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Original Article

Does age at the time of elective cardiac surgery or catheter intervention in children influence the longitudinal development of psychological distress and styles of coping of parents?

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Abstract *Aims:* To assess the influence of age at a cardiac procedure of children, who underwent elective cardiac surgery or interventional cardiac catheterisation for treatment of congenital cardiac defects between 3 months and 7 years of age, on the longitudinal development of psychological distress and styles of coping of their parents. *Methods:* We used the General Health Questionnaire to measure psychological distress, and the Utrecht Coping List to measure styles of coping. Parents completed questionnaires on average respectively 5 weeks prior to, and 18.7 months after, cardiac surgery or catheter intervention for their child. *Results:* Apart from one exception, no significant influence was found of the age at which children underwent elective cardiac surgery or catheter intervention on the pre- to postprocedural course of psychological distress and the styles of coping of their parents. Across time, parents of children undergoing surgery reported, on average, significantly higher levels of psychological distress than parents of children who underwent catheter intervention. After the procedure, parents of children who underwent either procedure reported significantly lower levels of psychological distress, and showed a weaker tendency to use several styles of coping, than did their reference groups. *Conclusion:* Age of the children at the time of elective cardiac surgery or catheter intervention did not influence the course of psychological distress of their parents, nor the styles of coping used by the parents. Future research should investigate in what way the age at which these cardiac procedures are performed influences the emotional and cognitive development of the children.

Keywords: Congenital heart disease; psychology; coping; parents

It has been reported that the presence of congenital cardiac disease in an infant appears to alter and complicate parental attitudes and behaviours toward their child, irrespective of the severity of the congenital cardiac malformation.[1–3] Research into the psychological impact of congenital heart disease on parents is often focussed on early caregiving problems with newborns, and the interactions between mothers and their infants.[4–5] More recently, parental reactions after fetal echocardiography,[6–7] and specific experiences of fathers of infants or young children with congenital cardiac malformations,[8–9] have received attention. Studies performed during the last decade often contained methodological weaknesses, such as small samples, use of non-standardised procedures for assessment, such as interviews, and lack of reference groups.

At present, there is a group of relatively healthy functioning children who need to undergo elective cardiac surgery or catheter intervention for certain

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congenital cardiac lesions which are not directly life-threatening, and which do not result in impairment of functions in the short term. Examples are atrial septal defects within the oval fossa, or tetralogy of Fallot. Without treatment, their congenital malformation will give rise to progressive impairment of the cardiac function, and/or may produce arrhythmias later in life. There are no medical or technical criterions to determine the optimal age at which elective operations for such lesions should take place. In the Netherlands, the time at which these children undergo surgical treatment or interventional catheterisation is determined, to a great extent, by the time of the first visit to the outpatient clinic. We instigated our present study with the intention of using its results to set an adequate timing for these interventions in those circumstances where the time for these interventions is not definitely set by either the medical or surgical facts.

Previously,[10] we documented the preprocedural psychological distress and styles of coping in a sample of parents of children awaiting elective cardiac surgery. This study investigates the longitudinal follow-up of the same sample of parents, using the same instruments for assessment. The previous study showed elevated levels of psychological distress, manifested as anxiety, sleeplessness, and social dysfunctioning, in these parents before surgery was performed on their children. The parents also demonstrated less adequate styles of coping. For example, they were less active in solving problems, and expressed their annoyance or anger to a significantly lesser extent than did reference subjects. The results indicated that the period prior to these elective cardiac procedures was perceived by the parents as very stressful and tense.

Very little systematic longitudinal research has been conducted into the development of the pre- to postprocedural state of mental health, and the styles of coping, of parents whose children underwent elective cardiac surgery or catheter intervention at different ages. Some indications[11,12] can be found that younger age at the time of intervention is more favourable for the adjustment of the parents and the psychosocial development of the child. The main aims of our present longitudinal study, therefore, were:

- To assess the influence of age during elective cardiac surgery or catheter intervention in children on the development of pre- to postprocedural psychological distress and coping of their fathers and mothers.
- To assess whether there were differences in the development of these variables between surgery as opposed to intervention.
- To compare the levels of postprocedural psychological distress and coping of parents of patients undergoing either procedure to those of normative reference groups.

