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Original Article

Cognitive, and behavioural and emotional functioning of young children awaiting elective cardiac surgery or catheter intervention

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Abstract *Aims:* To assess the cognitive, and behavioural and emotional functioning of children aged 3 months to 7 years shortly before elective cardiac surgery or elective interventional catheterisation. *Methods:* We used the Bayley Scales of Infant Development, and the McCarthy Scales of Children's Abilities, to measure cognitive functioning. The Child Behavior Checklist was used to assess behavioural and emotional problems. *Results:* We found no significant differences in mean cognitive scores for children scheduled for cardiac surgery or interventional catheterisation when compared with reference groups. This was also the case for children awaiting cardiac surgery as opposed to those awaiting interventional catheterisation, and for those below as compared to those above the age of 2.5 years. Overall, our results regarding behavioural and emotional functioning were comparable to those of normative reference groups. The only difference found was that the children scheduled for cardiac surgery and aged from 2 to 3 years had significantly higher scores on the Child Behavior Checklist than did peers from normative groups. *Conclusion:* Cognitive, and behavioural and emotional functioning, both for young children awaiting elective cardiac surgery and interventional catheterisation, can be considered as quite favourable.

Keywords: congenital heart disease, psychology, intelligence, children

RESEARCH CONCERNING EMOTIONAL AND cognitive functioning of children with congenital cardiac disease is limited, and shows contradictory results. Several investigators have reported negative emotional outcomes, such as anxiety, depression or diminished self-esteem, but others showed favourable outcomes.[1] It is difficult to draw firm conclusions from existing studies due to the variation in the methodologies employed. Methodological problems, such as small sizes of sample groups, their heterogeneous composition, with inclusion of those who have or have not undergone surgery within the same sample, differences with regard to cardiac diagnoses, use of non-standardized procedures for assessment, and lack of suitable reference groups, may also affect the results.[1]

Gomelsky et al.[2] described the mechanisms involved in cerebral injury in children with congenital cardiac disease. They postulated three periods of risk for neurologic injury in such children:

- Fetal development, with several chromosomal abnormalities possibly leading to cerebral and cardiac maldevelopment,
- The presurgical period with potential exposure to focal and generalized ischaemia, strokes or seizures,
- The intraoperative period, where neurologic deficit may result from less than optimal anaes-

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thetic and surgical management and cardiopulmonary bypass.

Over the last decade, most studies have pertained to long-term, post-operative intellectual functioning in patients with severe and frequently cyanotic heart disease, and focussed on intra- and postoperative variables.[2–6] Research regarding children with "mild" congenital heart disease, in the absence of cyanosis, as well as preoperative assessments, has been neglected.

Apart from effects of intra- and postoperative variables, parents are often very concerned about possible deleterious effects of a cardiac defect itself on the cognitive, and the behavioural and emotional, functioning of their child. It has been reported[7] that the intellectual performance of children with congenitally malformed hearts may be negatively influenced by parental anxiety, which may result in emotional overstimulation or limitations in life experiences, by reduction in social interaction, discontinuity in scholastic attendance, and also by low self-esteem, anxiety, and impulsiveness in the patients themselves. Poor emotional adjustment of children with such cardiac lesions has been reported to be related more to maternal anxiety than to the degree of incapacity or the severity of disease.[8] Further, maternal anxiety appears to be primarily a function of the presence of the congenital cardiac malformation itself rather than its severity.[8] Recently,[9] we found that the parents of the children who participated in the present study and who were about to undergo elective cardiac surgery, preoperatively showed elevated levels of anxiety and less adequate styles of coping. In contrast to previous studies, therefore, our present aim was to focus on preoperative intellectual and emotional functioning in a homogeneous sample of patients with congenital cardiac disease. Our sample consisted of a selected group of relatively healthy, well-functioning children, who needed to undergo elective cardiac surgery or elective interventional catheterisation for lesions which were neither life-threatening, nor resulted in physical impairment over the short term. This study focusses specifically on the preoperative period, since in previous studies it was difficult to differentiate between effects of the preoperative as opposed to the intra- and postoperative period. As far as we know, cognitive, and behavioural and emotional functioning of children prior to elective interventional catheterisation has not previously been studied. From clinical experience, we learned that parents can perceive interventional catheterisation as less invasive than cardiac surgery with, for example, the catheterisation producing no scar. Our previous study[9] nonetheless, showed no differences in parental reactions to whether cardiac surgery or interventional catheterisation had been planned. In the present study, therefore, we assessed children scheduled for interventional catheterisation to establish whether the differences in procedures, specifically surgery versus catheterisation, lead to differences in cognitive or behavioural and emotional functioning in the patients themselves.

