

## Long-term Psychosocial Outcomes in Children and Adolescents with Congenital Heart Disease, and in Their Parents: Rotterdam Follow-up Studies

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### Key words:

congenital heart, quality of life, children, adolescents, parents

**Background:** This review describes the main findings of two follow-up studies into long-term psychosocial outcomes in children and adolescents with congenital heart disease (ConHD) and their parents.

**Methods:** For both studies, all consecutive patients who underwent their first open-heart surgery or invasive treatment for ConHD (study 1: surgeries performed between 1968 and 1980; study 2: surgeries performed between 1990 and 1995) at the Erasmus Medical Centre Rotterdam, the Netherlands, and who were younger than 15 years of age at the time of surgery, were eligible. The first study was performed between 1989 and 1991, the second between 2003 and 2005.

**Results:** The first study demonstrated that 10–17-year-old ConHD children and adolescents who underwent surgical “correction” for ConHD before 1980 showed significantly higher levels of behavioral/emotional problems compared to normative groups, both according to parents’ reports (N = 144) and self-reports (N = 179).

The second, more recent study was executed in 7–17-year-old patients (N = 124). Despite improvements in medical treatment over the years, patients from this more recent study, still showed higher levels of behavioral/emotional problems and also a poorer health-related quality of life (HRQoL), compared to reference groups. Parents of patients showed favorable outcomes on psychosocial well being (N = 100 mothers, 61 fathers) and coping.

Overall, in both studies, no clear relationships were found between cardiac diagnoses and psychosocial outcomes.

**Conclusion and Discussion:** Considering the poorer behavioral/emotional functioning and poorer HRQoL of these children and adolescents with ConHD, we recommend early screening to identify children who are at risk.

### Introduction

Over the past decades, enormous advances in cardiovascular diagnostic and surgical techniques have reduced the mortality rates of children with congenital heart disease (ConHD) substantially. At the start of our studies in 1990 little was known about the long-term psychosocial outcomes of children and adolescents with ConHD. The few studies conducted in the field contained methodological problems such as the use of small and heterogeneous patients samples (operated and non-operated patients together) and the use of

non-standardized assessment instruments.

### Objectives

Therefore, in Rotterdam, the Netherlands, cohort studies were executed with the main aim of investigating long-term psychosocial functioning in consecutive series of children and adolescents with ConHD, and the adjustment of their parents.

This review presents the main findings of two follow-up studies in children and adolescents with ConHD and their parents. The review is based on the lecture given by Elisabeth

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Utens at the 44th Annual Meeting of the Japanese Society of Pediatric Cardiology and Cardiac Surgery. (A detailed description of the study samples and results had been presented previously.<sup>1-7)</sup>

## Methods

### 1. Assessment instruments

#### • Behavioral and emotional problems

To obtain standardized reports of children's behavioral and emotional problems, over the last half year, in both follow-up studies Dutch versions of internationally well-known, reliable, and valid questionnaires were used: the Child Behavior Checklist (CBCL)<sup>8)</sup> to be completed by parents regarding their child, and the Youth Self-Report (YSR)<sup>9)</sup> to be filled in by patients themselves.

Both questionnaires contain (about) 110 parallel so-called problem items. On both questionnaires, a total problem score and Internalizing and Externalizing score can be computed. Internalizing reflects internal distress and consists of the scales anxiety/depression, withdrawal, and somatic complaints. Externalizing reflects conflicts with other people and consists of the scales rule-breaking and aggressive behaviors. Furthermore, the scales social problems, thought, and attention problems are assessed (these scales belong neither to Internalizing nor to Externalizing).

#### • Health-related quality of life

The TNO-Academisch Ziekenhuis Leiden (TNO-AZL) Child Quality of Life Questionnaire (TACQOL)<sup>10)</sup> was used to assess health-related quality of life (HRQoL) (This was done in the second cohort study only). The TACQOL is an international questionnaire, with good psychometric qualities. It assesses general aspects of HRQoL in 8–15-year-olds. It has both a parent and child form, and covers 7 dimensions: 1) pain and physical symptoms, 2) motor functioning, 3) autonomy, 4) cognitive functioning, 5) social functioning, 6) global positive emotional functioning and 7) global negative emotional functioning. The TACQOL first assesses *how often* a specific complaint or limitation occurs. If such a problem exists, then the *subjective evaluation* of this problem is asked for. Thus in fact each item consists of two questions (except for the two scales on emotional functioning).

