Rehabilitation post paediatric cardiac transplant: a case report

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ABSTRACT

The purpose of this case report is to present the outpatient cardiac transplant rehabilitation of a paediatric patient in New Zealand. Currently there is little evidence in the field of rehabilitation post paediatric cardiac transplant. After reviewing the literature and contacting internationally renowned centres, a novel rehabilitation programme was instigated at Starship Hospital (Auckland) for this cardiac transplant recipient (Jack), specific to his needs as a child. Outcomes measures that assessed aerobic capacity, balance, and strength were used to monitor progress. In addition, child appropriate assessments were conducted reviewing gross motor skills specific to both patient age and stage of development. This programme resulted in quantifiable improvements in outcomes across all areas, but more importantly allowed Jack to acquire new skills not present pre-transplant, that he could use in the playground.

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INTRODUCTION

Cardiac transplant is a long established treatment strategy for children with severe forms of congenital cardiac disease and cardiomyopathy (Conway and Dipchand 2010). December 2012 marked 25 years of heart transplantation in New Zealand (Auckland DHB 2012), with the first paediatric heart transplant in 2002 being performed on an eight-year old. On average, there is only one paediatric heart transplant per year compared with 10-14 per year in adults.

End stage heart disease has a significant effect on the body; specifically it can cause skeletal muscle myopathy (Quivers 2008). The myopathy does not immediately improve post-transplant as the presence of immunosuppressants, such as corticosteroids and cyclosporines, can further impair skeletal muscle (Biring et al 1998). Furthermore, exercise performance remains low in the paediatric cardiac transplant recipient when compared to their peers (Davis et al 2006). The etiology for this decreased exercise capacity is further compounded by reduced chronotropic responsiveness (Dipchard et al 2009) and reduced cardiac output (Pastore et al 2001). There is an emerging body of evidence that supports the implementation of cardiac rehabilitation post-cardiac transplant to improve exercise capacity (Deliva et al 2012, Patel et al 2008). An editorial by Pahl (2012) unequivocally supports supervised exercise programmes post-transplant and recommends annual graded exercise testing and revision of exercise prescription as needed.

Cardiac rehabilitation post-transplant is an established treatment (Constanzo et al 2010). There is a plethora of research supporting post-transplant rehabilitation in adults. Current literature supports the implementation of rehabilitation post-cardiac transplant for paediatric recipients (Banks 2012, Chui 2012, Fricker 2002, Pahl 2000, Pahl 2012, Quivers 2008), however there have been only two studies (Deliva 2012, Patel 2008) that have looked at the impact of paediatric-specific rehabilitation programmes. This case report highlights the clinical complexities of implementing such a rehabilitation programmei nthe post-cardiactrans plant paediatricpop ulation.

CASE REPORT

History

A six-year-old boy (for the purposes of anonymity, here referred to as "Jack") with a history of complex congenital cardiac disease underwent a successful cardiac transplant at Starship Hospital (Auckland, New Zealand). He was extubated day three post-operatively and reviewed by a physiotherapist for airway clearance and early mobility. Jack made excellent progress post-operatively and was discharged 12 days following transplant. Traditionally cardiac rehabilitation post-transplant has been conducted by the adult physiotherapy department at Greenlane Hospital, however due to Jack's age and size, his post-transplant rehabilitation was completed at the physiotherapy department at Starship Children's Hospital (Auckland, New Zealand).

Baseline Physiotherapy Assessment

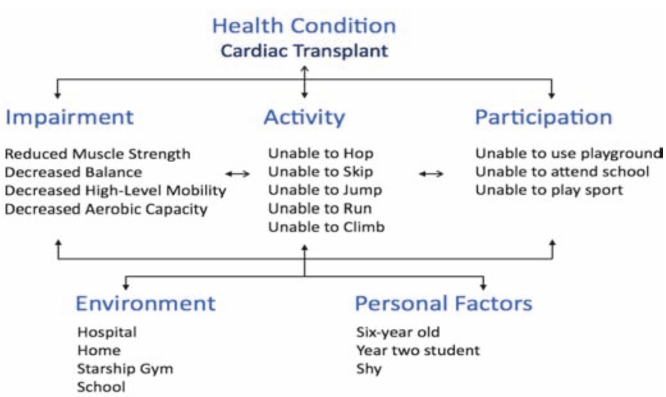
Prior to discharge from hospital, Jack was able to mobilise over 100m independently, climb a small flight of stairs with the use of a handrail, and wash, dress and feed himself unaided.

Based on observations from the family and information gathered by the Movement Assessment Battery for Children (Movement ABC) checklist (Henderson and Sudgen 1992), Jack's main difficulties were identified. The Movement ABC checklist comprises five sections related to the child either stationary or moving in an environment that is either stable or changing. It also takes into account behavioural problems related to motor difficulties. Items are individually assessed to provide a total score of 40, with a high score indicating a high level of difficulty. Each child is asked to complete 8 tasks in the areas of manual dexterity, ball skills, and static and dynamic balance. The scores from each of the areas are then added to come up with a total score. A total score is converted to a percentile. Scores less than the 5th percentile indicate a definite motor problem, and scores between the 5th and 15th percentiles indicate a borderline problem. Any score greater than the 15th percentile indicates that movement skills are within normal limits for the child's age.

