

## Quality of life in children after surgery for congenital heart disease - Univentricular heart and Tetralogy of Fallot.

Fraga B.(1), Sousa A.(2), Janeiro M.(3), Martins D.(2), Carvalho N.(2), Marinho J.(2), Teixeira A.(2), Nogueira G.(2), Menezes I.(2), Anjos R.(2)

Department of pediatrics, Hospital do Divino Espírito Santo de Ponta Delgada, E.P.E., São Miguel (Açores) (1);Hospital de Santa Cruz, CHLO E.P.E., Lisboa (2);Department of pediatrics, Hospital Prof. Doutor Fernando Fonseca, E.P.E, Lisboa (3)

**Introduction:** In the last decades there has been an outstanding improvement in survival of children with congenital heart disease, including children with complex forms, such as univentricular heart (UH). Nevertheless, this group of diseases is associated with a significant long-term morbidity. The aim of this work was to evaluate quality of life (QL) of children who underwent surgery for UH and a simpler cyanotic lesion, tetralogy of Fallot (ToF) and compared the two groups with normal values obtained previously in children with the same age.

**Methods:** We performed a cross sectional, descriptive study. We assessed QL of children with UH and ToF aged 8-12, using the *Peds QL™ 4th version* for parents. This is a QL questionnaire validated for this age group in our population. Additional data such as number of surgeries, cardiac catheterizations and hospital admissions were also assessed.

**Results:** 37 children with congenital heart disease participated in the study, including 21 with UH and 16 with ToF (60 children were randomly selected to participate but 23 were excluded due to unavailability to participate). Mean number of surgeries (ToF: 1.5, UH:2.76), catheterizations (ToF: 1.31, UH:2.45) and total admissions (ToF: 3.25, UH:6.04) in the 2 groups were significantly different ( $p < 0.01$ ). The results of total indices of QL and of subscales are presented in Table 1.

Table 1	ToF (n=16)	UH (n=21)	p	ToF (n=16)	Healthy Children	p	UH (n=21)	Healthy Children	p
Physical performance									
Mean ± SD	71 ± 27.7	68.2 ± 24.9	0.65	71 ± 27.7	83.5 ± 14.7	0.37	68.2 ± 24.9	83.5 ± 14.7	<b>0.035</b>
Emotional performance									
Mean ± SD	74.6 ± 16.4	71.6 ± 17.1	0.71	74.6 ± 16.4	73.3 ± 16.7	0.83	71.6 ± 17.1	73.3 ± 16.7	0.794
Social performance									
Mean ± SD	83.8 ± 18	76.4 ± 24.9	0.53	83.8 ± 18	84.6 ± 15.1	0.53	76.4 ± 24.9	84.6 ± 15.1	0.271
School performance									
Mean ± SD	61.2 ± 25.5	50.9 ± 20	0.22	61.2 ± 25.5	78.2 ± 15.8	<b>0.02</b>	50.9 ± 20	78.2 ± 15.8	<b>0.001</b>
Total									
Mean ± SD	72.8 ± 17	66.9 ± 17.3	0.27	72.8 ± 17	79.8 ± 12	0.31	66.9 ± 17.3	79.8 ± 12	<b>0.007</b>

Significance level was 0,05

**Conclusions:** Children with UH had lower QL indices in all categories, however there was no significant difference between this group and the ToF group. Compared to healthy children, ToF group had lower scores in all categories except emotional performance, however the only significantly lower score was school performance. Children with UH had lower scores than healthy children in all categories, particularly in physical, school and total QL scores. Mean number of cardiac surgeries, cardiac catheterizations and total number of hospitalizations were higher in the group of children with UH, contributing to a lower QL score. These results are in accordance with the known higher long term morbidity of UH.