Motor Development in Children with Congenital Cardiac Diseases

a report by

Birna Bjarnason-Wehrens, Sandra Schmitz and Sigrid Dordel

1. Institute for Cardiology and Sports Medicine; 2. Institute for School Sports and School Development, German Sport University, Cologne

Congenital malformations of the heart and vessels occur in five to nine per 1,000 live births.1 Some of these malformations (10–15%) do not require correction. Between 70 and 80% of defects can be corrected, and an increasing number of therapeutic procedures can be performed by interventional catheterisation techniques, avoiding the need for open heart surgery.1 Definitive therapeutic procedures are increasingly carried out in early infancy in order to avoid long-term complications resulting from the haemodynamic burden or from chronic cyanosis.2 Progress in the treatment of congenital heart disease (CHD) has led to a dramatic reduction of mortality.3 With improved survival, the focus of follow-up care has to shift from assessment of procedure-related mortality towards assessment of long-term quality of life. Preventive diagnostics and treatment have to be initiated early, aiming to find deficits and alleviate them through the use of specific measures. Motor development is one of the fields on which diagnostics and treatment must focus.4 Increased attention should also be given to the question of whether and to what extent physical activity should be recommended in order to improve quality of life. This article focuses on the impact of physical activity on motor development in children with congenital malformations of the heart.

Motor Development in Children

Children have a basic need for motor activity. Their perceptual and motor experience not only determines their physical, psychosocial and cognitive development. In contrast, physical inactivity in childhood is abnormal – regardless of whether it is due to physical, emotional, psychosocial or cognitive factors.5,6 The development of motor skills in children (infants, pre-school and school-age) takes place as a result of activity within an interaction between the person and his or her environment. Children influence their environment in an active way, and at the same time adapt their behaviour to their personal and material environment. In this way, children are the designers of their own development. Children’s elementary need to move is biologically based and guaranteed by the dominance of central nervous excitation processes. Movement serves as a catalyst in the child’s development, especially in younger children. A high level of movement ensures the advancement of the child’s physical development, especially the locomotor system, which through movement gains the impulses needed for normal development.

In infants and toddlers, perception and movement are the first possibilities for communication. They express wellbeing, discomfort and dissatisfaction by body movement, mimicking and their voice, and in these ways provoke a reaction from their environment. During the first months and years, the child’s movement abilities and security steadily increase. This results in improved mobility, as well as an enlarged radius of activity, which leads to advances in the child’s independence, self-assurance and self-awareness. Thus, improved perception and mobility significantly contribute to the child’s psycho-emotional stability. A varied tactile and kinaesthetic perception and movement experience is of special importance, since they improve the child’s comprehension as a basis for cognitive development. Attending nursery is associated with increased independence and social competence. Establishing contacts self-confidently, thoughtfulness, co-operation, benchmarking, competence, agreement, abiding by rules and participating in group activities are important behaviours that pre-school children mainly learn by taking part in active games with peers. As early as pre-school age, good motor abilities, skilfulness and strength improve a child’s social reputation with his or her peers, thereby improving self-confidence and supporting the development of emotional stability and a positive self-image; this is even more pronounced at early school age.6 Thus, perception and motor activities are catalysts not only for the child’s physical development, but also for his or her emotional, psycho-social and cognitive development. Deficiency in this field might affect the child’s entire personal development in a negative way.5,7

The Impact of Heart Disease on Motor Development

Often, cardiac disease means a restriction of the affected child’s perceptual and motor experience. Complex and severe heart defects may – at least temporarily – cause reduced symptom-limited exercise tolerance and therefore require a certain amount of rest. Times of inpatient examinations or corrective operations are always periods of more or less strict immobilisation. Depending on their duration and the child’s age and mental stability, cardiac diseases can lead to developmental stagnation or regression. Anxiety and worries about the ill child often cause parents to adopt overprotective behaviour. Great uncertainty exists, especially with regard to the danger to which one might expose children by allowing them to engage in physical activity. This is often – unnecessarily – also the case with children whose physical capacities are grossly normal.5,7 Figure 1 shows the conditional network of possible causes and effects of physical inactivity in children with heart diseases.

Numerous studies have investigated exercise tolerance in children with various forms of congenitally malformed hearts.6,8-20 Depending on the severity of the malformation, the success of corrective procedures and the presence and degree of residual sequelae, physical performance may be limited. Even children with mild uncorrected lesions, or those without...
residual sequelae after previous surgery, may reveal a substantial reduction in their physical performance. Relatively few studies have focused on the motor development of children with congenitally malformed hearts.