Materials and methods

We used the 28-item version of the General Health Questionnaire[13,14] to assess the level of psychological distress. This is a reliable and valid standardised self-report, consisting of four scales: somatic symptoms, anxiety and sleeplessness, social dysfunctioning and serious depression.

To assess styles of coping we used the Utrecht Coping List,[15] consisting of seven subscales. These involve: active solving of problems, palliative reaction (seeking diversion in an healthy or unhealthy manner, trying to relax by smoking or drinking), avoiding/waiting, seeking social support, passive patterns of reaction (inertia), expression of emotions (anger, irritation) and using reassuring thoughts (positive cognitions).

The target sample consisted of all 321 consecutive patients who underwent their first elective open cardiac surgical procedure, or elective catheter intervention, for a non-life threatening and, at that moment, non-function-impairing congenital cardiac malformation, between May 1994 and May 1997, in the University Hospital Rotterdam, and who were between 3 months and 7 years of age at the time of surgery or intervention. Surgery or catheter intervention was electively planned in all within 3–6 months. We included only patients with, at that moment, a non-life threatening diagnosis which did not impair their function.

Postprocedural measurements were performed between November 1995 and November 1998, when the patients were between 1 and 8.5 years of age. The patients needed to be living with their parents, and the parents were required to consent to participate in the study, and to be Dutch speaking. We excluded 102 patients who had undergone previous open-heart surgery or intervention, 4 patients with concomitant extracardiac congenital anomalies, 3 patients with mental retardation, 4 patients living abroad, and a foreign adopted child. It was also necessary to exclude 79 additional patients because they showed combinations of two or more of these exclusion criterions. This resulted in 128 eligible patients, 102 undergoing surgery and 26 undergoing catheter intervention.

Since the present study is longitudinal, we included only data of parents who completed questionnaires at both the pre- and postprocedural assessments. Parents of 3 children, who died after the cardiac procedure, could not complete the second assessment. One child died of sudden cardiac arrest 2 days after cardiac surgery, another died 30 days after the initial

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cardiac surgery during a second cardiac operation, and one child died due to a cerebral infarction after a cardiac operation, which was performed 2 weeks after an unsuccessful catheter intervention. Parents completed questionnaires on average 5 weeks prior to, and 18.7 months after, cardiac surgery or catheter intervention on their child.

At the preprocedural measurement, 75 mothers and 75 fathers of children awaiting surgery, and 19 mothers and 17 fathers of children scheduled for intervention, returned fully completed questionnaires. The detailed preprocedural results have been published previously.[10] At the postprocedural measurement, of the mothers whose children underwent surgery, 2 could not participate because their child had died, 2 were lost to follow-up, and 4 refused participation on practical or emotional grounds, resulting in 67 mothers completing the questionnaires. This comprised 94.4% of the preprocedural sample, and 68% of the original eligible sample of mothers with children scheduled for surgery. The rates of response have been corrected for parents of children who died, and for parents lost to follow-up. At the second assessment, from the fathers of children who underwent surgery, the child of 1 father had died, 2 fathers were lost to follow-up, and 12 fathers refused participation on practical or emotional grounds. This left 60 participating fathers, comprising 83.3% of the preprocedural sample and 61% of the original eligible sample. Of the mothers with children who underwent a catheter intervention, the child of 1 mother had died, and 1 mother refused participation, resulting in a corrected response percentage of 94.4%. This was 68% of the original eligible sample of mothers with children undergoing a catheter intervention. For the fathers with children undergoing interventional catheterisation, the child of 1 father had died, giving a postprocedural corrected response of 100% of the preprocedural sample and 64% of the original eligible sample.

