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When a family receives the news that one of their members has a chronic disease, structural changes occur, procedural and emotional at the itself. When a child is affected in the pediatric age, the family is the first social support and gives a protective function the child's illness is always a family problem and their quality of life is closely related to the support it receives.

Parents respond not only in terms of disease and treatment of the child, but also according to their own feelings and personal problems. Parents have to restructure all aspects of family life and most of the time they do according to the child's illness forgetting other important aspects of their lives because the threat of disease absorbs all their time, attention and energy.

The Quality of Life is understood as a central component of human welfare, which is related to aspects of its operation, such as health and the development of interpersonal skills or social interaction in the community. Has been recently introduced the concept Quality of Life Related to Health which arrived to the health field with the look of the welfare of patients is an important point to be considered in both treatment and throughout the health-disease process.

The aim of this study was to analyze and describe the impact multidimensional familial of the diagnosis of Hemophilia in a progenitors group registered in the register of the FHRM A.C.

MATERIALS AND METHODS

20 Progenitors

10 men / 10 women

Age

22-38 years old
X = 29.25
SD = 5.11
Range = 16

Instrument

PedsQL™ 2.0 Familial impact module developed by Varni et al. (2004)

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RESULTS

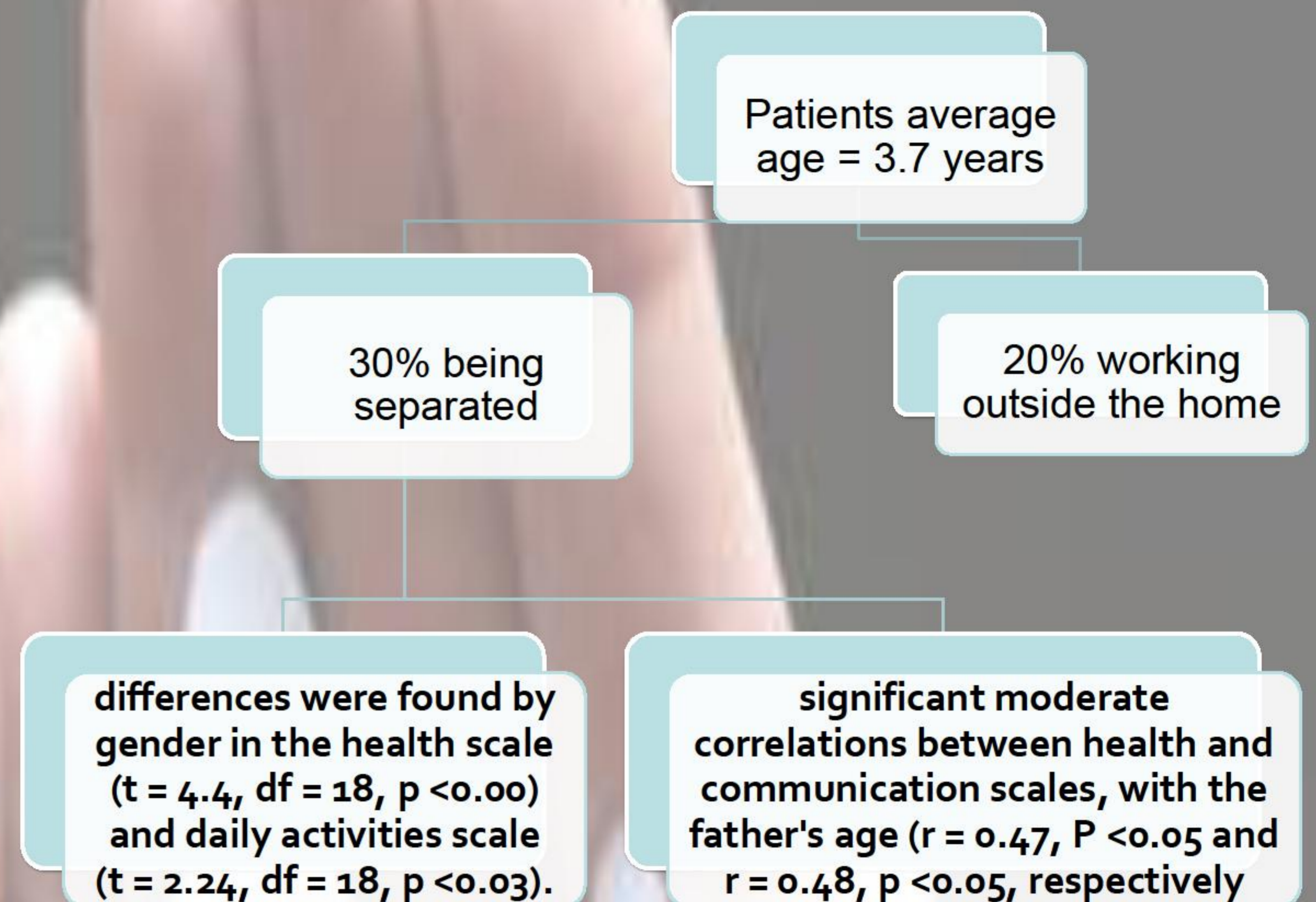


Table 1. Scores on each of the scales PedsQL™ Family Impact Module.

Sub-scales	# items	N	Average	S.D.
Total Score Impact	36	20	55.1	8.8
Rating Quality of Life Related to Health	20	20	60.5	7.5
Health and Physical Activities	6	20	51.7	14.8
Emotional State	5	20	61	12.2
Social Activities	4	20	59.1	16.5
Thinking and Concentration	5	20	71.5	17
Communication	3	20	50	20.6
Concern	5	20	39.5	15.3
Familiar Score	8	20	53.3	16.3
Daily Activities	3	20	48.3	27.4
Family Relations	5	20	56.3	22.5

The results denotes a level involvement biopsychosocial. Analyzing table 1 we can see that one of the most affected subscales is the concern which refers in general terms to disquiet generated by the side effects of treatment and medication.

Family relationships they expressed difficulty making decisions together as a family, an absence of communication between its members and the difficulty to resolve family problems together regarding their emotional condition reported feeling angry, sad, anxious, frustrated and helpless.

CONCLUSIONS

- The diagnosis of a chronic disease in pediatric patients impact not only in the daily routine of the family but directly on the quality of life for the patient progenitors.
- Characteristics such as age of the child, weak social networks, high levels of concern and separation problems with their respective partners, influenced in that there is a high impact of the disease in the family.
- Direct impact is evident in the physical health, emotional conditions, social area, and communication and familiar of the progenitors, this adversely affects the progenitors as a couple.
- Their relationship was highly affected by excessive tiredness also exteriorized physical and psychological discomfort by the lack of support in daily home activities.
- The proposal is generate workshops where they learn different relaxation techniques, social skills training and the attention of health professionals should be extended to them.