Below and in Table 1, the main results of studies investigating fine and gross motor development in children with CHD are summarised. Bellinger et al. demonstrated a retardation of psychomotor development at one year and at four-year follow-up after an uncomplicated neonatal arterial switch operation for transposition of the great arteries (TGA). The duration of total circulatory arrest (CA) was closely linked to gross motor skills, but not to fine motor skills. Distinctive limitations in fine motor skills and visual–spatial skills were observed at eight-year follow-up in the same patient cohort. Stieh et al. discovered significant deficits in gross and fine motor development in children with cyanotic heart defects as opposed to children with acyanotic heart diseases. The percentage of patients with cyanotic congenital malformations who scored with moderate and severe gross motor disturbances decreased after corrective surgery from 39 to 21% and from 46 to 33%, respectively. Children who were under 24 months of age at the time of corrective surgery scored better than those operated on later (motor quotient [MQ] 89.2±13.6 versus 75.6±15.3; p<0.05), indicating that the duration of hypoxaemia may also be an important factor influencing motor development. In contrast to the data of Stieh et al., other study groups have found deficits in gross and fine motor skills for both cyanotic and acyanotic heart defects. An earlier investigation from our study group involving 38 children with different diagnoses and varying levels of severity showed that 63.2% of the sample had significant decrees in gross motor skills. The results demonstrate that 75% of the children with cyanotic and 42% of the children with acyanotic heart defects had a moderate (25 and 26.3%, respectively) or severe (50 and 15.8%, respectively) delay in motor development. Unverdorben et al. demonstrated comparable results. Children with CHD scored significantly worse compared with healthy peers. Unverdorben et al. also observed that, independent of the severity of the disease, children who were excused from physical education classes showed significantly reduced motor performance compared with children participating in physical education in school.

In a recently published study from our group, the motor development of 194 subjects with congenital malformations of the heart was compared with that of a representative control group of healthy peers. The classification of motor development demonstrated 58.7% of the children with heart disease to have moderate to severe deficits in gross motor skills and 31.9% to have severe deficits. In contrast, the test revealed 78.1% of the healthy peers to have motor development that was normal or above average for their age. In the group of children with CHD, no differences were found for gender, but older children (11–15 years of age) had more severe deficits compared with younger children (five to 10 years of age; p=0.01). The mean age- and gender-adjusted MQ was significantly lower in the group of children with CHD compared with the control group. This was seen in the children with significant residual sequelae as well as in those with no or mild residual sequelae. Our findings also confirmed the findings of Stieh et al. that children with cyanotic CHD have a significantly lower mean MQ than children with acyanotic heart disease. However, in contrast to the results of Stieh et al., our investigation showed a significantly lower mean MQ in children with cyanotic as well as acyanotic defects compared with healthy peers. Children who had undergone open heart surgery had a lower motor performance than those without open heart surgery; however, both subgroups scored significantly lower than the healthy peers. In preliminary published results from our study group, Schmitz et al. demonstrated a significant delay in fine motor development in children with congenital malformations of the heart compared with a representative group of healthy peers. This was especially true for the fine motor abilities hand unrest/tremor and precision of arm–hand movements. The results indicate that the status after open heart surgery, as well as the presence and/or degree of residual sequelae, may influence fine motor development. Pre-operative persistent low cardiac output, acidosis and/or hypoxia, as well as the duration of hypothermic circulatory arrest during surgery, may contribute to this.

The impact of a congenital cardiac malformation on the development of the affected child depends on the type and severity of the malformation as well as the timing and success of therapeutic measures. For some complex malformations with single-ventricle physiology, only palliative solutions are available. Lesions such as tetralogy of Fallot, atrio-ventricular septal defect and TGA can be successfully corrected in infancy with good long-term outcome. After successful correction in infancy, most children born with cyanotic congenital malformations are able to participate in all normal age-appropriate physical activities with their healthy peers. While restrictions regarding physical activity may be recommended in children with significant post-operative clinical findings, the group of children with no or mild residual sequelae do not require any restrictions and should be taking part in normal physical activity. It is well recognised that neurological impairment may be caused by pre-operative persistent low cardiac output, acidosis and/or hypoxia, or by ischaemia related to surgery. The duration of hypothermic circulatory arrest during surgery and the duration of a persistent low-output state requiring intensive medical care after surgery are associated with later neurological deficits.