Normative data was derived from the manuals of the questionnaires used. The reference groups for the General Health Questionnaire consisted of random samples drawn from the general population.[13] The male reference group for the Utrecht Coping List consisted of a group of males employed on the Dutch railways, in combination with a random sample of the general population. The female reference group for the Utrecht Coping List consisted of a group of hospital nurses, combined with a random sample from the general population.[15]

The study complies with institutional and national guidelines for ethical matters. All parents were asked to participate by a paediatric cardiologist during a visit to the outpatient clinic, and signed a form granting informed consent. At both measurements, parents completed the questionnaires at home after having been interviewed by a psychologist during a home-visit.

Exact tests were used to test differences in distributions of gender and age of children undergoing surgery versus those undergoing intervention. Differences in socio-economic status between the parents of the patients submitted to surgery versus intervention were tested by Pearson Chi-square test.

T-tests were used to test differences in mean ages of parents and of children between those undergoing surgery versus intervention, and to test differences in mean scores on the questionnaires between parents of patients and their reference groups. Multivariate analyses of variance were used to investigate the influence of age at cardiac procedure on the longitudinal development of psychological distress and styles of coping of parents. Age at cardiac procedure was used as a "between factor" and categories of age varied from 0 to 6 years. In these analyses, the time of measurement was used as a "within factor" to examine the effect of time itself on the course of psychological distress and styles of coping in parents. Further, multivariate analyses of variance were executed using surgery versus intervention as a "between factor" to investigate the influence of type of procedure on the course of parental psychological distress and coping.

Results

No significant differences were found between the preprocedural mean ages of the mothers of those awaiting surgery (31.0 years, SD = 5.4) as opposed to those having intervention (32.9 years, SD = 5.0), nor between the preprocedural mean ages of fathers of those awaiting surgery (34.3, SD = 5.4) compared to intervention (34.6, SD = 4.4). The ages were missing for one couple with a child undergoing surgery, and for one couple with a child undergoing intervention. Socio-economic status was scored on a three-step scale of parental occupation.[16] Pre- and postprocedural differences in socio-economic status between parents of those undergoing surgery, as opposed to intervention, were not significant. No significant differences were found in the distributions of preprocedural age and sex of patients undergoing surgery as opposed to those undergoing intervention (Table 1). Nor was any significant difference found between the mean ages at the time of a cardiac procedure between the children undergoing surgery (2.4 years ± 2.1) compared to those having catheter intervention (3.4 years ± 1.9).

The only significant main effect of the age at which children underwent an elective cardiac procedure was found on the scale concerned with avoiding/waiting. This effect was found for mothers of

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children undergoing surgery ($p = 0.044$). On average, for mothers of children aged 0, 3 and 5 years, the tendency to avoid/wait decreased over time, whereas this tendency increased for mothers of 1, 2, 4 and 6-year-olds. No further significant effects, either main or interactive, were found for the age at which children underwent either elective cardiac surgery or catheter intervention, on the pre- to post-procedural course of psychological distress and styles of coping of their fathers and mothers.

Table 1. Age, gender and cardiac diagnoses of children undergoing cardiac surgery and catheter intervention, for whom data of mothers on both the pre- and postoperative measurement were available.

	CS	CCI	p*
Age distribution			
At preoperative assessment			0.41
3 months–1 year	19	2	
1	10	2	
2	7	–	
3	8	3	
4	10	5	
5	7	3	
6	6	2	
Total	67	17	
Gender distribution			
			0.28
Boys	35	6	
Girls	32	11	
Total	67	17	
Cardiac diagnoses			
ASD2	17	6	
VSD	21	0	
AVSD	7	0	
Fallot	5	0	
PAD	2	9	
Other	15	2	
Total	67	17	

