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Quality of Life, Psychosocial Adjustment, Psychiatric Morbidity, School Performance, Physical Limitations and Social Support in Adolescents and Young Adults with Congenital Heart Disease: How these variables play together?

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Objectives: The aims of this investigation were to study Quality of Life (QoL), Psychiatric Morbidity (PM), Psychosocial Adjustment (PSA), School Peformance (SP), Physical Limitations (PL), and Social Support (SS) of adolescents and young adults with Congenital Heart Disease (CHD).

Methods: 74 CHD patients, 41 male and 33 female, aged from 12 and 26 years (mean=18,76 ± 3,86), The original cardiac malformation was cyanotic in 45 and non-cyanotic in 29. Participants were interviewed once on topics as social support, family educational style, self-image, physical limitations and emotional adjustment, were administered a standardized psychiatric interview (SADS-L) and filled self-report questionnaires on QoL (WHOQOL-BREF) and psychosocial adjustment (YSR and ASR). One of their relatives filled the observational versions of the same questionnaires (CBCL, ABCL). Full clinical and demographic history was collected.

Results: There was 23% lifetime prevalence of psychopathology and 51.4% of retentions in school (M= 1.74 year + 0.86). There were no differences in QoL for severity or type of CHD, nor psychiatric diagnosis. Comparing our patients to healthy population, we found better social relationships (SR) (t=2,333; p=0,022) and environment (t=3,754; p=0,000) QoL. Patients' without pharmacological therapy revealed better QoL in SR domain (t=-2,226; p=0,029). Being submitted to surgical procedures decreases physical (t=-1,989; p=0,050), SR (t=-2,012; p=0,048) and general (u=563,000; p=0,037) QoL and leads to more withdrawn PSA (u=238,500; p=0,012). SS is very important in improving patients' physical (t=3,287; p=0,002), psychological (t=3,094; p=0,003), SR (t=3,669; p=0,000), environment (t=2,725; p=0,008) and general (u=323,000; p=0,005) QoL, but those with poorer SS had more withdrawn (u=767,500; p=0,005) and delinquent behavior (u=745,000; p=0,011). Patients' with PL showed worse physical (t=-2,910; p=0,005) psychological (t=-2,046; p=0,044) and general (u=947,500; p=0,001) QoL and more withdrawn PSA (u=449,500; p=0,016). Patients and relatives don't agree about gender expressions of PSA. Female patients refer more somatic complaints (u=886,000;p=0,021), anxiety/ depression (u=952,500;p=0,003), aggressive behaviour (u=999,000;p=0,005), thought problems (u=929,500;p=0,005), but relatives think that boys, instead of girls, show more withdrawn (u=341,500; p=0,019) and aggressive behavior (u=665,500; p=0,050).

Conclusions: While CHD patients seem to be more prone to PM, bad PSA and bad SP, SS plays a crucial role in all variables and in resilience.