Pre-operative neurodevelopmental assessment in young children undergoing cardiac surgery in central South Africa: feasibility and clinical value

Robyn Smith, Veronica Ntsiea, Stephen Brown, Joanne Potterton

Abstract

**Background**: Pre-operative neurodevelopmental assessment in children with congenital heart disease may assist in the early identification of children at risk for or presenting with developmental delays. This study determined the pre-operative neurodevelopmental status of young children undergoing cardiac surgery in central South Africa. Feasibility and clinical value of pre-operative assessment were also evaluated.

**Methods**: Children 30 months and younger, scheduled to undergo cardiac surgery, were recruited into this prospective observational analytical study. Neurodevelopmental status was assessed using the Bayley-III and neuromotor examination. Variables associated with developmental performance were determined using ANOVAs. Sociodemographic and medical information were collected using a self-developed questionnaire. Pre-operative neurodevelopmental assessment was completed for 40 children at a median age of 7.4 months, including 30 children without and 10 with Down syndrome. Mean cardiac disease severity was moderate. The inclusion rate for pre-operative developmental assessment was 68%, limited mainly by environmental barriers.

**Results**: Children with Down syndrome had significantly poorer motor ($p < 0.0001$), cognitive ($p < 0.0001$) and language ($p < 0.001$) performance compared to children without Down syndrome. Apart from Down syndrome, disease severity ($p = 0.02$), younger age at first cardiac surgery ($p < 0.01$) and growth failure ($p = 0.04$) were significantly associated with poorer cognitive, language and motor performance, respectively. Just more than half of the children without ($n = 16$) and all children with Down syndrome ($n = 10$) scored below one standard deviation of the test mean score (scores $< 85$) on at least one of the Bayley-III subscales, meeting the criteria for referral to rehabilitation therapies, including physiotherapy, occupational therapy and/or speech therapy.

**Conclusion**: Pre-operative neurodevelopmental assessment may be of high importance in South Africa to identify children at developmental risk, facilitating early referral to rehabilitation therapies.

**Keywords**: congenital heart disease, pre-operative neurodevelopmental assessment, developmental delay, rehabilitation therapies

Medical and surgical advances have significantly reduced mortality rates in children born with congenital heart disease (CHD), leading to improved survival rates. This has shifted the focus to longer-term outcomes, including neurodevelopment. There is convincing evidence that CHD survivors are at higher risk for developmental delay than the general population, with as many as half of children presenting with neurodevelopmental difficulties. Early developmental difficulties include impairments in gross and fine motor skills, cognition and language. Pre-operative growth failure is common in children with CHD and is associated with developmental delay. Aspects contributing to developmental delays are often multifactorial, interrelated and cumulative over time.

Until recently neurodevelopmental outcome-based research in the CHD population has focused on the impact of peri- and post-operative factors on neurodevelopmental outcome, based on the premise that the central nervous system was intact prior to cardiac surgery. There is growing evidence that many children with CHD have abnormal or delayed brain development, making them more vulnerable to acquired brain injury. Prenatal genetic disorders and altered foetal circulation can cause delayed brain development, while postnatal hypoxia and haemodynamic disturbances can result in white matter and focal brain injury. Contemporaneous to surgical and medical advances and improved survival, neurodevelopmental problems were increasingly being identified in survivors, suggesting that risks related to the cardiac surgery itself played a limited role in the neurodevelopmental morbidity seen in CHD survivors. This served to highlight the possible importance of abnormal brain development in determining neurodevelopmental outcomes.
Pre-operative screening for brain abnormalities and neurodevelopmental delay rarely occur in clinical practice, with only a few research studies having reported on neurodevelopmental performance in children with CHD prior to cardiac surgery.16-20 CHD disease severity is variable. For children who are critically ill or require emergency cardiac surgery, pre-operative neurodevelopmental assessment is not feasible. However, for those children who are medically stable, the feasibility, clinical value and format of pre-operative neurodevelopmental assessment remains poorly established.21-27

Pre-operative neurodevelopmental assessment in medically stable children with CHD may have several benefits, including the early detection of children at increased risk of brain injury and those presenting with neurodevelopmental delays prior to cardiac surgery.3,16-20,24 Pre-operative identification of children at risk for or presenting with development delays can inform future developmental care planning, including early referral for formal developmental evaluation, and where indicated, referral to rehabilitation therapies (physical, occupational and speech therapy) to address identified developmental delays.8,1728