The main aim of the study, therefore, was to

- compare cognitive, and behavioural and emotional functioning of children awaiting elective cardiac surgery or elective interventional catheterisation to the results of peers from normative groups on the same variables.

Further aims were:

- to compare results on these variables of children awaiting cardiac surgery to those of children awaiting interventional catheterisation
- to compare results on these variables of children undergoing cardiac surgery at a younger as opposed to an older age.

Materials and methods

Assessment procedure

Parents were asked by the paediatric cardiologist during a visit to the outpatient clinic whether they would participate in the study, with all agreeing signing a form for informed consent. The children were then tested by a psychologist during a home-visit. Parents completed questionnaires at home and returned them by mail.

Patients studied

The eligibility criterions included all consecutive patients scheduled to undergo their *first* elective cardiac surgical procedure or interventional catheterisation for a non life-threatening and, at that moment, a congenital cardiac malformation which did not impair function between May 1994 and May 1997. The patients attended the University Hospital of Rotterdam, and were between 3 months and 7 years of age at the time of cardiac surgery or interventional catheterisation. We also required that the patients had to be living with their parents, the parents had to consent to participate in the study, and had to be Dutch speaking. From 321 potential patients, we excluded 102 who had undergone cardiac surgical or interventional catheterisation procedures previously, 4 with non-cardiac congenital anomalies, 3 with mental retardation, and 5 who were living

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abroad or were adopted from abroad. Another 79 patients were excluded because they met two or more of these criterions. This left 128 patients who were eligible for the study.

Table 1 shows the age-distributions of the participants scheduled for cardiac surgery, and those scheduled for interventional catheterisation, corresponding with the age ranges covered by the four instruments we used for assessment. We needed four tests because no instrument covered the whole age-range from 3 months to 7 years. Each of the four instruments chosen was suited for a different age-range. Table 2 shows the distribution of cardiac diagnoses and gender according to age.

Cognitive functioning: Of the eligible 128 children, 102 were awaiting cardiac surgery and 26 interventional catheterisation. 26 of those awaiting cardiac surgery, and 7 of those awaiting interventional catheterisation, did not complete cognitive tests due to practical reasons or the refusal of their parents. Thus, 76 children scheduled for cardiac surgery, and 19 scheduled for intervention,

Table 1: Age distributions of those undergoing cardiac surgery ("surgery") and interventional catheterisation ("intervention") for the different instruments used in assessment.

Cognitive Functioning			**Behavioural and Emotional Functioning**		
Age-range	**3 months-**	**7years**		**2–7 years**	
BSID[1]	**surgery**	**intervention**	**CBCL/2–3** [3]	**surgery**	**intervention**
3 months-1year	25	2	2 years	8	-
1 – 2 years	12	2	3 years	10	4
2 – 2.5 years	4	-			
MSCA[2]			**CBCL/4–18** [4]		
2.5 – 3 years	4	-	4 years	10	5
3 – 4 years	11	7	5 years	8	4
4 – 5 years	7	2	6 years	5	2
5 – 6 years	8	4	7years	1	-
6 – 7 years	5	2			
total	76	19	total	42	15

[1] BSID = Bayley Scales of Infant Development.
[2] MSCA = McCarthy Scales of Children's Abilities.
[3] CBCL/2–3 = Child Behavior Checklist for 2 to 3 year olds.
[4] CBCL/4–18 = Child Behavior Checklist for 4 to 18 year olds

Table 2: Distribution of cardiac diagnoses and gender of those undergoing cardiac surgery ("surgery") and interventional catheterisation ("intervention") according to age-categories of the instruments used in assessment.