### 2. Inclusion criteria

Those eligible in both studies were as follows: all consecutive patients who underwent their first invasive treatment for ConHD in the Erasmus Medical Centre Rotterdam and who

were younger than 15 years of age at the time of surgery.

In the first study,<sup>1,2)</sup> the (first) heart operation had to have been executed between 1968–1980, such that at follow-up (1989-1991) the follow-up interval was at least 10 years ago or longer.<sup>1,2)</sup>

In the second study,<sup>3-7)</sup> the first invasive treatment for ConHD had to be executed between 1990–1995, such that at follow-up (2003–2004), the follow-up interval was at least 7 years ago.

### 3. Exclusion criteria

In both studies, patients with proven syndromes of mental retardation (including Down syndrome or velocardiofacial syndrome) were excluded.

### 4. Procedure

In both studies, patients were recruited uniformly and psychological examinations were performed by a licensed psychologist, in hospital, in the same standardized way (for details, see 1–7).

### 5. Patients

The first study (N = 144, 95 boys, response rate: 87.3%)<sup>1,2)</sup> encompassed five diagnostic groups: atrial septal II defect (ASD, N = 8, mean age: 12.9 years), ventricular septal defect (VSD, N = 43, mean age: 12.5 years), tetralogy of Fallot (ToF, N = 26, mean age: 12.5 years), transposition of the great arteries (TGA, N = 38, mean age: 12.7 years), pulmonary stenosis (PS, N = 9, mean age: 13.2 years) and a miscellaneous group consisting of small numbers of patients with varying or rare defects (N = 20, mean age: 12.5 years). All patients underwent cardiac surgery. The TGA group was operated using the Mustard technique. PS patients were operated by surgical valvotomy with the use of inflow occlusion or cardiopulmonary bypass.

In the second study (N = 124, 66 boys, response rate: 73%),<sup>3-7)</sup> owing to logistic reasons, patients with ToF and a miscellaneous group (small numbers of patients with varying or rare defects) were excluded. The treatment of the 4 recent cardiac diagnostic groups consisted of: surgical closure of ASD (N = 29, mean age: 14.0 years) and VSD (N = 50, mean age: 11.3 years). TGA patients (N = 32, mean age: 10.4 years) were operated with arterial switch operation. All operations were done with standard cardiopulmonary bypass. Pulmonary stenosis patients (N = 13, mean age: 12.5 years) all underwent valvuloplasty.

## Results

### 1. Study 1: mean level of behavioral and emotional problems<sup>1,2)</sup>

In comparison to the general population, both according to parents' (CBCL) and self-reports (YSR), 10–15-year-old ConHD children and adolescents obtained significantly higher total problem scores and showed more problems on each of the specific problem scales. Thus, ConHD patients showed more problems on Internalizing (withdrawn, somatic, anxious/depressed); Externalizing (rule-breaking and aggressive behaviors) and also on thought, attention, and social problems. The CBCL-parent reports showed the largest effects on social problems and attention problems. Parents often reported attention problems resulting in learning difficulties at school. On the self-reports patients themselves often reported being teased and/or feeling lonely and also having attention problems.

#### • Cardiac diagnosis

No significant differences were found between problem scores of different cardiac diagnostic groups, nor on parents' or patients' self-reports.

#### • Parent-child discrepancies

When directly comparing, within the ConHD sample, reports of patients themselves versus parent reports about them, it was found that significantly more problems were reported by youngsters themselves than by their parents.

#### • Prediction of long-term behavioral/emotional problems

The medical variables that most strongly and significantly predicted long-term behavioral and emotional problems, as reported by parents were: a greater number of heart operations and deep hypothermic circulatory arrest (below 22 degrees Celsius). Other significant predictors were a shorter duration of pregnancy, a relatively lower systemic oxygen saturation, and older age at surgical repair. Thus the greater the presence of these predictor variables, the higher the level of long-term behavioral and emotional problems in these ConHD children and adolescents.

#### • Conclusion

This first follow-up study showed that ConHD children and adolescents operated before 1980 showed unfavorable long-term behavioral and emotional outcomes.

### 2. Study 2: mean level of behavioral and emotional problems<sup>4)</sup>

Compared to a normative group from the general popula-

tion, parents of 7–17-year-old ConHD children reported more problems on the CBCL scales: somatic complaints, social problems, attention problems, Internalizing, and total problems. In contrast, reports of 84 11–17-year-old patients on the YSR were comparable to those of reference peers, which can be considered a favorable outcome.

