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Quality of life in Italian Adult Congenital Heart Disease

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Introduction: Advances in modern medicine have led to a noticeable increase in the survival of children born with congenital heart disease (CHD). Today, 85% of such children reach adulthood, and most deaths due to CHD occur after the age of 20 years. In the 2000s, the number of GUCH patients was approximately equal to the number of paediatric CHD patients. In the near future, it is estimated that there will be more GUCH patients than paediatric cases of CHD. Therefore, GUCH patients represent a new population in the health field. The study of GUCH cannot be reduced to only mortality and morbidity indicators but requires extensive investigations. Clinical practice has shown that quality of life (QoL), which is influenced by psychosocial aspects, is often a greater concern than cardiac malformation in GUCH patients.

Methods: A socio-demographic questionnaire and the Short Form-36 scale were administered to a convenience sample of 96 GUCH patients who had undergone surgery for complex CHDs and other CHDs.

Results: The sample (N = 96) contained an equal number of males and females. In the sample, 70% of the participants lived with their family of origin, and just over half had children. In all the dimensions of the SF-36, the patients perceived their QoL as good, regardless of the time of the initial diagnosis of CHD and age. However, age influenced "vitality". The time (duration) since the last surgical intervention influenced the emotional state of the patients, in fact more time passes from the surgical intervention and more low are these such specific scores.

Conclusion: The QoL of the GUCH sample was good, with no differences between the subgroups analyzed. The expectation of a reduced QoL among GUCH patients was not met in this study. This finding may be explained by the young average age of our sample and perhaps also by study methodology. The overall QoL of GUCH patients depends on various psychosocial aspects, and this requires further study using tools other than standardized questionnaires.