	Cognitive functioning				**Behavioural and Emotional Functioning**			
	3–30 months		**2.5–7 years**		**2–3 years**		**4–7 years**	
Cardiac diagnoses	**surgery (N= 4)**	**intervention (N= 4)**	**surgery (N= 35**	**intervention (N= 15)**	**surgery (N= 18)**	**intervention (N= 4)**	**surgery (N= 24)**	**intervention (N= 11)**
ASD	10	–	13	8	8	2	9	6
VSD	11	–	10	–	4	–	6	–
AVSD	4	–	4	–	2	–	3	–
Fallot	7	–	–	–	–	–	–	–
PAD	1	3	1	7	–	2	1	5
Other	8	1	7	–	4	–	5	–
Gender								
Male	24	1	16	6	7	3	14	3
Female	17	3	19	9	11	1	10	8
Total	41	4	35	15	18	4	24	11

ASD = atrial septal defect within oval fossa
VSD = ventricular septal defect
AVSD = atrioventricular septal defect
Fallot = tetralogy of Fallot
PAD = patent arterial duct

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completed the tests, giving response rates of 74.5% and 73.1%, respectively.

Behavioural and emotional functioning: Within the age-range of 2 to 7 years, 44 children awaiting cardiac surgery, and 17 awaiting catheter intervention, proved eligible. Of these, the parents of 42 children awaiting cardiac surgery, and parents of 15 children awaiting interventional catheterisation, provided usable Child Behavior Checklists, giving rates of response of 95.5% and 88.2%, respectively. For the patients awaiting cardiac surgery, 38 mothers and 36 fathers responded whilst, for those awaiting interventional catheterisation, responses were obtained from 16 mothers and 14 fathers. To increase reliability, the scores of the fathers and mothers were averaged, for both types of procedure.

Reference groups: For the Bayley scales, we had access to Dutch normative data, but this was lacking for the McCarthy scales. In order to enhance comparability, therefore, we used American normative data for both tests.[10,11] For the Child Behavior Checklist, we were able to use reference groups, matched for sex and age, derived from the general Dutch population.[12,13]

Instruments of assessment

Cognitive functioning: Patients aged between 3 months and 2.5 years of age were tested with the Dutch version of the Bayley Scales of Infant Development.[14] Those aged between 2.5 and 7 years were tested with the Dutch version of the McCarthy scales of Children's Abilities.[15] In this study, we used the Bayley-Mental Development Index, and the McCarthy-General Cognitive Index, since they are both global indexes of early cognitive functioning. Both indexes had norms for age, with a mean of 100, and a standard deviation of 16.

Behavioural and emotional functioning: We were unable to obtain information for patients aged between 3 months and 2 years, because of the absence of properly validated assessments. For those aged between 2 and 3 years, we used the Dutch version of the Child Behavior Checklist for 2 to 3 year olds,[12,16] while for those aged from 4 to 7, we used the Dutch Child Behavior Checklist designed for children aged between 4 and 18,[13,17] thus obtaining standardized parental reports on behavioural and emotional problems encountered in their children. The Child Behavior Checklist for 2 to 3 year olds contains 99 problem items, whilst that designed for the older age group contains 120 problem items. Both checklists permit a total problem score to be computed by summing the scores on all problem items. Both questionnaires measure two broad problem areas. These are: the "Internalizing" problem area, which reflects internal distress, and the "Externalizing" problem area, which reflects conflicts with other people.[16,17]

The Child Behavior Checklist for 4 to 18 year olds consists of 8 scales. The "Internalizing" area is measured by the scales Anxious-Depressed, Somatic Complaints, and Withdrawn. The "Externalizing" area is assessed by the scales: Aggressive and Delinquent Behaviour. The scales concerned with social problems, thought problems, and attention problems, belong to neither the internal nor the external areas.

