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Living With Fontan circulation- alive, active and happy? Adolescents and young adults experiences of their overall life situation.

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Background: Adolescents and adults living with Fontan circulation belong to the first generation of patients with this condition surviving into adulthood. To what extent the heart defect affects their overall life situation therefore needs to be investigated deeper.

Aim: To explore the overall life situation of young persons living with Fontan circulation and to evaluate the impact on quality of life (QoL), health and sense of coherence.

Method: The patient sample (n=48) all undergone their surgical palliation before 1995. Two self-report questionnaires were used for evaluating the overall life situation including QoL, by the study-specific Essence of Existence questionnaire along with the Sense of Coherence (SOC)-scale.

Results: Of the initial patient population from 1995 (n=48), 34 was reached and 20 replied. The majority (n= 18) were satisfied/very satisfied with their QoL and considered their general health as good/very good (n=16). The total mean SOC score was 61.3, showing significant correlations between SOC and QoL (0.52, n=20, p 0.018), between SOC and self-esteem, (r=.71, n=20, p 0.001) and a positive association between SOC and better health perception (good/very good health) (r=0.40, n=20, p .078). A majority (n=16) reported symptoms, both heart defect related and more general symptoms.

Conclusion: Present study shows that adolescents and adults are mainly satisfied with their life situation, their QoL and experience their health as good/very good, even when experience symptoms and restrictions in daily life. The result from the present study provides a deepened description of how life can be experienced when living with Fontan circulation.

KEY WORDS: Univentricular heart, Fontan circulation, Quality of life, questionnaire, sense of coherence (SOC).