This does not explain the deficits in motor development observed in children with CHD. The main studies cited excluded all children with recognised syndromes, disabilities or co-morbidities that might have affected their motor development. This was also true for all children with obvious mental retardation or abnormal neurological development from other causes. It is more likely that a significant proportion of the deficits in motor development observed are primarily due to lack of efficient perception and
Table 1: Summary of the Main Results of Studies Investigating Fine and/or Gross Motor Development in Children with Congenital Heart Disease

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study Group</th>
<th>Subgroups</th>
<th>Control Group</th>
<th>Test Procedures</th>
<th>Main Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bellinger et al.</td>
<td>Infants after an neonatal</td>
<td>Random assignment to vital organ support strategy used in infant heart surgery:</td>
<td>None</td>
<td>Psychomotor Development Index of the Bayley Scales of</td>
<td>n=55 (age 1 year)&lt;sup&gt;26&lt;/sup&gt;; Mean score 95.1±15.5; a) scored significantly lower than b; – mean difference 6.5 (95% CI 1.6–11.5; p=0.001). PDI inversely related to the duration of circulatory arrest (p=0.02)</td>
</tr>
</tbody>
</table>
|                  | arterial switch operation for TGA | a) Circulatory arrest (CA)  
  b) Low-flow cardiopulmonary bypass (LFB) |               | Infant Development (PDI)<sup>27</sup>; scored significantly lower for TGA in infant heart surgery: Infant Development (PDI)<sup>31</sup> |                                                                 |
|                  |                              |                                                                           |               |                                                      |                                                                 |
| Stieh et al.     | Various forms of CHD:        | i) Uncorrected cyanotic CHD (i.e., after palliative surgery):  n=16  
  ii) Cyanotic CHD after corrective surgery:  n=25  
  iii) Acyanotic CHD before corrective surgery:  n=4 (not analysed)  
  iv) Acyanotic CHD after corrective surgery:  n=32  
  v) Acyanotic CHD without haemodynamic significance:  n=25 |               | Peabody Developmental Motor Scales (Pdms);<sup>32</sup> Grooved Pegboard (GP)<sup>33</sup> | n=158 (age 4 years)<sup>29</sup>; Pdms: duration of CA inversely related to gross motor (p=0.06) but not to fine motor (p=0.23) score Time to complete (GP) slower in a) compared with b) (p=0.006)                                                                 |
|                  | n=102 (53 male, 49 female) 5–14.11 years of age | i) MQ=74.8±11.7 versus CG 102.8±11.8 (p<0.05)  
  ii) MQ=81.2±16.6 versus CG (p<0.05)  
  iii) MQ=101.1±16.6 versus CG (p=ns)  
  iv) MQ=103.3±13.6 versus CG (p=ns)  
  v) MQ=117.4±20.4 (p<0.01)  
  ZP: i) 87.7±9.9 versus CG 106.5±10.8 (p<0.01)  
  ii) 97.1±17.0 versus CG (p<0.01)  
  iii) 108.8±22.3 versus CG (p=ns)  
  iv) 114±25.9 versus CG (p=ns)  
  v) 118.6±16 versus CG (p=ns) |               | Body co-ordination test for children<sup>28</sup> (Körperkoordinationstest für Kinder (KTK))  
  Zielpunktiertest (dotting) (ZP); Kamel nachfahrtest (camel drawing test) (KA) | n=30 children with innocent heart murmur (14 male, 16 female) 5–14 years of age |                                                                 |
|                  |                              |                                                                           |               |                                                      |                                                                 |
| Dordel et al.    | Various forms of CHD:        | a) Cyanotic CHD:  n=12  
  b) Acyanotic CHD:  n=19  
  c) Mild RS:  n=12  
  d) Severe RS:  n=14 |               | Body co-ordination test for children<sup>30</sup> (Körperkoordinationstest für Kinder (KTK)) | n=31 children with no or mild RS 5–14 years of age | MQ=83±16.4 versus post-t 92.9±18.2 (p<0.001)  
  a) 75±11.5 versus post I 87.5±18 (p<0.001)  
  b) 88.1±17.3 versus post I 96.4±18 (p<0.001)  
  c) 98.4±15.3 versus post I 99.6±14.4 (p<0.001)  
  d) 83.6±15.5 versus post I 92.9±19.2 (p<0.001) |                                                                 |
|                  | n=31 (22 male, 9 female) 7–14 years of age | Intervention (I): 8 months’ participation in children’s heart group (75 minutes once weekly) |               |                                                      |                                                                 |
| Unverdorben et al. | Various forms of CHD:        | a) No or mild RS  
  b) Severe RS  
  c) Excluded from PE  
  d) Participating in PE | n=774 age-matched healthy children | Co-ordination test by Bös/Mechling (BKT)<sup>30</sup> | n=27 children with no or mild RS 10.5±1.2 years of age | CHD: 6.4±2.3 versus CG 10.1±3 (p<0.001)  
  a) 7.1±2 versus b) 5.5±0.6 (p=0.05)  
  c) 5.5±0.6 versus d) 6.9±2.3 (p=0.05) |                                                                 |
movement experience due to restrictions in physical activity. Overprotective behavior in the children’s parents and teachers could be the main reason for the observed deficits. Parents and other care-givers play an important role in children’s development, and the child’s health status is one factor that might influence parenting style. The parent’s attitude may significantly influence the child’s whole development, as well as his or her coping strategies. Parents of children with CHD may alter their child-rearing strategies to assimilate the child’s special needs. Parental anxiety often leads to overprotective behavior. A recent study revealed that mothers of children with CHD report higher levels of vigilance with their children than mothers of healthy children of the same age. Parental anxiety and overprotectiveness may reduce the child’s exposure to peers, not least regarding physical activity, which might influence the child’s social competence and motor development and cause retardation. Parents of children with CHD are more likely to report elevated levels of parenting stress compared with the normal population. This high level of stress is unrelated to the severity of the child’s disease. Parents of children with less severe malformations experience as much stress as parents of children with more complex heart defects. Parenting stress tends to be higher in parents with older children, as increasing age of the child makes it more difficult for parents to set limits and maintain control. Mothers are most concerned about the medical prognosis of their child, but also have concerns regarding the child’s quality of life, including aspects such as functional and physical limitations.