ConHD boys reported fewer somatic complaints than ConHD girls, but this gender difference was smaller in the ConHD group compared to that in the reference group. This was the only interaction effect of gender by group that was found.

#### • Cardiac diagnosis

On patients' self-reports no significant differences were found between problem scores of different cardiac diagnostic groups. Parents' reports, however, indicated that children with VSD showed more social and externalizing problems than children with ASD and PS. However, no further significant differences between different cardiac diagnostic groups were found.

#### • Parent-child discrepancies

On the scales withdrawn/depressed, social problems, attention, and on the total problem score, significantly more problems were reported by ConHD patients themselves than by their parents. These discrepancies between self and parent reports in the ConHD sample were smaller as those in the general population sample.

#### • Prediction of long-term behavioral/emotional problems

In contrast to the first follow-up study, in which clearly significant predictors emerged, in the second cohort long-term behavioral/emotional problems were only marginally predicted by medical variables.

#### • Conclusion

This second follow-up study showed that parents of ConHD patients reported more long-term behavioral and emotional problems compared to normative data, whereas patients themselves reported no long-term behavioral impairment.

### 3. Historical comparison between historical study 1 and the more recent study<sup>25)</sup>

#### • Background

Overall, results of the second, more recent study seemed more favorable than those of the first, so-called historical study, since in the first study elevated problem levels were found on all problems scales; this was not the case in the second study. However, inclusion criteria and age-ranges

Table 1 Patient characteristics of the Rotterdam “historical” and “recent” patient sample

	Recent CBCL (n = 90)	Historical CBCL (n = 98)	Recent YSR (n = 84)	Historical YSR (n = 123)
Gender				
Boys	45 (50%)	55 (56%)	44 (52%)	73 (59%)
Girls	45 (50%)	43 (44%)	40 (48%)	50 (41%)
Age at follow-up (years ± sd)	12.2 ± 1.5	12.7 ± 1.7	13.0 ± 1.7	14.4 ± 2.0
Cardiac diagnosis				
ASD	22	8	27	18
VSD	38	43	33	43
TGA	21	38	16	44
PS	9	9	8	18
Age at first invasive treatment (years ± sd)				
ASD	3.12 ± 1.32	2.28 ± 2.06	3.60 ± 1.42	3.88 ± 2.09
VSD	0.77 ± 1.10	0.63 ± 0.59	1.01 ± 1.60	1.32 ± 1.67
TGA	0.24 ± 0.60	0.58 ± 0.54	0.23 ± 0.66	0.74 ± 0.73
PS	1.28 ± 0.94	1.40 ± 1.40	1.79 ± 1.37	2.43 ± 1.87
Contacts with mental health care services last two years before follow-up				
Regional institute for outpatient mental health care for youth	10 (11.1%)	5 (5.1%)	NA	NA
Department of child and adolescent psychiatry	6 (6.7%)	2 (2.0%)	NA	NA
Social worker	2 (2.2%)	4 (4.1%)	NA	NA
Psychologist, pedagogue(private clinic)	6 (6.7%)	13 (13.3%)	NA	NA

CBCL: Child Behavior Checklist, YSR: Youth Self-Report, sd: standard deviation, ASD: atrial septal defect, VSD: ventricular septal defect, TGA: transposition of the great artery, PS: pulmonary stenosis, ConHD: congenital heart disease, TACQOL: TNO-AZL Child Quality of Life Questionnaire, NA: not available

differed between both studies and moreover a more recent reference group was used in the second study. This hampered directly comparing outcomes from these studies.

Since 1980 many aspects of medical treatment for ConHD have been improved. All these changes were believed to result in improved cardiac outcome. Our hypothesis was that improvements in medical care would also result in more favorable psychosocial outcomes for children with ConHD treated recently, compared to patients operated before 1980.

#### • Aim

Our aim was: to make a historical comparison between the level of the behavioral and emotional problems of our second sample (treated between 1990 and 1995) and the historical sample operated between 1968 and 1980.

#### • Methods

For this aim we used the same, comparable diagnostic groups (ASD, VSD, TGA and PS), selected on the same in- and exclusion criteria (see above) and the same age-range: 10–15 years.

#### • Patients

Patient characteristics of both samples are presented in Table 1. As to the distribution of gender, age at first treatment and contacts with mental health care services, no significant differences were found between the recent and historical sample. However, since differences were found as to cardiac diagnosis and age at follow-up between the historical and recent sample (Table 1), in statistical analyses these variables were controlled for.