Furthermore, the availability of pre-operative neurodevelopmental data allows for the monitoring of changes in neurodevelopmental status after cardiac surgery, providing information on the impact of peri-operative and post-operative factors on neurodevelopmental outcome.2031 The value of pre-operative neurodevelopmental assessment in predicting later developmental outcome is unknown as historically longitudinal outcome studies have only included post-operative neurodevelopmental assessments.2 Recently there has been increased focus on including pre-operative neurodevelopmental assessment where feasible and safe to do so, in order to better determine the value thereof as a potential indicator of later neurodevelopmental performance.28,31,37

Many children with CHD in South Africa are exposed to multiple risks for poor developmental outcome in addition to their CHD. These risks include poverty, maternal stress and depression, low levels of maternal education and poor socio-economic environments.20,28 These risks are strongly associated with the long-term outcomes of children with CHD.29 Paediatric cardiac services in South Africa are overburdened, often resulting in extended waiting periods for cardiac surgery.2,23 In light of this, it is considered important to determine the feasibility, clinical value and format of pre-operative neurodevelopmental assessment in medically stable children with CHD in South Africa as it may assist in the early identification of developmental delays and facilitate the initiation of individualised rehabilitation therapies and parent support while children are awaiting cardiac surgery, potentially improving later neurodevelopmental functioning.20

This study aimed to determine the pre-operative neurodevelopmental status of young children with CHD undergoing cardiac surgery in central South Africa. The study was also poised to provide the first developing-country perspective on recruitment, feasibility, clinical value and format of pre-operative neurodevelopmental assessment.

**Methods**

Forty-one consecutive children younger than 30 months were included in this prospective, observational, analytical study at a large tertiary academic hospital in central South Africa over a 17-month period. The main inclusion criteria were medically stable children with congenital heart defects requiring cardiac surgery. Pre-operative neurodevelopmental assessment was mandatory. Neonates, children who were critically ill, and those who had undergone previous or emergency cardiac surgery were excluded.

Children with genetic disorders were included in the study as a sub-group of special interest. The presence of a genetic disorder is independently associated with developmental delay. The difference in pre-operative developmental status and need for rehabilitation therapies in children without and with Down syndrome (DS) was of interest.26-28 This article reports on the pre-operative phase of a larger longitudinal study that went on to follow up participants at three and six months post cardiac surgery.29

Ethical clearance was obtained from the Health Sciences Research Ethics Committee, University of the Free State (ECUFS 177/2013) and the Committee for Research on Human Subjects, University of the Witwatersrand (M131056). Parents provided written informed consent for their own and their children’s participation. All participant information was kept confidential.

Development was assessed using the Bayley Scales of Infant and Toddler Development (third edition) (Bayley-III) prior to cardiac surgery. The Bayley-III scale assesses development across cognitive, language and motor subscales.32 Scores below one standard deviation of the test mean score of 100 (scores < 85) were used to identify children at risk, and below two standard deviations (scores < 70) as developmentally delayed, qualifying them for referral to rehabilitation therapies.46 Neuromotor examination included the assessment of muscle tone.47 Growth status was assessed using the World Health Organisation (WHO) child growth standards and DS-specific growth charts.2,42,43

Sociodemographic information was collected from parents using a verbally administered questionnaire. Medical information was collected from the child’s medical record. Cardiac disease was categorised according to the nature of the defect and the medical severity was rated using the Cardiologist’s Perception of Medical Severity scale.4445 Socio-economic status was calculated using the Hollingshead index of social position.48 Parenting stress was measured using the Parenting Stress Index – Short Form (PSI-SF).49 All participant materials were available in Sesotho, English and Afrikaans in accordance with local language demographics.

**Statistical analysis**

Recruitment data were used to calculate the screening, eligibility and inclusion rates.46-48 Sample characteristics and clinical variables are presented as means with standard deviations, medians with ranges for continuous data, and frequencies with percentages for categorical data. Bayley-III subscale composite scores were classified according to the measure-specific classification system. Classification data is reported using frequencies with percentages. Difference between means and proportions for children without and with DS were calculated using a two-sample t-test and chi-squared test, respectively. Associations between known risk factors and cognitive, language and motor developmental outcomes for the entire sample were determined using analysis of variance (ANOVA).
Results
Seventy-two children, identified from the surgery lists, were screened for eligibility. Twelve children were ineligible and 11 were lost to enrolment. Forty-nine children were screened for inclusion, of whom eight could not be included due to unexpected changes to the surgery list or late hospital admission, preventing pre-operative assessment. Forty-one children were included in the study.