The Impact of Special Psychomotor Training Programmes

Results of empirical studies show that the physical performance and motor skills of children and adolescents with CHD can be enhanced through regular engagement in autonomous or supervised physical activity. These results also demonstrate that such participation not only improves physical performance and motor abilities, but also positively influences the child’s emotional, psychosocial and cognitive development. Figure 2 illustrates how possibly negative consequences of the disease can be compensated through the improvement of motor abilities and skills by special motor training programmes. Participation in specific, possibly medically supervised programmes for the promotion of motor abilities can help to limit motor deficits and prepare and support the integration of children into their peer group. In Germany, special therapeutic services have been launched to promote psychomotor skills in children with CHD. The Children’s Heart Group (CHG) is a medically prescribed, supervised outpatient therapy option led by a qualified exercise therapist. Children in need of this therapy are given the opportunity to be physically active in a medically supervised ‘protected area’. Here, potentially existing psychomotor deficits can be identified and treated. The primary aim of such programmes is to improve perceptual and movement experience in order to compensate for existing deficits. The children gain knowledge about their physical limitations: they learn to become aware of their physical reactions to high load and learn how to respond accordingly. Most children need only short-term participation (90–120 sessions or units). For children who, as a result of the severity of their disease, urgently require medical supervision during physical activity, longer-term participation (possibly for years) is desirable and practical in order to provide a means for them to be physically active at all. In 31 children with various types of CHD who participated in a specific psychomotor training programme for eight months, with one 75-minute exercise unit per week, significant improvements in their motor performance were achieved. The number of children classified with deficits in motor performance decreased from 54.8 to 29.0%. In a recent study, revealed that mothers of children with CHD report higher levels of vigilance with their children than mothers of healthy children of the same age. Parental anxiety and overprotectiveness may reduce the child’s exposure to peers, not least regarding physical activity, which might influence the child’s social competence and motor development and cause retardation. Parents of children with CHD are more likely to report elevated levels of parenting stress compared with the normal population. This high level of stress is unrelated to the severity of the child’s disease. Parents of children with less severe malformations experience as much stress as parents of children with more complex heart defects. Parenting stress tends to be higher in parents with older children, as increasing age of the child makes it more difficult for parents to set limits and maintain control. Mothers are most concerned about the medical prognosis of their child, but also have concerns regarding the child’s quality of life, including aspects such as functional and physical limitations.