#### • Results

On no scale of the CBCL-parent report a significant difference was found between the recent and historical sample. On the YSR, only on the scale withdrawn/depressed was a small group effect found, indicating that ConHD children in the recent sample showed significantly fewer problems on withdrawn behavior and depressive complaints than children in the historical sample.

#### • Conclusion historical comparison

(1) Despite evident improvements in the medical treat-

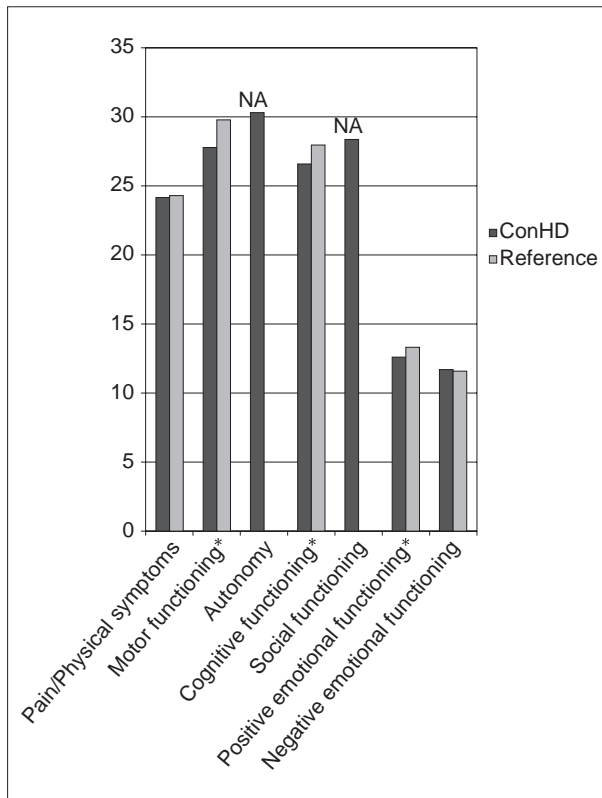


Figure 1. Results on health-related quality of life self-reports (TACQOL child-form) for ConHD sample and reference group, for ages 8–15 years.

\*Significant ( $p < 0.05$ ) difference between ConHD sample and corresponding reference group  
NA: for these scales normative data were not available

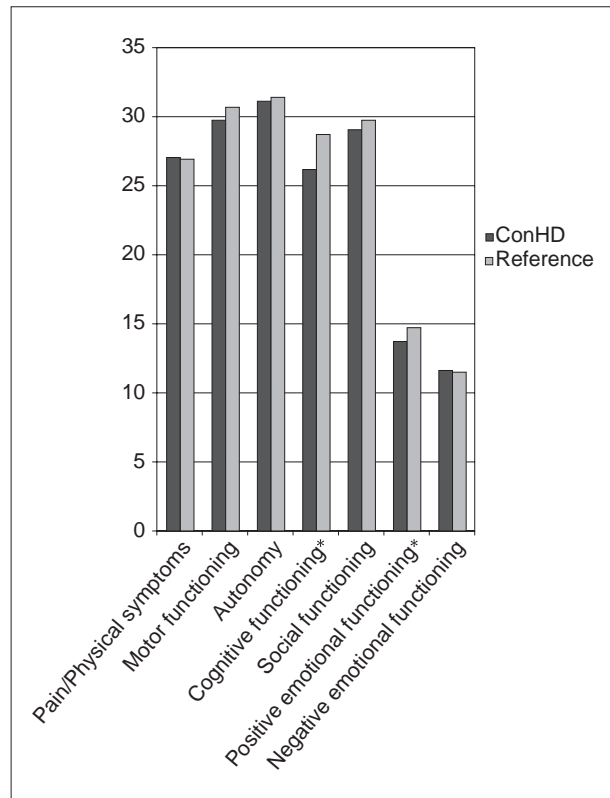


Figure 2. Results on health-related quality of life parent reports (TACQOL parent-form) for ConHD sample and reference group, for ages 8–11 years.

\*Significant ( $p < 0.05$ ) difference between ConHD sample and corresponding reference group

ment of ConHD, overall no significant improvement was found as to behavioral/emotional outcomes between our ConHD children treated recently versus our first cohort, operated before 1980.

(2) No differences were found between the recent and historical sample in contact seeking with mental health professionals (social workers, psychologists, etc.) for emotional/behavioral problems of patients.

