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29 May 2008 Study proves that children suffering from cancer, and their families, undergo social isolation

How does the suffering caused by childhood cancer develop? What feelings and worries arise? What are the patients' needs and the experiences they live? And how does the disease affect the lives of both the children and their families? These are some of the issues analyzed by **Pilar González Carrión**, researcher from the Department of Social Anthropology of the University of Granada, in her doctoral thesis.

This study, led by **Arturo Álvarez Roldán**, aspired to understand the implications of cancer for children diagnosed with the disease as well as their families, their experiences and worries, their relationship with the health system and their care needs during the disease treatment. In order to carry out this study, the author interviewed 14 children staying at the Hospital Universitario Virgen Nieves or the Hospital Universitario San Cecilio de Granada and 22 mothers between June 2003 and October 2005, as well as their families during the three years previous to the study. This work combined participatory observation together with individual and group interviews with children and mothers in 14 clinic interviews.

Strong emotional impact

According to the results of her work, the researcher states that cancer diagnosis "causes a strong emotional impact" on the child, with negative feelings of uncertainty, fault, powerlessness and significant confusion". From that moment on, the child, mother and, partly, the rest of the family life "revolve around the disease and treatment."

The most traumatic experiences are connected with the procedures, the treatment side effects and the isolation imposed by neutropenia, affecting the children not only physically and psychologically but also at a social and a school level.

In the work, carried out by the University of Granada, there appears a significant quantity of needs and improvement proposals, notably that of adapting the sanitary resources to the children and mothers' specific needs and providing real, comprehensive attention to these patients. Nevertheless, the care received is well appreciated by those affected, who value the professional support.

Since the diagnosis of the disease, mothers express a change in their life values, "giving more importance to the day by day, to each moment, to the emotional aspects, and not to future or material things," explains González Carrión.

The stigma goes on

"The data about successful treatments has not had a profound effect," says the researcher, "as the diagnosis is still related to the idea of a death threat. The metaphors used when talking about cancer aroused suffering, which contributes to the perpetuation of the disease's negative aspects. The stigma surrounding the disease, together with the delicate state of health in certain periods produces social isolation in the child and the family."

The information obtained through the surveys of the doctoral thesis is of great interest for getting to know situations experienced by those affected, which means the possibility of naturally providing a more suitable assistance, adapted to their situation. The results of this research have been published in the magazine "NURE Investigation".

Reference

Pilar González Carrión. Department of Social Anthropology of the University of Granada

Tlf. Number: +34 958242321

E-mail: mariap.gonzalez.sspa@juntadeandalucia.es

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