* By Fisher's exact test.
Abbreviations: CS: Cardiac Surgery; CCI: Cardiac Catheter Intervention; ASD: atrial septal defect secundum type or sinus venosus defect; VSD: ventricular septal defect; AVSD: either primum defect or complete AVSD with small ventricular component; Fallot: tetralogy of Fallot; PAD: Patent Arterial Duct

With regard to the type of medical procedure, mothers of children undergoing surgery, on average, reported significantly more problems, pre- and post-procedurally, concerning anxiety and sleeplessness (Table 2). They also reported more psychological distress than mothers of children undergoing intervention. Fathers of children undergoing surgery reported, on average, before and after the procedure, significantly more psychological distress and somatic symptoms. They showed a weaker tendency to use reassuring thoughts than did fathers of children undergoing intervention. No interaction was found between the type of procedure, surgery versus intervention, and any of the dependent variables mentioned above.

After the procedure, in comparison with reference groups, parents of children who underwent either type of procedure reported significantly lower levels of psychological distress. Significant differences between parents of patients and reference groups as assessed on the Utrecht Coping List are shown in Table 3. Significant differences were found for six of its seven scales, indicating overall a weaker tendency for parents of patients to use these styles of coping compared to reference groups.

Finally, significant improvements over time concerning anxiety and sleeplessness were found for parents of children undergoing surgery, and for mothers of those having catheter intervention. Parents of children undergoing surgery showed significant improvements over time concerning the style of coping which is called a palliative reaction. Mothers of children having surgery further showed significant improvements in terms of psychological distress, somatic

Table 2. Pre- and postprocedural mean scale scores and mean total scores on the General Health Questionnaire of parents of children who underwent elective cardiac surgery, parents of children who underwent cardiac catheter intervention, and "reference" groups.

	Cardiac Surgery				Cardiac Catheter Intervention				Reference	
	Mothers (N = 67)		Fathers (N = 60)		Mothers (N = 17)		Fathers (N = 16)		Females (N = 258)	Males (N = 216)
	Pre	Post	Pre	Post	Pre	Post	Pre	Post		
Somatic symptoms	7.34[3]	4.52[2,3]	4.80[1]	3.82[1,2]	5.94	3.53[2]	2.13[1]	2.81[1,2]	6.7	5.4
Anxiety and sleeplessness	8.91[1,3]	4.19[1,2,3]	4.93[3]	3.30[2,3]	6.41[1,3]	2.88[1,2,3]	3.44	2.06[2]	6.0	5.5
Social dysfunctioning	8.58[3]	6.88[3]	7.67	6.78	8.12	6.94	7.25	6.81	6.9	7.1
Serious depression	1.45	0.85[2]	0.78	0.95[2]	0.82[3]	0.18[2,3]	0.19	0.19[2]	1.6	1.5
Total-score	7.78[1,3]	2.73[1,2,3]	4.05[1]	2.20[1,2]	4.94[1]	1.00[1,2]	1.94[1]	1.13[1,2]	4.69	4.00

A high total score and high sub-scale scores indicate unfavourable functioning . The total score indicates the level of psychological distress.
[1]Significant ($p < 0.05$) effect of type of procedure on mean scores of "cardiac surgery"-mothers versus "intervention"-mothers, and of "cardiac surgery"-fathers versus "intervention"-fathers.
[2]Significant ($p < 0.05$) difference between postoperative mean scores of parents of patients versus mean scores of reference groups.
[3]Significant ($p < 0.05$) effect of time (i.e. changes in scores over time) on mean scores of parents of patients.

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Table 3. Pre- and postprocedural mean scale scores on the Utrecht Coping List of parents of children who underwent elective cardiac surgery, parents of children who underwent cardiac catheter intervention and "reference" groups.