#### 4. Study 2: HRQoL<sup>3)</sup>

Since relatively little was known about HRQoL in children with ConHD, this domain was also investigated in the second study. The concepts “health status” and “HRQoL” are often used as equivalents. Health status, however, refers to assessment by a person of his actual, *objective* problems in functioning, whereas HRQoL is a multidimensional construct, which includes the person’s *subjective*, emotional evaluation of and reaction to such problems.

#### • Results

Figure 1 illustrates that on the self-reports, 8–15-year-old ConHD children obtained significantly lower scores, thus reporting poorer functioning compared to a normative group, on motor, cognitive, and positive emotional functioning. Figure 2 shows that parents of 8–11-year-old patients reported significantly poorer outcomes on cognitive and positive emotional functioning, compared to parents from the general population.

#### • Impact of gender, cardiac diagnosis, and type of treatment

No differences were found between cardiac diagnostic groups, and no differences were found between ConHD boys versus girls, and neither on the child’s nor on the parents’ reports of HRQoL. Furthermore, no differences were found between children treated by surgical intervention (ASD, VSD and TGA) and those treated by catheter intervention (PS). However, we must be careful in drawing firm

conclusions considering the small number of patients with PS (N = 12).

- Parent-child discrepancies on HRQoL

ConHD children reported significantly poorer quality of life than their parents did regarding them, on four of the seven scales: 1) pain and physical symptoms, 2) motor functioning, 3) autonomy, and 4) positive emotional functioning.

- Conclusion

Findings on HRQoL reflect poorer functioning on motor, cognitive, and positive emotional functioning. Furthermore, HRQoL results are in line with those on emotional and behavioral functioning, indicating that ConHD youngsters themselves report more problems than parents report about them.

## 5. Study 2: parental wellbeing and styles of coping<sup>6)</sup>

- Aim

In the second study we also studied parental wellbeing and parental styles of coping.

- Methods

The General Health Questionnaire (GHQ)<sup>11)</sup> was used to assess parental wellbeing and the Utrecht Coping List to assess coping styles.<sup>12)</sup>

- Results

Parents of our recent sample showed better wellbeing on the GHQ (N = 100 mothers, 61 fathers). They reported less distress, i.e., fewer somatic symptoms, less sleeplessness/anxiety and less serious depression, compared to normative reference groups.

Parental coping styles (N = 103 mothers, 59 fathers) were similar to those of reference groups. Parents less often used reassuring thoughts and less often expressed negative emotions.

- Conclusion

Overall parental outcomes were favorable, or even better compared to reference groups.

## Conclusion and discussion

### 1. Overall, elevated levels of behavioral and emotional problems and poorer HRQoL were found for children and adolescents with ConHD

Our “historical comparison” study was the first study directly investigating recent and historical outcomes, using the same cardiac diagnostic groups and the same standardized procedures. Results indicated that despite medical improvements over the past decades, children with ConHD are still

at risk for behavioral and emotional problems. Our findings are in line with those of international research; a meta-analysis<sup>13)</sup> demonstrated that older children (from 10 years of age and older) and adolescents with ConHD display an increased risk, overall, internalizing and to a lesser extent externalizing behavior problems than controls.

In addition, international research has shown neuropsychological and cognitive sequelae in children with ConHD.<sup>7, 14)</sup> A review<sup>14)</sup> shows that the largest group of children with isolated congenital heart defects presents with overall normal intellectual capacities, but ConHD children also tend to show language deficits and motor dysfunction.<sup>14)</sup> In line with this review, patients from our second study obtained IQ-scores that fell within the “normal range”, but showed deficits on verbal intelligence, verbal comprehension, and a poorer HRQoL as regards motor functioning.<sup>3, 7)</sup> Cognitive deficits are known to be associated with elevated levels of behavioral and emotional problems.<sup>1)</sup>

Several pre-, peri- and postoperative factors are predictors of intellectual and developmental impairments after open-heart surgery for ConHD. Preoperative risk factors encompass, for example: genetic factors (syndromes), neurobehavioral abnormalities before surgery, prematurity, structural brain injury (such as periventricular leukomalacia) and severity of disease. (International research shows that children with hypoplastic left heart syndrome, having had surgery with deep hypothermic circulatory arrest, perform more poorly on cognitive outcomes than children with other congenital heart defects<sup>14)</sup>). Peri-operative factors involve age at operative repair, deep hypothermic arrest versus low-flow cardiopulmonary bypass, pH management during core cooling, and postoperative factors. Postoperative factors of influence are: number of heart operations, length of stay in cardiac intensive unit, and short- and/or long-term complications (such as EEG –seizures).<sup>2, 14)</sup>