The Child Behavior Checklist for 2 to 3 year olds has six scales. The scales Anxious and Withdrawn – Depressed measure the internalizing area, whilst the scales Oppositional Behaviour, Aggression, and Overactivity measure the externalizing area. This checklist also contains the scale Sleep problems. This is a separate construct, and belongs to neither the internal nor the external areas.

The two checklists contain 60 overlapping items with the same content, the other items are different because of the different age-ranges targetted. Because both questionnaires measure the internalizing and externalizing areas, but contained some different items and scales, raw scores were transformed into T-scores which had a mean of 50, and standard deviation of 10. In this way, we were able to compare the total problem scores, and those for the internalizing and externalizing areas, between the two questionnaires.

Statistics: Fisher's exact test and Pearson's Chi-Square were used to test differences in distributions of gender and age for those awaiting cardiac surgery and interventional catheterisation in the samples who completed the Bayley or McCarthy test, and Child Behavior Checklists. T-tests were used to test differences in mean cognitive scores and mean behavioural- or emotional problem scores between independent samples or within one sample. Differences were tested between patient samples and reference groups, between those awaiting cardiac surgery as opposed to interventional catheterisation, and between younger and older patients.

Results

Cognitive functioning

No significant differences were found between the distributions of gender and age, using age-cate-

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gories of 3 to30 months and of 2.5 to7 years, amongst the 76 patients scheduled for cardiac surgery and the 19 patients scheduled for catheter intervention, who completed the cognitive tests. Socio-economic status was scored on a three step scale of parental occupation.[18] We found no significant differences in the distribution of socio-economic status between the 76 families awaiting cardiac surgery and the 19 families awaiting interventional catheterisation.

Table 3 shows the mean cognitive scores of the two age-groups and the "total cognitive sample". No significant differences were found for mean cognitive scores between those awaiting surgery or interventional catheterisation when compared with reference groups, nor for those scheduled for surgery as opposed to interventional catheterisation, nor for the younger and older patients. Gender had no effects on mean cognitive scores of the younger and older patients awaiting cardiac surgery or interventional catheterisation.

Behavioural and emotional functionin: Again, we found no significant differences for gender and age distribution between the 42 patients awaiting cardiac surgery and the 15 patients awaiting interventional catheterisation, for whom parents completed Child Behavior Checklists. Similarly, there were no significant differences in the distribution of socioeconomic status of the corresponding families.

Table 4 lists the total problem scores, and those for the internalizing and externalizing areas, as derived from the checklists. The mean total problem score, and the mean score for the externalizing area, were higher in patients aged from 2 to 3 who were awaiting cardiac surgery when compared to the reference group. These patients also showed more internalizing problems than did those aged from 4 to 7 who were also awaiting surgery. After applying Bonferroni correction for 9 comparisons, however, the *only* difference which remained significant was on the total problem score for patients aged from 2 to 3 years who were awaiting cardiac surgery when compared to the reference group. No effects of gender were found for the Child Behavior Checklist-scores of the younger and older patients awaiting either cardiac surgery or intervention catheterisation.

Discussion

Parents are often concerned about harmful effects of congenital cardiac malformations on the emotional and cognitive functioning of their child. The most striking finding of the present study, therefore, is the overall lack of differences in the level of cognitive, and behavioural and emotional functioning between children awaiting elective cardiac surgery or interventional catheterisation when compared with reference groups. On mean cognitive scores we found no differences between patients undergoing these procedures and reference groups, nor were differences found between those scheduled for cardiac surgery as opposed to those waiting for interventional catheterisation. Similarly, no differences were found amongst patients above and below the age of 2.5 years. As to emotional functioning, the only significant difference found was that patients aged from 2 to 3 who were awaiting cardiac surgery obtained higher total problem scores on the Child Behavioural Checklist than did the reference group. No further differences were found regarding behavioural and emotional functioning. Overall, we can conclude that our children who were scheduled for elective cardiac surgery or interventional catheterisation were comparable in terms of cognitive and behavioural and emotional functioning to normative reference groups. These favourable results, therefore, can be regarded as an important and reassuring message for the parents. Previously, we had found that the parents of our children scheduled for cardiac surgery showed elevated levels of psychological distress and less adequate mechanisms for coping (9). From these results, we can conclude that the parental distress was not associated with cognitive or behavioural and emotional dysfunctioning in their children.