The Impact of Special Psychomotor Training Programmes

Results of empirical studies show that the physical performance and motor skills of children and adolescents with CHD can be enhanced through regular engagement in autonomous or supervised physical activity. These results also demonstrate that such participation not only improves physical performance and motor abilities, but also positively influences the child’s emotional, psychosocial and cognitive development. Figure 2 illustrates how possibly negative consequences of the disease can be compensated through the improvement of motor abilities and skills by special motor training programmes. Participation in specific, possibly medically supervised programmes for the promotion of motor abilities can help to limit motor deficits and prepare and support the integration of children into their peer group. In Germany, special therapeutic services have been launched to promote psychomotor skills in children with CHD. The Children’s Heart Group (CHG) is a medically prescribed, supervised outpatient therapy option led by a qualified exercise therapist. Children in need of this therapy are given the opportunity to be physically active in a medically supervised ‘protected area’. Here, potentially existing psychomotor deficits can be identified and treated. The primary aim of such programmes is to improve perceptual and movement experience in order to compensate for existing deficits. The children gain knowledge about their physical limitations: they learn to become aware of their physical reactions to high load and learn how to respond accordingly. Most children need only short-term participation (90–120 sessions or units). For children who, as a result of the severity of their disease, urgently require medical supervision during physical activity, longer-term participation (possibly for years) is desirable and practical in order to provide a means for them to be physically active at all. In 31 children with various types of CHD who participated in a specific psychomotor training programme for eight months, with one 75-minute exercise unit per week, significant improvements in their motor performance were achieved. The number of children classified with deficits in motor performance decreased from 54.8 to 29.0%. In a recent study, revealed that mothers of children with CHD report higher levels of vigilance with their children than mothers of healthy children of the same age. Parental anxiety and overprotectiveness may reduce the child’s exposure to peers, not least regarding physical activity, which might influence the child’s social competence and motor development and cause retardation. Parents of children with CHD are more likely to report elevated levels of parenting stress compared with the normal population. This high level of stress is unrelated to the severity of the child’s disease. Parents of children with less severe malformations experience as much stress as parents of children with more complex heart defects. Parenting stress tends to be higher in parents with older children, as increasing age of the child makes it more difficult for parents to set limits and maintain control. Mothers are most concerned about the medical prognosis of their child, but also have concerns regarding the child’s quality of life, including aspects such as functional and physical limitations.
Paediatric Cardiology

Figure 2: Compensation of Negative Consequences of Congenital Heart Disease by Means of Goal-orientated Improvement of Motor Development

Conclusion

In conclusion, the results of the available studies show that it is necessary to pay attention to the motor development of children with congenital malformations of the heart. This applies to gross as well as fine motor abilities. The results demonstrate that deficits in motor development occur not only in children with significant post-operative clinical findings, but also in those with no or only mild residual sequelae and/or acyanotic heart disease. Most of these children do not necessarily require any restrictions regarding their physical activity due to the heart disease. Paediatricians, cardiologists and others who care for these children should co-ordinate their focus on their future motor development in order to identify deficits as early as possible and, if necessary, to implement appropriate therapeutic measures. It is therefore crucial to take sufficient time and patience to educate parents regarding their child’s physical activity and education. To avoid anxiety and overprotective parenting, as well as to reduce concerns about physical limitations and safe activities, physicians should regularly address these issues when talking to the parents and provide clear and comprehensive advice, as well as giving the parents the opportunity to bring up their own concerns and special questions. Improvement of physical activity in children with CHD should start as early as possible. In this way deficits in perceptual and motor experience and their negative consequences can be minimised. Children need to be provided with the opportunity to act out their basic need for physical activity and should be stopped only if there is a specific danger of sudden death. Over-worried parents should be encouraged to grant their children enough independence for exercise and trust their own judgement. Children with CHD should therefore participate in physical activity (indoors and outdoors) with their peers in an unrestricted fashion, as far as possible. This applies to play and guided activity in nursery, school and/or sports clubs. Numerous groups of experts have provided recommendations concerning exercise for children with CHD. These recommendations can contribute to the avoidance of unnecessary exclusion of children and adolescents with heart diseases from physical activity and sport. Moreover, they can minimise the insecurities of children, parents and teachers with regard to the affected child’s physical abilities.
European Society of Cardiology
Future Congresses

Versailles, France - 25-28 October 2008
www.escardio.org/AcuteCC

Lyon, France - 10-13 December 2008
www.euroecho.org

Berlin, Germany - 21-24 June 2009
www.escardio.org/EHRA

Barcelona, Spain - 29 August - 2 September 2009
www.escardio.org

Nice, France - 30 May-2 June 2009
www.escardio.org/HFA

Barcelona, Spain - 10-13 May 2009
www.icnc9.org

Dublin, Ireland - 24-25 April 2009
www.escardio.org/Nursing

Stockholm, Sweden - 6-9 May 2009
www.escardio.org/EuroPrevent

www.escardio.org