Pre-operative neurodevelopmental assessments were completed for 40 children. Data for a single child were excluded as the assessment could not be completed due to the surgery unexpectedly being moved forward (Fig. 1).

Screening and eligibility rates were 84.7 and 83.3%, respectively. The rate of inclusion however was considerably lower at 68.3% (Table 1).

A quarter of the children (n = 10) were diagnosed with DS. Children without and with DS had comparable sociodemographic and clinical backgrounds. The median age of the children at pre-operative neurodevelopmental assessment was 7.4 months (range 1.4–20.9 months). Mean cardiac disease severity was moderate. Only 10 children (25%) had cyanotic defects. Most of the children (n = 27) were malnourished pre-operatively. Most children (n = 28) were scheduled to undergo definitive corrective cardiac surgeries (Table 2).

With regard to the children’s families, the average level of education of parents was grade nine to 11 (lower to upper level of secondary education in the South African education system) and most families (n = 35) were from low socio-economic backgrounds. Sixty per cent of parents (n = 24) experienced clinically significant parenting stress at the time of their child’s pre-operative neurodevelopmental assessment (Table 2).

Pre-operative developmental performance for children with CHD without DS (n = 30) was average, with mean composite scores across all three subscales of the Bayley-III within one standard deviation of the test mean score of 100 (scores > 85). There was considerable variability in individual developmental performance as reflected in the wide-ranging scores (Table 3). Eight children (26.7%) had hypotonia (Table 2).

For children with CHD with DS (n = 10) language performance was at risk (mean score 70–84), while motor and

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**Table 1. Recruitment rates**

<table>
<thead>
<tr>
<th>Recruitment aspects</th>
<th>Definition</th>
<th>Numbers</th>
<th>Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening rate</td>
<td>Percentage screened of total number of children &lt; 30 months operated on over the period</td>
<td>72 out of 85</td>
<td>84.7</td>
</tr>
<tr>
<td>Eligibility rate</td>
<td>Percentage eligible of those screened</td>
<td>60 out of 72</td>
<td>83.3</td>
</tr>
<tr>
<td>Inclusion rate</td>
<td>Percentage included of those eligible</td>
<td>41 out of 60</td>
<td>68.3</td>
</tr>
</tbody>
</table>

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**Fig. 1. Recruitment for pre-operative neurodevelopmental assessment.**
cognitive performance was delayed (mean score < 70). There was considerable variability in individual developmental performance (Table 3). All children with DS (n = 10) had hypotonia (Table 2).

Children with DS had significantly poorer motor (p < 0.0001), cognitive (p < 0.0001) and language performance (p < 0.001) pre-operatively on the Bayley-III compared to children without DS (Table 3). Disease severity (p = 0.02) and DS (p < 0.01) were significantly associated with poorer cognitive outcomes. Younger age at first cardiac surgery (p < 0.01) and DS (p < 0.01) were significantly associated with poorer language outcomes. Growth failure (p = 0.04) and DS (p < 0.01) were significantly associated with poorer motor outcomes.

Prior to cardiac surgery, 13.3% (n = 4) of children without DS had motor delays, 7% (n = 2) had cognitive delays and 3.3% (n = 1) had language delays. Six children (20%) had developmental delays in one or more areas of development. In addition, a third (n = 10) of children were at risk for developmental delays (Table 3).

In children with DS, prior to cardiac surgery, 70% (n = 7) had motor delays, 60% (n = 6) had cognitive delays and 40% (n = 4) had language delays. Nine children (90%) had developmental delays in one or more developmental area. Proportionally, significantly (p = 0.0001) more children with DS had developmental delays compared with children without DS (Tables 2, 3).

Children scoring below one standard deviation of the test mean score (scores < 85) on Bayley-III met the criteria for referral to relevant rehabilitation therapies.44 Based on pre-operative developmental performance on the Bayley-III, 65% of the children (n = 26) qualified for referral to rehabilitation therapies, including all 10 children with DS (100%) and 16 without DS (53.3%). Proportionally, significantly more children with DS (p = 0.008) qualified for rehabilitation therapies compared with children without DS (Table 3).

