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29th International Conference on **Pediatric Nursing & Healthcare**

31st World Congress on **Advanced Nursing Practice**

August 16-17, 2018 | Madrid, Spain

Quality of life and perception of children with anorectal malformation, hirschsprung's disease and idiopathic constipation

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Introduction: Anorectal malformations, Hirschsprung's disease and idiopathic constipation are diseases with changes in bowel function, with fecal incontinence and constipation, and can impair the quality of life.

Objective: To evaluate the perception and quality of life of the child with anorectal malformation, Hirschsprung's disease and idiopathic constipation accompanied by an outpatient clinic in a public hospital in Brazil.

Method: It is a cross-section of 08 children from aged 5 to 18 years, diagnosed with anorectal malformation and/or Hirschsprung's disease or idiopathic intestinal constipation that had a medical return between October/17 and March/18. The data collection was initiated after approval of the research ethics committee. The SPSS was used for statistical analysis and Wilcoxon (Mann-Whitney) was applied for independent variables. Qualitative analysis was performed according to Bardin.

Results: In the children interviewed the total quality of life had an average of 69 (\pm 15). The school aspect was the most impaired (51 \pm 13); however, the physical aspect had a better score (83 \pm 13) and was better in children with a higher socioeconomic level. Children with lower socioeconomic status had worse (p=0.02) social aspect (72 \pm 35). The mean of the psychosocial aspect was 62 (\pm 18). The majority of the children were male with a better emotional aspect (64.38 \pm 23) than the girls (p=0.05). Children diagnosed at birth had better bowel functioning (continent) (p=0.00). Fifteen categories were identified in the perception of the children, demonstrating: basic knowledge about the disease, unfamiliarity about the pathology and reason for monitoring. Some children felt good going to the hospital, others did not like it. There was a report of bullying.

Conclusion: The monitoring of the quality of life and perception of the child can guide the multi professional assistance mainly in the children with lower socio-economic level. Multicentric studies are needed.

Biography

Camila Foresti Lemos is a Nurse, has worked for four years in the private area and for six years as a public servant. She loves to take care of children and has a profile for acting in an emergency unit. However, she faces in Brazil the difficulties of standardization of routines that promote the constant evaluation of patient safety in public hospitals. The difficulties for the system of nursing assistance instigate her to conduct research that seeks to contribute to nursing assistance in Brazil. She has worked for four years in an adult intensive care unit. She is a Postgraduate in Nephrology Nursing, and has a Master's degree from the University of Brasilia. She acted in the last six years with children in a public hospital in Brazil; of these four years she was in the pediatric surgical clinic and also attended children with fecal incontinence and intestinal constipation. She is currently a Researcher, Nurse Controller of the hospital admission regulation service of the Federal District and Professor at the School of Health Sciences in Brasilia, DF, Brazil (ESCS).

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