In 1991, Bellinger et al.[5] stated that, although the mean cognitive development of 28 children operated upon for transposition of the great

Table 3: Mean cognitive scores of patients undergoing cardiac surgery ("surgery") and interventional catheterisation ("intervention"), aged below and above 2.5 years, along with the total cognitive sample for those aged from 3 months to 7 years.

	surgery			intervention		
Age	**N**	**x**	**SD**	**N**	**x**	**SD**
3 months– 2.5 years	41	101.2	15.5	4	99.5	31.4
2.5 – 7 years	35	101.8	11.4	15	96.7	12.7
Total: 3 months – 7years	76	101.5	13.7	19	97.3	17.1

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Table 4. Mean T-scores on the total problem score and the internalizing and externalizing problem areas on the Child Behavior Checklist (CBCL) for patients undergoing cardiac surgery ("surgery") and interventional catheterisation ("intervention"), who were aged from 2 to 3 as opposed to 4 to 7, and for the age-range from 2 to 7.

	surgery		reference		intervention		reference	
	x	SD	x	SD	x	SD	x	SD
CBL 2–3	**(N= 18)**		**(N= 15)**		**(N= 4)**		**(N= 5)**	
Total problem	[1]53.3	8.1	46.6	0.7	46.8	9.3	46.9	0.9
Internalizing	52.3	8.0	48.9	1.0	47.0	3.5	49.9	0.5
Externalizing	52.1	6.9	48.1	1.1	45.0	11.1	48.3	1.4
CBCL 4–7	**(N= 24)**		**(N= 25)**		**(N= 11)**		**(N= 11)**	
Total problem	48.7	8.5	49.2	1.0	49.3	9.2	49.0	0.8
Internalizing	46.8	8.8	47.5	0.8	49.4	9.6	47.8	0.8
Externalizing	48.0	9.4	49.2	1.6	46.5	11.5	49.1	1.2
CBCL 2–7	**(N= 42)**		**(N= 40)**		**(N= 15)**		**(N= 16)**	
Totabl problem	50.7	8.6	48.2	1.6	48.6	8.9	48.4	1.3
Internalizing	49.2	8.8	48.1	1.1	48.8	8.3	48.5	1.2
Externalizing	49.8	8.6	48.8	1.6	46.1	11.0	48.8	1.3

1) Significant difference between surgery patients and reference group: p= 0.002
T-scores: x= 50, SD= 10

arteries, measured with the Bayley and McCarthy scales, was near 100, this may not correspond to "average" performance. His criticism was that the normative data were published about two decades ago, and recent cohorts of children tend to achieve scores averaging 110. Since we used the same instruments as did Bellinger et al.,[5] our results should be interpreted with caution. As mentioned, we used American normative data for the McCarthy and the Bayley scales so as to permit comparability between the results of both instruments. Further statistical analyses that we performed with more recent Dutch normative data for the Bayley scales showed no significant difference in mean cognitive scores for patients scheduled for cardiac surgery when compared with reference groups. This lends support to our conclusion that our results regarding intellectual functioning can be considered as favourable. Further, Visconti et al.[19] recently studied children after surgical versus interventional closure of atrial septal defects within the oval fossa. They mentioned that, although children with acyanotic heart disease tend to have better outcomes than those who are cyanotic, they appear to perform worse than healthy controls who lack cardiac malformations. Their statement gives further strength to our conclusion that our results regarding preoperative intellectual functioning are favourable.