By six months post cardiac surgery, 22 children were still available for assessment, including 17 children without and five children with DS (Fig. 1). At six months post cardiac surgery, 11.8% (n = 2) of children without DS had motor delays, 5.8% (n = 1) cognitive and 11.8% (n = 2) language delays (Table 4). There was a slight decline in the prevalence of motor and cognitive delays post cardiac surgery, but an increase in language delays. Proportionally, the number of children with developmental delays pre and post cardiac surgery was comparable. Two of the three (66.7%) children with developmental delays prior to cardiac surgery still presented with delays at six months post cardiac surgery. A comparable proportion of just over a third of children were still at risk of developmental delays (Table 5).

By six months post cardiac surgery, 80% (n = 4) of children with DS had motor delays, 100% (n = 5) had cognitive delays and 80% (n = 4) had language delays (Table 4). Developmental deficits in children with DS became more pronounced post cardiac surgery, over time, and with increasing age across all developmental domains. Proportionally, the number of children...
with developmental delays pre and post cardiac surgery was comparable. All five children (100%) with developmental delays prior to cardiac surgery still presented with delays at six months post cardiac surgery.

By six months post cardiac surgery, 68.2% of the children qualified for rehabilitation therapies (n = 15), including all five children with DS (100%) and 10 without DS (58.8%) (Table 4). The proportion of children without DS qualifying for rehabilitation therapies before and after cardiac surgery was comparable at just more than half. Seven of the children without DS (70%) and all five of those with DS (100%) who qualified for rehabilitation therapies before cardiac surgery still qualified at six months post cardiac surgery.

### Discussion

Recruiting parent and child pairs into CHD research is a known challenge. Based on current evidence and our own experience, perhaps recruitment challenges rather than a lack of indication and/or possible clinical value may explain why pre-operative neurodevelopmental assessment is rarely undertaken in research practice, even in medically stable children with CHD.

Screening and eligibility rates in the current study were acceptable at 84.7 and 83.3%, respectively. The rate of inclusion was however considerably lower at 68.3%, with 20 children being lost to inclusion, mainly due to environmental barriers or factors external to the child. Environmental barriers preventing pre-operative assessment in this study included language, parent-related and logistical barriers. Similar environmental barriers to pre-operative neurodevelopmental assessment have been reported.

Once children were included, there was a high rate (98%) of completion of pre-operative neurodevelopmental assessment. The only other study mandating comprehensive pre-operative neurodevelopmental assessment has similarly reported a high rate of completion of neurodevelopmental assessment of 93.3%, once children were included. Other investigators have reported wide ranging rates of completion of pre-operative neurodevelopmental assessment, ranging between 24 and 68.7%.

Variable participant profiles, set inclusions and study protocols likely explain the variable rate of completion of pre-operative assessment.

Cardiac neurodevelopmental follow up did not form part of standard cardiac care offered at the study site at the time of the study. In our experience, putting systems in place to allow for sufficient time for recruitment and pre-operative neurodevelopmental assessment was a challenge. Clinical staff in the admitting ward were unfamiliar with the processes involved as there was not yet a strong neurodevelopmental focus with the necessary infrastructure at the site to accommodate these assessments. Fostering collaborative relationships with clinical staff was essential in getting their support and ensuring successful participant recruitment in this study.

Similar challenges in establishing recruitment systems where cardiac neurodevelopmental follow up is not well established have been reported.

Time constraints did not allow for the building of a good rapport with parents beforehand and pre-operative neurodevelopmental assessment was often the first contact parents had with the investigator and a neurodevelopmental component to their child’s cardiac care. Consistent with previous findings, language barriers where parents spoke non-local languages challenged recruitment. Lower levels of parent education and language barriers requiring the services of an interpreter placed an additional strain on the limited time available for pre-operative assessment, as more time was needed to gain informed consent and to complete the questionnaires and the developmental assessment.