In addition, parental anxiety and overprotection may negatively influence the emotional adjustment of ConHD children. Clinical experience has shown that for parents the symbolic meaning of “a heart defect” is still associated with underlying fear of sudden death of the child and concerns for the future. An overprotective parenting style in ConHD may be a possible risk factor for internalizing problems. Alternatively, hormonal and brain changes during adolescence, triggering the expression of genetic vulnerabilities in combination with potential stressful disease experiences may increase behavior problems.<sup>13, 15)</sup> Majnemer and colleagues<sup>16)</sup>

found that five years following open heart surgery in infancy, many parents continue to feel either stressed or defensive about their child, particularly if the child exhibits behavioral difficulties.

Considering all the findings above, we conclude that multiple factors interact together in the development of emotional and behavioral problems in children with ConHD.

## 2. In both studies, overall no effect was found of cardiac diagnosis on behavioral/emotional outcomes

With regard to our “historical comparison”: the distribution of cardiac diagnoses and mean age at follow-up differed between the recent and the historical sample. However, it appeared that these variables did not influence our results, when they were adjusted for in statistical analyses. Our results as to cardiac diagnosis are in line with those of international research findings. A meta-analysis<sup>14)</sup> also shows that psychopathology in ConHD children is not related to disease severity.

In our recent sample patients we found no differences in emotional adjustment between children who were operated with standard cardiopulmonary bypass (ASD, VSD, TGA) versus children who underwent a balloon dilatation (PS). However, numbers of patients with balloon dilatation were very small. Furthermore, to what extent differences in operative procedures influenced our findings is unknown.

## 3. In both studies, ConHD children/adolescents reported more problems than their parent did about them

A possible explanation for these results is that ConHD adolescents tend to struggle with their problems by themselves, so that their problems become less visible to their parents. In our general population, however, this same phenomenon is known that adolescents tend to report more problems on the YSR than their parents do about them.<sup>17)</sup> Moreover, in the recent sample the discrepancies between parent-child reports were smaller in the ConHD sample, compared to the general population.

## 4. The second study showed favorable parental wellbeing and styles of coping

These results were in line with those from another Rotterdam cohort study into parents of younger ConHD children who underwent elective cardiac surgery or catheter intervention.<sup>18)</sup> In this study, using the same assessment instruments, parents also reported significantly lower levels of psycho-

logical distress than reference groups, 19 months after an elective cardiac procedure in their children. An explanation for the favorable results on parental well-being may be that parents may have left behind the very frightening period and stressful period, in which they were confronted with the diagnosis of ConHD and a cardiac procedure for their child. Because of this overwhelming experience parents may have developed other values and norms than parents in the general population; this phenomenon is called: response shift.<sup>19)</sup> The past experiences of a cardiac procedure in their child may have made parents stronger and may have resulted in an attitude of worrying less about futurities in life.

## 5. Clinical implications

Considering the findings of the Rotterdam follow-up studies, the following guidelines for clinical practice in counseling children and adolescents with ConHD and their parents can be given.

### • Screening

Regarding the poorer behavioral/emotional functioning of the ConHD children and HRQoL as to cognitive and motor functioning, we recommend early (neuro-developmental) screening, by a standard follow-up, to identify children at risk. This should be done preferably at young age since psychopathological problems are less persistent and better treatable at a younger age. Then adequate service can be provided to prevent the development of additional problems.

### • Multi-informant approach

Patients themselves reported more problems than their parents did about them, both as to behavioral/emotional functioning and as to HRQoL. Therefore we recommend a multi-informant approach, including information from ConHD children, their parents, and also their teachers. In the second study deficits as to verbal intelligence and verbal comprehension were found.<sup>7)</sup> Therefore it is important to include teachers as informants in order to detect learning problems or attention problems at an early stage. If necessary, remedial teaching or other interventions can then be undertaken.

### • Motor functioning

The second study showed poorer motor function,<sup>3)</sup> as reported by ConHD children themselves. Motor dysfunction was also reported in a review.<sup>14)</sup> Considering these problems, monitored physical training or a cardiac rehabilitation program can be a worthwhile intervention to help patients with poor physical condition to feel more secure about their

bodily functioning and to discover their physical boundaries.

• Attention to parents at risk

Overall, our present parents' results were favorable, but with progressing medical possibilities and more complex cardiac defects becoming operable, we need to remain alert for individual parents at risk of adjusting poorly.

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