	Cardiac Surgery				Cardiac Catheter Intervention				Reference	
	Mothers (N = 67)		Fathers (N = 60)		Mothers (N = 17)		Fathers (N = 16)		Females (N = 542)	Males (N = 599)
	Pre	Post	Pre	Post	Pre	Post	Pre	Post		
Active problem solving	17.31	17.67[2]	19.00	18.83	18.12	18.06	19.75	19.94[2]	18.8	18.3
Palliative reaction	16.72[3]	15.93[2,3]	14.58[3]	13.52[2,3]	16.12	14.59[2]	15.19	15.13	16.8	15.3
Avoiding/waiting	14.42*	14.66*	14.35	14.53	15.06	14.65	14.44	15.00	14.6	14.7
Seeking social support	14.91[3]	13.55[2,3]	11.35	11.55	14.00	13.88	11.94	12.63	14.7	11.3
Passive reaction pattern	11.19[3]	10.34[3]	10.22	9.92[2]	9.71	9.35[2]	9.31	9.50[2]	10.3	10.6
Expression of emotions	5.81	5.82[2]	5.42	5.38[2]	5.88	5.53[2]	5.50	6.13	6.4	6.3
Using reassuring thoughts	12.25	11.44	11.17[1,3]	10.52[1,2,3]	12.12	11.59	12.25[1]	11.94[1]	11.6	11.6

On each scale, a high score indicates a strong tendency to use this coping style. A total score cannot be computed.
*Significant ($p < 0.05$) main effect of age at cardiac surgery on avoiding/waiting of mothers of children undergoing cardiac surgery.
[1]Significant ($p < 0.05$) effect of type of procedure on mean scores of "cardiac surgery"-mothers versus "intervention"-mothers, and of "cardiac surgery"- fathers versus "intervention"-fathers.
[2]Significant ($p < 0.05$) difference between postoperative mean scores of parents of patients versus mean scores of reference groups.
[3]Significant ($p < 0.05$) effect of time (i.e. changes in scores over time) on mean scores of parents of patients.

symptoms, social dysfunctioning, showing a passive pattern of reaction and seeking social support. Fathers of children undergoing surgery improved significantly over time with regard to using reassuring thoughts, and mothers of children undergoing intervention showed improvements on serious depression.

Discussion

Our study has shown that, the age at which the children underwent elective cardiac surgery or catheter intervention, did neither negatively nor positively influence the course of psychological distress and styles of coping used by the parents. This implies that there is no optimal age at which the cardiac procedure should be performed when psychological wellbeing of the parents is taken as the measure of outcome. The only significant effect of age at cardiac surgery, found on the scale concerning avoiding/waiting, is difficult to interpret. Furthermore, it barely reached the level of statistical significance. Considering the fact that only one effect became significant out of the 48 statistical tests we performed for our first research question, we regard this as a chance finding.

We are not aware of any other longitudinal study questioning the optimal age for elective cardiac procedures to be performed in relation to the psychological wellbeing of the parents. We had previously reported[10] a small, though significant, negative correlation between age at surgical repair and preprocedural psychological distress in mothers of children awaiting elective cardiac surgery. Results showed higher levels of distress in mothers of younger children awaiting surgery. In statistical analyses of the present study, cells could have been too small to find effects, due to the multiple age categories being used. For this reason we repeated the analyses again, now dividing the sample in two larger groups, comparing those aged up to 2 years with those aged from 3 to 6 years. This hardly changed our findings. Again, for all the 48 tests we performed, no significant effects were found for age at cardiac surgery or catheter intervention on the course of psychological distress and styles of coping of parents. This strengthens our overall conclusion that our results do not indicate an optimal age for children to undergo these cardiac procedures when set against the psychosocial wellbeing of the parents.

No study has thus far longitudinally compared parental reactions of children undergoing elective cardiac surgery versus catheter intervention. Previously[10] we anticipated finding more favourable results in parents of children undergoing catheter intervention, since the parents could view this type of intervention as less invasive than cardiac surgery. This was endorsed by our present findings. On average, before and after the procedure, the parents of children undergoing surgery showed more psychological distress than did parents of those undergoing catheter intervention.

