Quality of life after congenital heart surgery

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Introduction

• It has been considered more and more important to know about the perception of well being and quality of life (QoL) of patients affected by chronic illness and about the variables that may buffer the confrontation with life difficulties and increase resilience.

• Congenital heart disease (CHD) is a chronic illness with a high frequency in the world-wide population, and is normally diagnosed at birth or in utero.

• Because of better conditions in diagnosis and early medical and surgical treatment, patients have survival rates of 85% and go further and further in life, facing different challenges in life cycle.

• Thus, it is getting very important to study the psychosocial and emotional status of this population of patients, their psychiatric morbidity, their perception on quality of life, their school and job achievements.
Objectives

☑ To measure the QoL of adolescents and young adults with CHD and to analyze which variables play a role in buffering stress and promoting resilience and which ones have a detrimental effect.

☑ To investigate the situation on school performance and failures, social and family support, physical limitations and body image of these patients.
Methods – Inclusion Criteria

• Subjects who were diagnosed as CHD patients

• Who were followed in consultation in the Pediatric Cardiology or Adult Cardiology Departments

• Who were at the time of the interview $\geq$ 12 and $\leq$ 26 years old

• Who had a basic educational level to enable understanding and filling the questionnaires in an unbiased way

• And who had complete medical records
Population - Design

- 72 (39 male, 33 female) patients with CHD
- Aged 12 to 26 years old (mean=18.72 ± 3.890)
- 44 cyanotic, 28 acyanotic
- 62 relatives

- The subjects were evaluated only once
- The psychiatric evaluation was retrospective and covered all the life time before the interview
- One relative of each patient was also interviewed and asked to fill an observational version of the questionnaires
Methods – Assessment Instruments

• **QOL-BREF**: assessment of Quality of Life

• Interview (covering topics on family and social support, school achievements, physical limitations and body image)

• Questionnaire about demographic and clinical information
1. The QoL of CHD patients is better than the normal population, especially for the Environmental (M=70.94/ RV=64.89; SD=13.347; t=3.791; p=0.000), and except for the Physical Domain (M=75.99/ RV=77.49; SD=14.251; t=-0.892; p=0.375).

2. Patients submitted to surgery have worse perception on QoL (Physical and General Domains) than those who were not operated.

3. Patients submitted to a greater number of surgeries have worse perception on QoL for the Physical (p=0.03), the Environmental (p=0.055) and General Domains (p=0.059).
4. Cyanotic patients have worse perception on QoL (Physical and Environmental Domains) than the acyanotic.

<table>
<thead>
<tr>
<th>Domains</th>
<th>Cyanotic (N = 44)</th>
<th></th>
<th>Acyanotic (N = 28)</th>
<th></th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
<td></td>
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<tr>
<td>Physical</td>
<td>27.52</td>
<td>3.763</td>
<td>29.46</td>
<td>4.114</td>
<td>-2.058</td>
<td>0.043</td>
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<tr>
<td>Psychological</td>
<td>23.58</td>
<td>3.187</td>
<td>25.46</td>
<td>10.895</td>
<td>-1.069</td>
<td>0.289</td>
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<tr>
<td>Social relationships</td>
<td>12.00</td>
<td>2.013</td>
<td>11.56</td>
<td>1.685</td>
<td>0.907</td>
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<tr>
<td>Environmental</td>
<td>29.88</td>
<td>4.324</td>
<td>31.93</td>
<td>3.953</td>
<td>-2.008</td>
<td>0.049</td>
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<tr>
<td>General</td>
<td>7.80</td>
<td>1.374</td>
<td>7.86</td>
<td>1.113</td>
<td>-0.199</td>
<td>0.842</td>
</tr>
</tbody>
</table>
5. Patients with complex CHD have worse perception on QoL than those with moderate and mild forms, on Physical (Complex: M=27.19, SD=4.142; Moderate-to-Mild: M=28.93; SD=3.792; t=-1.829; p=0.072) and on Environmental Domains (Complex: M=29.50, SD=4.510; Moderate-to-Mild: M=31.41; SD=4.008; t=-1.839; p=0.070).

6. 50% of CHD patients have at least one year withheld in studies (mean 1.75 ± 0.874).
Discussion

• An intriguing finding of our study, even though confirming previous data from other authors (Fekkes, Kamphuis, Ottenkamp et al, 2001; Moons, Van Devk, Marquet et al, 2006) is that CHD patients have a better perception on their QoL than the healthy population. That fact may be explained by the presence of some buffer variables, like family environment and cohesion, social support and personal resources.

• However, when we look at the different subgroups, we find that patients submitted to surgery, cyanotic vs. acyanotic, those with more complex vs. those with mild-to-moderate forms of CHD, and those with severe vs. those with mild-to-moderate residual injuries show a worse perception on their QoL than the whole group. These facts, more expected, may be explained by the daily life restrictions and residual side effects that limit physical performance and activity, by the feeling of life threat and fragility, the need for a greater amount of additional care and the experience of discomfort situations.

• These patients tend to have more often school failures, as 50% have at least one year withheld.