Age appropriate activities for a typically developing six-year-old include sitting to stand from a low seat, getting on and off the floor, kneeling and half kneeling, running, jumping, skipping, hopping and ball skills. Jack had difficulty with all of these and more. His main difficulties were with gross motor tasks including jumping over obstacles, using fixed apparatus such as a climbing frame, and running to catch an approaching ball. The Movement ABC checklist also identified that Jack was timid or fearful of more challenging activities leading to an underestimation of his own ability. It is important to note here that Jack had never had the opportunity to learn many of these activities due to his physical condition pre-transplant. Unfortunately due to Jack's health at the time, his ability to perform gross motor skills was not able to be formally assessed prior to transplant.

The International Classification of Functioning, Disability and Health model (ICF) was utilised to define Jack's ability and participation within the context of his environment (WHO 2002). Consideration of Jack as an individual and the influences of his health condition were also explored (see Figure 1).

Figure 1: Defining Jack's abilities and participation within the context of his environment (using the International Classification of Functioning, Disability and Health model)



Outcome Measures

Jack was assessed with several outcome measures prior to the programme, at the end of the programme, and at a six-week post programme follow up appointment. In addition to the Movement ABC (described above), several outcome measures were used to establish Jack's strength, balance, high-level mobility, and exercise capacity.

Manual Muscle Testing (Clarkson et al 2000) was used to measure strength; it has been validated for use in both a paediatric and an adult population (Rider et al 2010). For balance, the Paediatric Balance Scale (Franjoine et al 2003) and the HiMat (Williams 2006) were used. The Paediatric Balance Scale has been adapted from the adult version, the Berg Balance, and found to be a valid and reliable method of assessing balance in children. The HiMat is a dynamic balance and high-level mobility assessment tool which assesses walking forwards and backwards, running over an obstacle, bounding, and mobilising up and down stairs.

The six minute walk test (6MWT) (American Thoracic Society 2002) and then subsequently the incremental shuttle walk test (ISWT) (Singh 1992) were used to assess exercise capacity. The 6MWT has been shown to be a valid and reliable measure of exercise capacity in children (Geiger 2007, Li 2005, Moalla 2005). As Jack was unmotivated by the 6MWT, the 12-point ISWT was used. The ISWT has been shown to be a safe and valid measure for peak VO_2 in the paediatric cardiac population (Lewis 2001). The ISWT is a symptom-limited maximal test that is externally paced and has incremental increases in speed. The test allows for running which the 6MWT does not. Both the 6MWT and ISWT have been validated in the paediatric population (Bartels et al 2013, Selvadurai et al 2003).

Treatment

To decide on the optimal type of physiotherapy programme to provide for Jack, the literature was searched. The current available paediatric literature tends to examine exercise capacity and cardiopulmonary function rather than describe specific protocols or guidelines for rehabilitation post-transplant. Two studies have assessed post paediatric cardiac transplant rehabilitation programmes (Deliva et al 2012, Patel et al 2008). Both studies demonstrated improvements in aerobic fitness and strength after either home based or hospital attended rehabilitation programmes, but failed to provide specific guidance.

As the literature was found to be emergent and sparse in this area, three overseas centres recognised for their clinical excellence in the field of paediatric transplant rehabilitation were contacted for advice. Toronto Sick Kids in Canada, the Royal Children's Hospital in Australia, and the Great Ormond Street Hospital in the United Kingdom were approached. All three centres responded providing advice, protocols and guidelines. The hospitals' programmes ranged in duration from 8 to 12 weeks with 3-4 gym sessions per week plus a home exercise programme. Gym sessions consisted of aerobic and strength training in older children (>6 years) and gross motor activities for younger children (< 6 years). The advice from Toronto Sick Kids was based on the findings of their published paper (Deliva et al 2012) which demonstrated improved health related fitness in children post cardiac transplant. In addition to their advice, each centre was further contacted to complete a benchmark questionnaire, designed by the author, to establish basic demographic data for their patient groups along with specific information regarding outcome measures and intervention frequency, intensity, time and type.

From this literature search and the recommendations received from overseas centres, we were able to formulate an evidence informed rehabilitation regime for Jack. Jack attended the gym for three one hour sessions per week for 12 weeks. The format of these sessions consisted of a warm up, functional and impairment based activities, aerobic activities and then a cool down. The warm up, cool down and other activities used changed at every treatment. Because Jack is a six-year-old boy, these sessions were individualised to his interests, ensuring maximal participation and effort.

