Institutional report - Congenital

Children subjected to cardiac surgery for congenital heart disease.
Part 2 – Parental emotional experiences

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Abstract

Parents experience considerable distress when their children are subjected to cardiac surgery. This study investigated their psychological and emotional experiences. As part of a prospective study reviewing the emotional and psychological outcomes of children aged 2–12 years subjected to cardiac surgery, that age group being chosen to allow for objective testing following infancy and before adolescence, their parents were assessed prior to and 12–50 months following the surgery. The measures reviewed their mental health, locus of control, family functioning and social support. There were 39 children. Most of the parental information was obtained from the mothers, who reported increased anxiety, and a tendency to attribute events to luck and/or chance greater than published norms, irrespective of the cardiac anomaly, whether the surgery was ‘curative’, or if further surgery was required. At follow-up, their ratings approximated to norms, except for a continued perception that life events were a function of fate and beyond one’s control. The results confirmed that a substantial increase in the emotional distress of mothers at the time of surgery essentially resolved by 12 months or later. In contrast, they still seemed not to feel in ‘control’ when reviewed on follow-up.

Keywords: Congenital heart disease; Parents; Psychological/emotional outcomes

1. Introduction

Parents experience considerable stress when their child undergoes any serious or potentially fatal interventions including cardiac surgery [1–4]. Many may still be grieving over the loss of a normal child [5, 6]. They may still harbour a feeling of guilt that they may have been partially responsible and remain concerned that despite the best efforts, their child may die or be disabled [7]. It is therefore not surprising that parents experience grief and anxiety as the consequences for the correction of heart abnormality may be serious or even fatal [8, 9]. That reality is especially meaningful when they come face to face with their surgeon prior to their child’s operation. It has been our practice, as is the case in many centres, to spell out in detail the potential mortality and to run through the risk of major complications, such as heart block, stroke, serious infection etc., prior to the surgery. Added to that is the stress of having to sit through the time of the operation, particularly if the surgery is delayed or takes longer than anticipated. That is followed by the parents then seeing their child in the intensive care unit usually for a respirator, sedated or unconscious, with multiple drainage tubes, infusions, etc., which may be a very traumatic experience for the family [10–13].

Our companion paper concentrated on the emotional outcomes of children subjected to cardiac surgery and seemed to indicate essentially good outcomes for these children when compared to normative data and to a small non-cardiac surgical hospital control group [13]. This paper will concentrate on the findings of the parents pre- and post-surgery, reviewing their anxiety, mental health, locus of control, family support and family cohesiveness.

2. Material and methods

Children aged between 2.5 and 12 years subjected to cardiac surgery were prospectively recruited into the study following informed consent and Institutional Ethics approval [13]. This age group was chosen to allow for reasonable objective testing following the rapid changes occurring during infancy and prior to the onset of adolescence. In addition, following a detailed medical and surgical review,
the children and their parents participated in a series of assessments by interview and questionnaires conducted by a post-graduate psychology student (ZP) prior to the child’s surgery, and again 12–50 months post-surgery. The measures carried out on the parents are outlined in Table 1. The measures were completed by the mother, and by the father wherever possible, prior to and subsequent to their child’s cardiac surgery, either at the time of the hospital visit or at home. The measures used had published validated norms.

3. Statistical analysis

Following data entry and screening (clearing), descriptive statistics were generated for all data collected. Comparisons were made with normative and standardised data wherever available. Pearson product-moment correlations were calculated to ascertain associations between status pre-surgery and post-surgery, and published normative data.

4. Results

Of the 103 children who were eligible for recruitment, it was possible to contact only 69 families prior to their surgery, of whom 39 participated for reasons given earlier [13]. In total, 16 could not be interviewed prior to the surgery, 6 declined, 4 did not respond and 4 had their surgery postponed. Of the 39 children, 37 had bypass surgery, including 9 who had their Fontan completed, with 2 having had a closed procedure (Table 2). Overall, there were optimal or very good technical outcomes in all but one case [13]. There was no mortality and the median hospital stay was 6 days (range 4–36 days).

