Quality of life as an object of study for psychology and behavioral sciences is a core component of human well-being, related to aspects such as health and the functionality of interpersonal and social interactions. It is important to consider both in treatment and in the whole health disease process. To analyze and describe the perception of quality of life levels associated to the hemophilia risk (parents and children); plus their quality of life is below that of the patients with other chronic diseases, which is why it is necessary to implement institutional programs that can guarantee an integral treatment that changes their perception.

RESULTS

To analyze the effect size was applied the D of Cohen which as one can see in Table 1. Have negative values, this indicates that average levels related quality of life (HRQOL) reported by patients with hemophilia and their parents are lower than those reported by the sample where the instrument was validated. It can also be noted that these effects are moderate.

Comparison of averages between the PHM and chronic patients. It was considered important to compare the scores obtained for this sample with the theoretical values proposed by the author (Varni, et al., 2003), in this way they were compared from the students’ test scores of both samples, finding significant differences in favor of patients with chronic diseases, in all areas of the instrument, except emotional functioning in the reporting of children (Table 1).

Effect size of D of Cohen

To analyze the effect size was applied the D of Cohen which as one can see in Table 1. High negative values, this indicates that average levels related quality of life (HRQOL) reported by patients with hemophilia and their parents are lower than those reported by the sample where the instrument was validated. It can also be noted that these effects are moderate. These values indicate that the average for sample in the Physical Health 0.85% exceeds the average of the PCH. Regarding the scores of parent reports show that the average total scores of parents of patients with chronic disease exceed approximately 0.85% to the average of the parents of PCH (Table 1).

CONCLUSIONS

It is important to give account to the perception of patients and their parents about the levels of quality of life in order to know first hand how they live and how they really the difficulties they face.

The results show as perceived by patients and their caregivers most of them are at high and there are significant differences between this category and risk levels and good quality of life.

The results indicate as perceived by patients and their parents about the levels of quality of life in order to know first hand how they live and how they real the difficulties they face.

The supplementary analysis contracts the average (D of Cohen) showed that the values were negative which means that the scores of PCH are below the scores of chronic patients, in less physical, social and school functioning.

In the same way, the scores of parents in the sample were below the scores of parents of patients with chronic diseases, significantly.

It is necessary to design intervention programs and catch the attention of all those involved in the treatment of these patients- politicians, authorities, doctors, psychologists- about the importance of receiving adequate medical treatment and how it will provide a better quality of life to which patients are entitled.

REFERENCES