Well-Being and Agency in Parents of Children With Congenital Heart Disease: A Survey in Chile

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Abstract

Parents of children having congenital heart diseases (CHDs) develop symptoms of depression, distress, anxiety, and hopelessness more frequently than parents of healthy children. Associated with the described symptoms, parents may experience a lack of control and disempowerment, which decreases the parent’s agency, a construct from development studies, and which may have negative consequences on adherence to treatment. The primary aim of this study was to assess the effect of medical treatment on well-being and agency in parents of children having CHDs, in Chile, and to compare it with reference values.

Methods:

Forty parents of children having CHDs (before surgery and before hospital discharge) and 115 parents of healthy children were surveyed. The following scales were applied to this population: the General Health Questionnaire, the Basic Psychological Needs Scales, the Self-Determination Scale, the Beck Hopelessness Scale, and a socioeconomic survey.

Results:

Children’s surgery decreased parents’ hopelessness (3.13 ± 0.35 and 2.18 ± 0.40, P = .04), and no significant differences were found in the remaining scales. Parents of children with CHDs scored significantly worse than parents of healthy children on the General Health Questionnaire (13.82 ± 1.03 and 9.21 ± 0.64, P = .001). This difference was not found using the others scales.

Conclusion:

Children’s surgery has a positive effect on parent’s hopelessness, but it does not have any impact on their well-being nor agency. Parents of children with CHD have a decreased well-being compared to parents of healthy children but have a similar level of agency. Socioeconomic level and gender may influence this association.

Keywords Comorbidity, Congenital heart disease, Ethics, Postoperative care, Quality of life, Pediatric cardiac-surgery, Psychological distress, Mothers, Hopelessness, Empowerment, Infants, Context, Cardiovascular System & Cardiology