The patients were of Caucasian origin. Their demographic and social economic status are summarised in Table 3. Table 4 summarises the findings. The information was obtained almost exclusively from the mothers. Only 10 fathers completed their questionnaires, though they seemed to provide similar information as the mothers. Prior to surgery, mothers reported higher state and trait anxiety, more mental health concerns including depression, and a greater tendency to attribute events to luck and chance than previously published normative groups (lower than normal ‘locus of control’). Those findings were irrespective of the nature of the cardiac abnormality and whether the scheduled surgery was ‘curative’, or if further surgery would be required. At follow-up, 12 months or later, the parent ratings on the same measures approximated to normative values, except for a continued perception from mothers of low locus of control, i.e. that life events were more a function of fate and chance than under one’s own control.

5. Discussion

Parents, most of the data being obtained from mothers, showed heightened anxiety and emotional distress prior to surgery, as well as attributing events to chance both pre- and post-surgery. These results confirmed that parents experienced significant stress in the period immediately prior to their child’s surgery, as reported by other workers [4, 10–12], but that given time, when reviewed 12 months or later, the anxiety level fell to normative levels. These findings would suggest a need to provide extra support to the parents before and at the time of surgery. An additional apparent novel finding was that mothers of these children attributed events to chance or luck and beyond their control, a finding noted prior to surgery but also present when reviewed 12 months or later. The reasons for this finding were unclear. One possible explanation is the likely

<table>
<thead>
<tr>
<th>Measure</th>
<th>Administration</th>
<th>Construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>State-trait anxiety inventory</td>
<td>Parent questionnaire</td>
<td>Parent anxiety</td>
</tr>
<tr>
<td>General health questionnaire</td>
<td>Parent questionnaire</td>
<td>Parent mental health screen</td>
</tr>
<tr>
<td>Levenson’s locus of control questionnaire</td>
<td>Parent questionnaire</td>
<td>Parent locus of control</td>
</tr>
<tr>
<td>Family assessment device</td>
<td>Parent questionnaire</td>
<td>Family functioning</td>
</tr>
<tr>
<td>Index of social support</td>
<td>Parent questionnaire</td>
<td>Family social support</td>
</tr>
</tbody>
</table>
Table 3
Demographic and socio-economic status

<table>
<thead>
<tr>
<th></th>
<th>Number of parents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
</tr>
<tr>
<td>CHD</td>
<td>(n=29)</td>
</tr>
<tr>
<td>Complete tertiary</td>
<td>5</td>
</tr>
<tr>
<td>Attended tertiary</td>
<td>1</td>
</tr>
<tr>
<td>Complete secondary</td>
<td>13</td>
</tr>
<tr>
<td>Attended secondary</td>
<td>10</td>
</tr>
</tbody>
</table>

Education

- Completed tertiary: 5 mothers, 6 fathers
- Attended tertiary: 1 mother, 0 father
- Complete secondary: 13 mothers, 7 fathers
- Attended secondary: 10 mothers, 13 fathers

Occupation

- Managers and administrators: 2 mothers, 2 fathers
- Professionals: 8 mothers, 5 fathers
- Associate professionals: 4 mothers, 7 fathers
- Tradespersons and related workers: 0 mothers, 6 fathers
- Advanced clerical and service workers: 2 mothers, 0 fathers
- Intermediate production and transport workers: 0 mothers, 2 fathers
- Intermediate clerical, sales and service workers: 8 mothers, 0 fathers
- Elementary clerical, sales and service workers: 4 mothers, 1 father
- Labourers and related workers: 0 mothers, 6 fathers

Occupational prestige rating

- M: 37.98 mothers, 31.66 fathers
- S.D.: 18.27 mothers, 20.27 fathers
- Minimum: 9.50 mothers, 5.90 fathers
- Maximum: 69.10 mothers, 69.70 fathers

Note: Information regarding education and occupation was not available for all of the mothers and fathers of subjects in the study. All available data are listed.

Consequence of having a child with a serious cardiac condition, a random event out of their control and with a perceived unpredictable outcome at least prior to surgery. Why it persisted despite a good surgical outcome remained unclear. Maybe the parents still felt they were unable to predict the future outcomes of the child. It may be that if the child continued to do well over the years this finding of a lower locus of control may return to normal. It is possible that such a return to normal levels would only be manifest with a longer follow-up.