The only significant finding concerning behavioural and emotional functioning in our study was that those patients awaiting cardiac surgery who were aged from 2 to 3 obtained higher total problem scores on the Child Behavior Checklist than did the reference group. For these patients, no further significant differences were found for the internalizing and externalizing problem areas. Furthermore, no differences compared to reference groups were found for those aged from 4 to 7 who were awaiting cardiac surgery, nor for those aged from 2 to 7 and awaiting interventional catheterisation. These findings are also favourable considering the fact that, in a previous study,[1] children aged from 10 to 15 with congenital cardiac malformations obtained significantly higher mean total problem scores on the Child Behavior Checklist, as well as higher scores on the internalizing and externalizing areas. Oates et al.[20] found higher mean total problem scores, and higher scores for the internalizing area, on the Child Behavior Checklist for children aged from 7 to 15 who had undergone successful cardiac surgery 4 to 8 years previously. In our opinion, the contrast between our favourable findings and the less favourable results of earlier studies can be explained by the fact that the previous populations consisted of older patients, and contained patients with more severe and cyanotic lesions, tested after one or more cardiac surgeries and hospitalizations. Further, patients in both retrospective studies had undergone cardiac surgery before 1982, with both medical treatment of cardiac conditions and surgical techniques improving markedly in the meantime.

Several investigators[1,20,21] found that behavioural differences reported by parents of children with congenital cardiac disease were predominantly in the internalizing aspects of behaviour. Thus,

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parents described their children as more fearful and inhibited, but smaller or no differences were being found in externalizing behaviour. These findings are not confirmed by our study. We examined a selected, homogeneous, sample of patients scheduled for elective cardiac surgery, and with a different age-range, which may explain the differences in the results.

Goldberg et al.[21] stated that internalizing problems are underreported and difficult to study in young children, since these problems have less impact on others than do the externalizing problems. In a previous study[22] we found that a higher level of internalizing problems was associated with older age at surgical repair. In contrast, in our present study, it was the younger patients aged from 2 to 3 who were awaiting cardiac surgery, who tended to show more internalizing problems than did older patients awaiting the same procedure. This finding might be explained by the fact that, since the toddlers awaiting cardiac surgery had increased levels of behavioural and emotional problems, the parents might be more alert, or over-interpret internalizing problems in their children. Our present findings further indicate that being scheduled for elective cardiac surgery or interventional catheterisation at an older age has no negative influence on the intellectual nor the behavioural and emotional functioning of the patients.

To our knowledge, cognitive and emotional functioning of children awaiting elective interventional catheterisation has not previously been studied. Although our interventional group was small, and chance fluctuations may have influenced the data and the statistical results, we tentatively conclude that no significant differences in intellectual and emotional functioning are found in those awaiting interventional catheterisation when compared with reference groups, nor between these children and those awaiting cardiac surgery.

Parents of children with congenital cardiac malformations often express worries about the possible deleterious effects of the cardiac lesion on the cognitive, and on the behavioural and emotional, functioning of their child.[22] In research, very little attention has been paid to preoperative assessment of these variables in children awaiting elective treatment of their cardiac defect. The strengths of our study were that we tested a large consecutive, homogeneous sample of patients, with satisfactory rates of response, using standardized, reliable, valid and internationally accepted tests. This was done prior to cardiac surgery or interventional catheterisation so that we could rule out possible adverse influences of peri- and postprocedural variables. Our most important finding was the overall lack of differences in cognitive and behavioural or emotional functioning between the patients awaiting elective cardiac surgery or interventional catheterisation and reference groups. Furthermore, no differences were found on these variables between those awaiting surgery as opposed to interventional catheterisation, nor between younger versus older patients. In our opinion, these data indicate favourable functioning of those examined. The only difference we could find was that, according to the parents, those aged from 2 to 3 years old who were awaiting elective cardiac surgery showed more behavioural and emotional problems than did their reference group.

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