Children undergoing cardiac surgery were admitted only the day before the scheduled surgery, as was standard practice at the clinical site. After admission, children underwent routine

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**Table 4.** Six-month post-operative developmental performance on the Bayley-III subscale

<table>
<thead>
<tr>
<th>Bayley-III subscale</th>
<th>CHD with DS (n = 5)</th>
<th>CHD without DS (n = 17)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (range)</td>
<td>55 (55-65)</td>
<td>90 (55-100)</td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>58 ± 4.5</td>
<td>90.9 ± 13.3</td>
<td><strong>0.001</strong>*</td>
</tr>
<tr>
<td>Language</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (range)</td>
<td>65 (57-79)</td>
<td>91 (65-109)</td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>66.2 ± 6.9</td>
<td>88.8 ± 13.5</td>
<td><strong>0.002</strong></td>
</tr>
<tr>
<td>Motor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (range)</td>
<td>55 (49-70)</td>
<td>97 (49-121)</td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>57.4 ± 8.3</td>
<td>92.3 ± 18.9</td>
<td><strong>0.001</strong>*</td>
</tr>
</tbody>
</table>

**Table 5.** Predictive value of pre-operative developmental assessment

<table>
<thead>
<tr>
<th>Bayley-III subscale</th>
<th>Before cardiac surgery, n (%)</th>
<th>Six months post cardiac surgery, n (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At risk</td>
<td>0 (100)</td>
<td>2 (11.8)</td>
<td>0.43</td>
</tr>
<tr>
<td>Delayed</td>
<td>5 (100)</td>
<td>1 (5.8)</td>
<td><strong>&lt; 0.0001</strong>*</td>
</tr>
<tr>
<td>Language</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At risk</td>
<td>1 (20)</td>
<td>6 (35.5)</td>
<td>0.52</td>
</tr>
<tr>
<td>Delayed</td>
<td>4 (80)</td>
<td>2 (11.8)</td>
<td>0.003**</td>
</tr>
<tr>
<td>Motor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At risk</td>
<td>1 (20)</td>
<td>3 (17.6)</td>
<td>0.9</td>
</tr>
<tr>
<td>Delayed</td>
<td>4 (80)</td>
<td>2 (11.8)</td>
<td><strong>0.0001</strong>*</td>
</tr>
<tr>
<td>Number of children with delays in one or more areas of development, n (%)</td>
<td>5 (100)</td>
<td>3 (17.6)</td>
<td><strong>&lt; 0.0001</strong>*</td>
</tr>
<tr>
<td>Number considered to be at risk for developmental delays, n (%)</td>
<td>1 (10)</td>
<td>6 (35.3)</td>
<td>0.13</td>
</tr>
</tbody>
</table>

Children qualifying for referral to rehabilitation therapies (scores < 85) (n = 22)

| Cognitive           | 5 (100)                      | 3 (17.6)                               | 0.001   |
| Language            | 5 (100)                      | 8 (47.1)                               | 0.04*   |
| Motor               | 5 (100)                      | 5 (29.4)                               | 0.007*  |
| Number of children qualifying for rehabilitation therapies, n (%) | 5 (100) | 10 (58.8) | 0.09** |

Bayley-III subscale scores: < 70 delayed, 70-84 at risk and > 85 normal.

Statistical significance: *p < 0.05, **p < 0.01, ***p < 0.001.
pre-operative medical examinations, which left some children irritable at the onset of the neurodevelopmental assessment. Furthermore, children were unfamiliar with the test environment and it was difficult to create an environment conducive to developmental assessment in a busy clinical ward.46,47 The Bayley-III assessment is also lengthy, taking up to an hour to complete, depending on the child’s age.48 It is important to consider that these circumstances may have negatively impacted on the children’s developmental performance during testing.

Although assessment at an earlier time point following diagnosis would have been preferred, in our experience, this would not have been feasible at the study site. Children were seldom referred to neurodevelopmental services pre-operatively, and the increased hospital costs and inconvenience to families associated with earlier pre-operative hospital admission was not found to be acceptable.

The majority of parents (60%) in this study experienced clinically significant parenting stress on the admission of their child for cardiac surgery, making it more challenging to engage with them in the pre-operative neurodevelopmental assessment.49,54,55 This was often parents’ first exposure to a developmental component of their child’s cardiac care, which may have contributed to their stress at the time. It is possible that the children could have taken on their parents’ stress and anxiety, which may also have negatively affected their developmental performance during testing.

