the repercussions of the illness on the intra and interpersonal relations, the elaboration of life projects, the implications in their work, the perceptions of the different phases in the management and the feelings implied in this process.

This study was carried out in the period from December 1998 until December 1999, in the city of Porto Alegre-RS. The *locus* of the study was the Sanitary Dermatology Clinic of Rio Grande do Sul's Health and Environment Secretariat. The participants in the research consisted of eleven sick people with leprosy being supervised in the clinic, of both sexes, regardless of their partner's

economic level, instruction degree and profession, with ages ranging from 22 to 76 years.

In this research, a phenomenological analysis was used, the collection of information being carried out by means of dialogued and half- structured interview, having a basic guiding question: What does having leprosy mean to you?

The information collected had been analyzed by the phenomenological method considered by Giorgi (1985 and 1997) and Comiotto (1992). From this analysis seven phenomenological essences and their respective dimensions emerged:

The difficult path from the necessary diagnosis to the beginning of the correct management: Leprosy as a biblical illness: unfamiliarity of leprosy as a current illness. The impact of diagnosis confirmation when the patient admits to be leprosy. The seek for medical features: from difficulties found until the beginning of current management.

Being (human) leprosy: feelings as essential characteristic: What it means to have leprosy. Gave rise to dichotomic feelings from this experience.

About the intrapersonal: the relation that is exactly the truest to me: Coexisting prejudice and discrimination. Coexisting physical sequels. Refinding themselves: from the loss of self-esteem to its rescue.

Community, prejudice and discrimination: Family: from support to rejection. Friends: from the support of some to the abandonment of the majority.

The **body as a mirror of the stigma:** On the occultation of the illness and the body: to tell the truth or to occult leprosy. Self-segregation of the body.

About health teams: The perception on health professionals. The desire of being treated.

Health education in leprosy: About the sick person and its illness: sharing information. Stimulating care. Family life with the leprous: ready for the family and community.

From the context studied has emerged the necessity of: stimulating actions elucidating that leprosy is not a "biblical", incurable illness from the past; elaborating continued education programs and promoting training for health professionals; creating opportunities of experiences and orientation for future health professionals during college and specializing courses, about the importance of the human relation that's established with the leprous; strengthening, during medical education, the study of Dermatology; providing the leprous boarding with more human management, valuing his/her feelings, elaboration of educational programs for health in leprosy, aiming at sharing information about the illness with the leprous and to stimulate self-care; providing the leprous's family with moments of dialogue and doubt clarification; promotion of educative campaigns on the media, aiming to clarify to the community referential subjects to the transmission,

clinic, management and curability of leprosy; Promotion of lectures about leprosy in schools of the private and public systems.