

Shall we treat congenital heart lesions, their suffering patients or also their families, and surrounding societal ambience?

José Fragata

Department Cardiothoracic and Congenital Heart Surgery, Hospital de Santa Marta, Nova Medical School, Lisbon, Portugal

Correspondence to: José Fragata, MD, PhD, FETCS, FESC. Department Cardiothoracic and Congenital Heart Surgery, Hospital de Santa Marta, Nova Medical School, Lisbon, Portugal. Email: jigfragata@gmail.com.

Abstract: Results with the treatment of congenital heart defects (CHD) have improved markedly. However these patients, in their teens and adulthood ages, suffer from psychological dysfunctions of different natures, even psychiatric diseases, that must be thought and be properly managed. Not only these dysfunctions are related to clinical history profiles, but they are clearly related to social support, with impacts on the way quality of life (QOL) is perceived.

This new vision creates a window of opportunities to act, now, on the aspect of their social modelling and psychological support, to improve QOL and psychological adaptation for these patients, already living longer, in order to make them living better.

Keywords: Congenital heart defects (CHD); psychological adjustment (PSA); quality of life (QOL) perception; psychiatric dysfunction; social support

Submitted Jul 06, 2013. Accepted for publication Jul 26, 2013.

doi: 10.3978/j.issn.2224-4336.2013.07.05

View this article at: <http://www.thetp.org/article/view/2370/3228>

Over the last two decades evolving management strategies for congenital heart defects (CHD) led to superb clinical results. More precise diagnosis, early infancy correction and combined surgical plus interventional therapeutic approaches, have all contributed to much superior clinical outcomes, with survival rates from infancy through adulthood, well over 90%, at the moment.

Now that survival and functional status have reached such sustainable quality, even despite the fact that GUCH patients still carry lower life expectancies, other dimensions, as the perception of quality of life (QOL), the way psychological adjustment (PSA) is done and the prevalence of any psychiatric dysfunctions, all became major concerns. Over recent years, different studies have suggested that these dimensions are grossly affected, for this group of patients, but very few shed light on the complexity of their underlying causative mechanisms.

This is mainly way the most recent paper by Areias and co-authors (1), in this issue of *Translational Pediatrics*,

is so truly unique: Besides characterizing psychosocial dysfunction profiles in patients suffering from CHD, it focus on the potential causative or contributing underlying mechanisms—demographic, clinical and psychosocial—namely, relating gender, clinical severity and type of intervention, along with school performance and social support, to those well identified psychosocial dysfunctions.

Previous studies have led to, somehow, divergent results, may be due to patient heterogeneity and also due to too much limiting single factorial analysis methodologies. The newer inter relational methodological concept used by Areias, seems most adequate for the thorough assessment of these complex psychosocial dimensions, in this ever challenging patient population. Furthermore by the use of regression analysis tools, aiming at associating independent risk factors to identified target psychometric outcomes. This has not, to my knowledge, been done before, in such an extension. However, a word of methodology concern, for the reduced sample size, and the lack of multivariate

analysis, that if used, would have further potentiate many of the study conclusions.

Coming now to their conclusions, it is impressive that 18.7% of CHD patients will have lifetime prevalence of psychopathological entities, females being twice more prone to that. This tendency to psychiatric disorders was recently described, for a larger population (2), seeming however particular to CHD, and less related to the chronic nature of diseases or the history of surgical trauma in early infancy.

Also, school retention has reached 57.1% for this group, certainly a surrogate of clinical dysfunction, but also due to lack of social support and to poor academic surrounding. Higher academic performance also impacted favourably on QOL perception and PSA levels, suggesting that those dimensions are much more complex than the isolated physical sense of wellbeing would justify on its own. Also, the problem of school retention, that is so prevalent in this group, appears clearly linked to multiple surgeries in infancy and this is not surprising, since it is known that neurodevelopment status is at risk, when given techniques of deep circulatory arrest were used during surgery for these patients in early infancy, as was the use at the time these patients received treatment.

