Psychosocial needs of children undergoing an invasive procedure for a congenital heart defect and their parents

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Introduction
Needs for specialized psychosocial care from the parents’ and patients’ perspectives have been neglected in research

Aim: to investigate the psychosocial needs of parents and/or children with ConHD the week before cardiac surgery/catheter intervention

We expected:• different needs for psychosocial care for different age groups;• that needs for psychosocial care would not be related to the severity of the ConHD.

Methods
Inclusion criteria:• all consecutive patients (0-18 years) and their parents;• undergoing elective cardiac surgery/catheter intervention in our centre between 2012-July 2013.

For patients with a mental impairment only parents participated.

Instruments:Psychosocial needs: specifically designed online disease-specific questionnaires, for parents of children (0-18 years) and two child-versions (8-12 and 13-18 years), on 5 domains: 1) physical/medical 2) emotional 3) social 4) educational/occupational 5) health behaviour.

Intervention: if parents/patients reported a need for psychosocial care, they were referred to health care professionals in our hospital, or if necessary, elsewhere.

Results:
Eligible: 282 patients.
Final samples: 161 parents, 38 children (> 8 years).
• > 40% of parents and > 50% of children reported a need for psychosocial care on each of the 5 domains.
• Parents of children aged 0-12 years expressed the highest needs for psychosocial care for themselves.
• Psychosocial care interventions in our hospital increased significantly due to this study.

Conclusion:
psychosocial care is rated as (very) important by parents and children during this stressful period before cardiac surgery/catheter intervention

Needs for psychosocial care reported by parents and children
(per domain within a specific age-group, in %)

| Parents for children | 0-2 yrs, n=76 | 3-7 yrs, n=32 | 8-12 yrs, n=22 | 13-18 yrs, n=27 | p
|----------------------|---------------|---------------|---------------|---------------|---
| Physical/medical     | 68.4          | 87.5          | 86.4          | 81.5          | .09
| Emotional            | 48.7          | 59.4          | 63.6          | 70.4          | .21
| Social               | 30.7          | 59.4          | 54.5          | 63.0          | <.01
| Educational/occupational | 12.0    | 46.9          | 40.9          | 51.9          | <.01
| Health behaviour     | 57.5          | 78.1          | 68.2          | 85.2          | .03

Children for themselves

| Physical/medical     | 82.4          | 85.7          | 100.0         | 100.0         | p
| Emotional            | 88.2          | 52.4          | 56.2          | 63.0          | .64
| Social               | 64.7          | 57.1          | 51.9          | 64.7          | .64
| Educational/occupational | 64.7    | 64.7          | 65.0          | 64.7          | .64

Health behaviour 76.5

Parents for themselves

| 0-2 yrs, n=74 | 3-7 yrs, n=32 | 8-12 yrs, n=22 | 13-18 yrs, n=25 | p
|---------------|---------------|---------------|---------------|---
| Physical/medical | 76.8          | 81.2          | 100.0         | 100.0         | .01
| Emotional      | 46.4          | 50.0          | 75.0          | 75.0          | .06
| Social         | 38.2          | 43.8          | 75.0          | 66.7          | .05
| Educational/occupational | 16.4    | 31.2          | 50.0          | 54.2          | <.01
| Health behaviour | 63.6          | 60.0          | 75.0          | 78.3          | .20

In general

| 0-2 yrs, n=74 | 3-7 yrs, n=32 | 8-12 yrs, n=22 | 13-18 yrs, n=25 | p
|---------------|---------------|---------------|---------------|---
| Physical/medical | 66.7          | 66.7          | 100.0         | 100.0         | .37
| Emotional      | 66.7          | 66.7          | 100.0         | 100.0         | .77
| Social         | 66.7          | 66.7          | 100.0         | 100.0         | .77
| Educational/occupational | 33.3    | 66.7          | 100.0         | 66.7          | .97
| Health behaviour | 0.0           | 83.3          | 100.0         | 66.7          | .37

Needs for psychosocial care reported by parents and children
(per domain within a specific cardiac diagnosis, in %)

<table>
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<tr>
<th>ASD/VSD/ PDA/AVSD</th>
<th>obstructive simple</th>
<th>cyanotic simple</th>
<th>obstructive complex</th>
<th>cyanotic complex</th>
<th>cardiac dysrhythmia</th>
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<td>60.0</td>
<td>75.0</td>
<td>78.3</td>
<td>81.2</td>
</tr>
</tbody>
</table>

Children

| N=3               | N=3               | N=6             | N=1                | N=3              | N=22               | p<.01 |
| Physical/medical  | 66.7               | 66.7            | 66.7               | 100.0            | 100.0              | 90.9 |
| Emotional         | 66.7               | 66.7            | 83.3               | 100.0            | 100.0              | 59.1 |
| Social            | 66.7               | 66.7            | 50.0               | 100.0            | 100.0              | 54.5 |
| Educational/occupational | 33.3    | 66.7           | 66.7               | 100.0            | 66.7               | 59.1 |
| Health behaviour  | 0.0                | 66.7            | 83.3               | 100.0            | 66.7               | 72.7 |

p indicates if a difference between cardiac diagnostic group with regard to a specific domain is present.
Row and column % do not add up to 100%.

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