Assessment on the Bayley-III required the children to be alert and able to tolerate physical handling and position changing.56 Children included in the current study were medically stable, but most were malnourished. Current malnutrition practice guidelines however deem it safe to perform neurodevelopmental assessment when the child is medically stable.57,58 Child-related barriers that prevented pre-operative neurodevelopmental assessment in this study included critical illness and the need for emergency cardiac surgery. This is consistent with barriers to pre-operative neurodevelopmental assessment identified in previous studies.59-62

Pre-operative developmental performance of children with CHD without DS was considered to be average and the prevalence of pre-operative developmental delays was within the estimated range of 13 to 16% for the general population.63 Motor delays were found to be most prevalent pre-operatively, which is consistent with the published evidence on early developmental outcomes in children with CHD.64,65 The cause of the motor delays are likely multifactorial, including hypotonia, periods of pre-operative immobilisation and maternal overprotection.12,20,58,60 In addition, cardiovascular compromise and related limited physical endurance may also have compromised the acquisition of motor skills.12,58,61 Growth failure was significantly associated (p = 0.04) with pre-operative motor delay. Malnutrition is associated with muscle weakness and poor physical endurance, which would prevent children from engaging in typical age-appropriate developmental activities.2 Several studies have confirmed the positive association between growth failure and delayed gross motor development in children with CHD.42,56,66

Pre-operative neurodevelopmental assessment proved valuable in identifying children, both with and without DS, with developmental delays. This allowed for the prioritisation of post-operative neurodevelopmental follow up and early referral for individualised rehabilitation therapies to address developmental delays, as well as the provision of appropriate education and advice to parents. Referral to early rehabilitation therapies during hospitalisation or at hospital discharge can be discussed with parents in the context of their child’s neurodevelopmental assessment findings, which may improve the uptake of these important services.

The proportion of children without and with DS at risk for and presenting with developmental delays, qualifying them for referral to rehabilitation therapies, was comparable at six months post cardiac surgery. Importantly, most of the children identified as being at risk or delayed pre-operatively were also identified to be so at six months post cardiac surgery, which would suggest pre-operative neurodevelopmental assessment findings may potentially be predictive of shorter-term post-operative outcomes. The changing developmental profile of children with CHD without and with DS over time and with increasing age in the current study affirms the need for regular ongoing developmental assessment throughout childhood.60

**Strengths and limitations**

This is the first study to determine the pre-operative neurodevelopmental status of young children with CHD undergoing cardiac surgery in South Africa, and to report on the feasibility, clinical value, and format of pre-operative neurodevelopmental assessment from a developing-country perspective. The findings of this study however need to be considered in light of several limitations. The outcomes reported are for a single cardiac centre, making the findings specific to this population, and not necessarily generalisable to the CHD population at large. The study was limited by a small sample size, and therefore small sub-group size, which does not allow for definitive conclusions to be drawn from the findings. Child-related and particularly environmental barriers challenged recruitment and the completion of pre-operative neurodevelopmental assessments.

**Recommendations**

Despite the challenges of performing pre-operative neurodevelopmental assessment in medically stable children with CHD, the potential benefits cannot be overlooked in the South African context where children often wait for extended periods before undergoing cardiac surgery. It is recommended that medically stable children with CHD be referred for developmental screening after diagnosis and while awaiting cardiac surgery. It would be optimal to perform this screening, where possible, at a routine clinic visit prior to hospital admission for cardiac surgery. It is advised that for clinical practice, pre-operative developmental screening makes use of a brief standardised
screening test or a parental questionnaire such as the Ages & Stages Questionnaires (third edition) (ASQ-3). Clinicians should clearly explain the value of pre-operative developmental assessment to parents, and adequate reassurances and support should be provided to reduce their anxiety.

Children identified as being at risk for or presenting with developmental delays should be referred for the initiation of individualised rehabilitation therapies adapted to the child’s clinical condition while awaiting surgery. Therapy should be aimed at improving developmental performance, addressing musculoskeletal impairments, and limiting the extent of developmental delay post-operatively.

Further research and analysis of clinical recruitment data in a larger sample are needed to better determine the feasibility, clinical value and best format of pre-operative neurodevelopmental assessment as part of routine cardiac neurodevelopmental care. Cardiac centres will need to track recruitment data to investigate strategies to overcome modifiable barriers to pre-operative neurodevelopmental assessment.

Conclusions

Pre-operative neurodevelopmental assessment was clinically valuable in identifying children at risk for and those presenting with developmental delays, facilitating early referral for formal developmental evaluation and rehabilitation therapies. Pre-operative neurodevelopmental assessment may be of high importance in South Africa where there are often extended waiting periods for cardiac surgery. Effective referral systems and recruitment strategies, and the fostering of collaborative relationships with clinical staff and parents are essential to the feasibility of pre-operative neurodevelopmental assessment.

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