

## Late outcomes of congenital heart disease

Nestor Santos Daudt, Paulo Zielinsky

Division of Pediatric Cardiology, Institute of Cardiology of Rio Grande do Sul, Porto Alegre, Brazil

Correspondence to: Paulo Zielinsky. Brazil, Fetal Cardiology Unit, Division of Pediatric Cardiology, Institute of Cardiology of Rio Grande do Sul, Porto Alegre, Brazil. Email: zielinsky@cardiol.br.

**Abstract:** In our days, more than 90% of children with congenital heart disease (CHD) reach adolescence and adult life, and therapeutic procedures are performed with late quality of life (QOL) in mind. Rates of success are now assessed at long range by sequels, residues and adaptation of the individuals to normality. The attempt to identify factors to avoid psychopathological sequels in this group of “new” cardiac patients is one of the most important aspects of studies on late outcome of congenital heart disease. This fact remains valid in the current era and is in consonance with the attitude to more and more value child-adolescent and adolescent-adult transitions in patients with CHD submitted or not to surgical or percutaneous intervention in childhood. Resilience and ability to adapt could also be improved by a multiprofessional approach of attitudes, abilities and psychological characteristics, aiming to prevent the psychopathologic effects of the disease.

**Keywords:** Congenital heart disease (CHD); risk factor; quality of life (QOL); psychosocial adjustment (PSA); late outcomes

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Congenital heart diseases (CHDs) are nowadays more frequent in adolescents and adults than in children. In 1985 the estimate was 1:1 and in 2005 it was of 60% adults for 40% children (1).

In the first decades of pediatric cardiac surgery the aim was to avoid early death, with almost no questioning toward the quality of life (QOL) of survivors. This is not surprising, since all the efforts were directed to survival. At this time, the effectiveness of a cardiac surgery team was assessed by immediate mortality rate.

In our days, more than 90% of children with congenital heart disease (CHD) reach adolescence and adult life, and therapeutic procedures are performed with late QOL in mind (2). The excellent article by Areias and co-workers (3) in this issue of *Translational Pediatrics* addresses psychosocial and demographic aspects of QOL in adults and adolescents surviving congenital heart disease. Rates of success are now assessed at long range by sequels, residues and adaptation of the individuals to normality (4), addressed in this study

considering “the different challenges of life cycle”... The main issues considered in the rich statistical analysis are perception of QOL, psychosocial adaptation and psychiatric morbidity in 150 patients with CHD between 12 and 26 years, after cardiac surgery or not.

The study by Areias *et al.* (3) triggers an important challenge for future observations. Older services of cardiac surgery deal today with postoperative patients with more than thirty, forty and even fifty years of the procedure, from the time when saving life was the main purpose. It is in some ways a different sample of patients than the one analyzed in the mentioned study. For example, the issue of the possibility or expectation of pregnancy (5-7) has to take in account the finding of worse psychological compromise in female patients described by Areias *et al.* (3). Another point to be considered is that percutaneous, nonsurgical intervention will probably be able to modify one of the more negative aspects on psychosocial alterations, namely the severity of residual heart compromise (8).

The attempt to identify factors that could have been previously addressed, in order to avoid psychopathological sequels in this group of “new” cardiac patients is one of the most important aspects of the study. This fact remains valid in the current era and is in consonance with the attitude to more and more value child-adolescent and adolescent-adult transitions in patients with CHD submitted or not to surgical or percutaneous intervention in childhood.

The apparent paradoxical response of a better QOL than expected in the patients studied by Areias *et al.* (3) is well seen on a daily basis in clinical practice, being the support by the family and the social group the responsible for this finding. Another point clearly demonstrated was a worse academic performance in the studied group. Many factors may contribute to this result. When comparing children operated on at the first decades of cardiac surgery with those submitted to surgery at the current era, an important improvement is perceived, proportional to the striking advances in extracorporeal circulation (9). Here, again, the fundamental role of percutaneous procedures should be stressed. Resilience and ability to adapt, as addressed by the authors, could also be improved by the identification of attitudes, abilities and psychological characteristics, aiming to prevent the observed psychopathologic effects.

It is interesting that the analysis of the cardiac diagnosis in the group studied by Areias *et al.* (3) shows that only two patients had single ventricle circulations. Adolescents and adults with this disease are today a large group in most busy cardiac centers, and inclusion of these patients in a future study as detailed as this one could somewhat modify some of the observed numbers.

An important result stressed in the study of Areias *et al.* (3) is the expected poorer long term outcomes in patients submitted to multiple surgeries. Avoidance of multiple procedures would probably have a positive effect, but would this be possible with improved techniques, lower invasivity and earlier approaches?

The major difficulty nowadays in the late cardiological care of patients with CHD stays with adults submitted to so-called “corrective” surgical treatment more than twenty years ago, with high risk and limitant morphological and functional residues and sequels predicted or already present, added to the well discussed psychosocial impairments. On this matter, individual personality characteristics should play a major role in QOL, independently of the cardiac diagnosis and its severity.

Late clinical and psychosocial outcomes in adults

and adolescents with CHD are in the current era a most important subject, which must be addressed with a multiprofessional approach. The cardiologist or the pediatric cardiologist just do not have the necessary ability to provide all the necessary care to these patients in isolation.

In the timeline of an adolescent or adult with congenital heart disease, previously submitted or not to cardiac surgery, physical difficulties and overcomings are added to the universe of feelings of hope and abandon, guilt and rage, nurturing and gratefulness, fear and faith, dreams and gratification which are part of the late outcome. It is the role of the multidisciplinary team responsible for his/her care to understand those conflicts, to accept its limitations, and to adequate the knowledge and technical advances to the individual reality. Adaptation of the patients with congenital heart diseases, at the long range, to life as a whole, ought to be the fundamental focus in the search of their physical, psychological and social well-being.

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### Footnote

*Conflicts of Interest:* The authors have no conflicts of interest to declare.

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