Can one relate this finding to current clinical practice? One can ask the question as to the appropriateness of giving parents complete autonomy and responsibility for the decisions made about their child’s surgery. A colleague of ours (A. Duke, personal communication) described parents feeling overwhelmed if given the opportunity to decide whether he should proceed to ablation if thought appropriate at an electrophysiological study if a treatable mechanism was found to explain their child’s arrhythmia. Most surgical and cardiological colleagues tend to recommend the best options, rather than leave it to the parents to decide whether or not the child should be subjected to surgery, or as to what the surgery should be [9, 15]. A similar ongoing sense of lack of control has been documented in victims of natural disasters, famine, and war, and has been well described in Holocaust survivors, “in the laps of the gods”, “in the hands of the almighty”. It may not be best practice for parents to have substantial autonomy on what treatment their child should have. The common practice of involving the parents in the important decision making, but at same time providing a recommendation as to what are the best options, may be the optimal approach, rather than leaving it to the parents, the cardiologist or cardiac surgeon to decide [14].

Qualitative observations also indicated that parents especially appreciated recounting what their children were able to do and what their achievements were, rather than reciting any disabilities that they might have had. That however may have been encouraged by having an interested listener (here the clinical psychologist researcher) who was not directly responsible for their child’s care [15]. Parents remain fearful about expressing any negative feelings towards their attending clinician who has the life of their child in his/her hands. It is important for clinicians to realise that parents are very keen to highlight their child’s successes as observed in this study, rather than concentrate on what their child is unable to do. Likewise, children of parents who have a more optimistic perception of their child’s functioning seemed to have better outcomes and were better able to accept and live up to parental expectations.

Table 4
Results of emotional measures carried out on mothers prior to and 1–4 years following their child’s surgery compared to published normative data

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-surgery mean (S.D.)</th>
<th>Pre-surgery comparison to norms</th>
<th>Follow-up mean (S.D.)</th>
<th>Follow-up comparison to norms</th>
<th>Comparison of pre-surgery vs. follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State</td>
<td>47.69 (15.29)</td>
<td>More difficulties than norms</td>
<td>31.56 (7.58)</td>
<td>ns</td>
<td>Reduced, P=0.0001</td>
</tr>
<tr>
<td>Trait</td>
<td>41.23 (12.98)</td>
<td>More difficulties than norms</td>
<td>33.37 (7.40)</td>
<td>ns</td>
<td>Reduced, P=0.02</td>
</tr>
<tr>
<td>Mental health</td>
<td>25.03 (13.69)</td>
<td>More difficulties than norms</td>
<td>16.42 (9.40)</td>
<td>ns</td>
<td>Reduced, P=0.02</td>
</tr>
<tr>
<td>Locus of control</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal</td>
<td>36.18 (6.72)</td>
<td>ns</td>
<td>35.84 (6.04)</td>
<td>ns</td>
<td>ns, P=0.86</td>
</tr>
<tr>
<td>Other people’s degree of control over one’s life</td>
<td>15.96 (7.51)</td>
<td>ns</td>
<td>17.68 (7.80)</td>
<td>ns</td>
<td>ns, P=0.46</td>
</tr>
<tr>
<td>Chance what does this mean?</td>
<td>19.74 (8.40)</td>
<td>More difficulties than norms</td>
<td>18.74 (6.58)</td>
<td>More difficulties than norms</td>
<td>ns, P=0.67</td>
</tr>
<tr>
<td>Fam functioning</td>
<td>1.76 (0.41)</td>
<td>ns</td>
<td>1.72 (0.41)</td>
<td>ns</td>
<td>ns, P=0.78</td>
</tr>
<tr>
<td>Social support</td>
<td>29.70 (9.12)</td>
<td>ns</td>
<td>28.16 (9.12)</td>
<td>n/a</td>
<td>ns, P=0.55</td>
</tr>
</tbody>
</table>

ns, not significant; n/a, not available; fam, family.
As is frequently found in this genre of research, fathers did not seem too keen to be involved in the study. Unlike the study of Wray and Sensky [10], most failed to return their questionnaire. It may be that they did not take on the burden of their children’s surgery as much as the mothers. One could speculate that they saw themselves as busy breadwinners and did not appreciate that the information they provided was as important and valid as that provided by the child’s mother. They may have accepted their major role as a support of their partner.

The study is limited by the relatively small numbers and the short- to medium-term follow-up. There was a paucity of information obtained from fathers. A longer-term follow-up of parents of the same cohort of children is currently being planned.

In summary, parents of children who have cardiac surgery experienced heightened state and trait anxiety and emotional distress prior to surgery. That returned to normal within 12 months. Secondly, the feeling of lack of control of their life persisted beyond 12 months for reasons that were unclear.

References


Appendix A: Supplementary data

Supplementary data associated with this article can be found in the online version at doi:10.1510/icvts.2007.171066.