QOL perceptions are difficult to evaluate in health care contexts and, may be, tools as the SF—36 and alike, will lack sensitivity or specificity power, by not considering the all psychosocial components implicated, that do affect these patients, also due to their rich and traumatizing clinical history profiles. QOL has been found, by most studies and for the all spectrum of patients with CHD, as globally better than normal. However, the study by Areias has further identified a cluster of patients referring sub normal QOL perceptions: those with more severe forms of disease, deeper cyanosis or suffering from any residual lesions. The same for the female gender, those with lower academic performance or the ones lacking a noughsocial support. This association of female sex to behaviour—emotional problems is well known, but seems to be further potentiated by the social context, leading to more severe PSA dysfunction and to poor QOL perceptions.

It has already been recognized that PSA and QOL perceptions predict anxiety more than any medical physiological variables (3) and this was also described by Areias's paper, through the influence of social support on PSA and on QOL perceptions, also suggesting a new way to model clinical profiles, also one for use to promote patient improvement strategies.

Dr Areias's conclusions point to the combined negative impacts of female gender, poor academic performance and poor social support to, both low PSA and poor QOL perceptions. However, I presume their work allows us a much more deeper insight into the complex effects of demographic, clinical and psychosocial profiles on those same, under study, perceptions—a unique and most valuable characteristic to their study. That is to say, their work allows us to understand that CHD's patients, and the ever expanding GUCH population, is enormously vulnerable to different psychosocial disturbing influences that, at the same time interact, both as causes and as consequences.

These acting factors can be the result, partially or in combination, of the following mechanisms:

- ❖ In uterus physiological characteristics, namely brain blood flow patterns, own to CHD lesions;
- ❖ Patient age and female gender;
- ❖ Impact of multiple surgical interventions, bringing the need to improve neuroprotection strategies at surgery, namely when performed in early infancy and for neonates;
- ❖ Impact of deep cyanosis and long standing chronic heart failure or any residual lesions. These demanding more anatomical and physiological corrections, putting the need for more exigent technical expertise;
- ❖ Improving social and academic support for these patients, as this might model their pre-existing risk and promote their QOL perceptions and their PSA patterns, making them happier.

Finally, not as a psychological analyst, but rather as a long practicing cardiac surgeon, having looked after many children with CHD and also after their families, over the years, this paper from Areias has brought to my attention and has made objective that CHD are more than mere physical disorders—they represent the potential for global family dysfunctions, that should be thought and integrated in treatment strategies. So far, the focus has been on CHD's physical cure. Into that direction, all the efforts on early correction and safer *all body* protection strategies should be continued and even further developed; however, a totally new approach is emerging, from studies alike to the one that has motivated this editorial comment, and that is that family and the social environment should be considered in the treatment portfolio strategy, namely social support and academic levelling, as these may help to promote happier life perceptions and better social inclusion levels. By the end of the day, this is what Medicine and Caring is all about,

as William Osler used to say “*Care more particularly for the individual patient than for the especial features of the disease*”.

Acknowledgements

None.

Footnote

Conflicts of Interest: The author has no conflicts of interest to declare.

Cite this article as: Fragata J. Shall we treat congenital heart lesions, their suffering patients or also their families, and surrounding societal ambience? *Transl Pediatr* 2013;2(3):87-89. doi: 10.3978/j.issn.2224-4336.2013.07.05

References

1. Areias ME, Pinto CI, Vieira PF, et al. Long term psychosocial outcomes of congenital heart disease (CHD) in adolescents and young adults. *Transl Pediatr* 2013;2:90-8.
2. Olsen M, Sørensen HT, Hjortdal VE, et al. Congenital heart defects and developmental and other psychiatric disorders: a Danish nationwide cohort study. *Circulation* 2011;124:1706-12.
3. Kovacs AH, Saidi AS, Kuhl EA, et al. Depression and anxiety in adult congenital heart disease: predictors and prevalence. *Int J Cardiol* 2009;137:158-64.