We have also found that parents of children who underwent either type of procedure reported significantly lower levels of psychological distress after the procedure than normative reference groups. This favourable outcome could be explained by the mechanism of "denial". "Denial" has been described to occur in parents of children with congenital heart disease,[17] and possibly also in young adults with congenital heart disease.[18] According to Garson et al.,[19] denial was especially seen in parents of asymptomatic children. These parents frequently referred to

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the asymptomatic state of their child in order to reassure themselves of the normality. Parents have been reported to use "denial" after they have learned about the cardiac diagnosis of their child.[17,19] In our study, however, parental reactions were assessed about 18 months after the cardiac procedure. Another explanation for our positive findings could be that, once parents have left behind them the stressful and frightening period of the cardiac procedure, and have returned back to their normal lives, they feel very relieved and may worry less about futilities in life. They can have the feeling that they have come out stronger from the experience, which could explain their lesser urge to use several styles of coping.

Over time, parents of children undergoing cardiac surgery or catheter intervention showed significant improvements on scales concerning psychological distress and on several styles of coping, such as palliative reaction and passive reaction pattern. These findings are favourable considering the fact that anxiety, stress, and problems with coping have often been reported to exist in parents of children with congenital cardiac malformations.[2,3,7,20] In one of the few existing longitudinal studies, Stinson and McKeever[1] reported anxiety and concerns to occur in 30 mothers 10 days after cardiac surgery. Their study differs from ours since they used a short-term post-procedural assessment, their sample was small, and consisted of mothers of only young infants. Our results are in line with those of the longitudinal study of Gardner et al.[21] They reported a significant reduction in psychological distress, also assessed with the General Health Questionnaire, in 20 mothers 2 days before and 6 months after elective, corrective, cardiac surgery for their infants. Van Horn et al.[20] also reported a decrease in anxiety and depressed mood in 38 mothers of children with heterogeneous congenital cardiac malformations following discharge from hospital. Their sample, however, was small and they used non-standardised measures to assess anxiety and depressed mood.

The improvements over time we discovered with respect to parental psychological distress are favourable, considering the fact that maternal anxiety and distress are held to be associated with the emotional adjustment of children with congenital cardiac lesions.[20,22] Garson et al.[19] reported that the psychological needs of parents are not dependent on the seriousness of the cardiac malformation of their child. Van Horn et al.[20] reported that overall improvements in the state of patients with congenital cardiac malformations may lead medical providers to underestimate the level of concern and stress experienced by families. Considering the fact that our sample consisted of parents of children with non-life threatening, and at that moment non-function impairing, congenital malformations, who may have had less time-consuming medical support than parents of children with more severe defects, we conclude that overall our parents showed a favourable reaction.

The strengths of our study were that we investigated prospectively mothers and fathers of children with congenital cardiac lesions of varying ages. The sample of parents of children undergoing cardiac surgery was sufficiently large, the response rate was satisfactory, and we used standardised instruments for assessment. A limitation is that our sample of parents of children undergoing catheter intervention was small, which restricts us when drawing conclusions comparing the treatment of both groups. Further, whether the length of the interval between the definitive diagnosis and the moment of the procedure influenced the development of wellbeing for the parents was not evaluated.

Chang et al.[23] reported that, in California, besides medical variables, non-medical variables such as type of insurance, and a higher surgical case volume in centres where cardiac surgery is performed, play important roles in determining the age for definitive repair of congenital cardiac lesions in children. At present, the policy in the university centres of the Netherlands, where elective cardiac surgery or catheter intervention is performed on children, is to treat children with these procedures at a young age. Our results, however, when viewed from the stance of the psychological wellbeing of the parents, do not indicate an optimal age at which either procedure should be performed. Future research should investigate in what way the age at which these cardiac procedures are performed influences the emotional and cognitive development of the children themselves.

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