The programme first addressed Jack's specific body structure and functional limitations, namely, muscle strengthening, and improving exercise capacity and balance. Subsequent treatment focused more on Jack's goals. To facilitate Jack's engagement with the programme, exercise activities were chosen that were fun and functional. For example, skittles were played in varying positions, such as half kneeling, kneeling or standing, and an obstacle course was used, choosing obstacles that promoted strength, gross motor function and balance. The Nintendo Wii® (Nintendo, Redmond, Washington) was used as a warm-up activity. Other activities included "shuttles", "bear walks", "crab crawls", or "bunny hops". "Wheelbarrow" exercises were used for improving upper limb strength and aerobic fitness, and "hopscotch" for working on the power capacity of his muscles and improving skill based hopping.

Any activity completed in the gym was then added to Jack's home exercise programme. Jack completed his home exercise programme on the days he was not in the gym, with rest days typically on the weekend or whenever his parents felt he required them. Jack's home exercise programme incorporated four to five activities which were updated and progressed weekly. Of note, the whole family ended up completing the exercises including Jack's parents and grandparents.

In addition to improving his previous learnt activities and skills, other age appropriate skills that Jack had previously never been able to do, such as hopping, skipping and jumping, were taught and progressed appropriately.

RESULTS

Results from the three measurement time points for the Manual Muscle Testing, Paediatric Balance Scale, the HiMat, 6MWT and ISWT are shown in Table 1.

Table 1: Results of the strength, balance and exercise capacity tests

Measurement	Start of Programme	End of Programme	6 week follow-up
Manual Muscle Test (/5)	3 UL, 4 LL	5 UL & LL	5 UL & LL
Paediatric Balance Scale (/56)	52	56	56
HiMat (/54)	17	20	27
6MWT	310m	NC	NC
ISWT	410m	530m	660m
(approximate speed)	(1.52 m/s)	(1.69 m/s)	(1.86 m/s)

Note: UL, upper limb; LL, lower limb; NC, not completed; 6MWT, six minute walk test; ISWT, incremental shuttle walk test

At the start of the programme Jack had a total Movement ABC score of 18.6 (out of 40) and was ranked on the 1st percentile. At the end of the programme Jack's total Movement ABC score had reduced to 6 and he was ranked on the 36th percentile. At follow-up six weeks later, Jack had a total score of 4.5, placing him on the 49th percentile.

Jack demonstrated significant improvement in both his body structure and function limitations and in his activity limitations. At his six week follow-up appointment, his mother commented on his teacher's report, saying he was constantly 'on the go' and able to keep up with his peers both in physical education sessions and on the playground. Further formal rehabilitation and assessment were deemed unnecessary and his family was encouraged to make contact with Starship Therapy if there were concerns with his development or exercise capacity in the future.

DISCUSSION

Jack made good recovery post cardiac surgery. Not only did his measures of strength, balance and exercise capacity improve, but at his six week follow up appointment Jack was assessed as having gross motor skills on the 49th percentile for well, typically developing six-year-olds. He was able to participate in physical education at school as well as engage with other children on the playground.

The literature is sparse in this area so it is difficult to compare Jack's results to those published previously. Both Deliva 2012 and Patel 2008 compared strength, flexibility and exercise tolerance pre- and post-intervention in children receiving cardiac or lung transplants, however Jack only just fits within the demographics of patients studied (Deliva: 6-16, Patel: 7-18). Furthermore, each study used different assessments to measure these outcomes. Deliva (2012) used the 6-minute walk test, dynamometry and goniometry, whilst Patel (2008) used the standard Bruce protocol and dynamometry. Neither dynamometry nor goniometry was felt to be clinically relevant for Jack because they were not a functional measure of his ability. The standard Bruce protocol was not used as this would have to be performed in a specialised unit and was thus not clinically available. The 6-minute walk test (as per Deliva (2012)) was only used once post-operatively because Jack found it too easy and refused further assessment. Subsequently the incremental shuttle walk test was used as a measure of exercise tolerance. Therefore, it is difficult to compare Jack's results with the published literature. However both Deliva (2012) and Patel (2008) demonstrated significant increases in overall exercise tolerance post- intervention, which was in line with Jack's results.

Due to the small number of paediatric cardiac transplants performed in New Zealand, recipients have historically received their post-operative outpatient rehabilitation via the adult service. However, due to Jack's age, stage of development and size it was felt that age related rehabilitation in a child friendly environment would benefit him. Therefore the case was put forward for Jack to receive his rehabilitation at Starship Hospital. As there was little published evidence to then guide paediatric post-operative rehabilitation, contacting other internationally prominent paediatric centres to gather information related to their rehabilitation programmes became the next step in ensuring that the programme developed for Jack was as evidence informed as it could be.

CONCLUSION

This case report highlights the need for evidence informed practice to achieve optimum patient care. Favourable outcomes were achieved in this case from conducting a post-operative rehabilitation programme based on the best available evidence in conjunction with expert advice from internationally renowned centres. This case report lends to the growing evidence of the importance of treating the paediatric transplant recipient using a child appropriate programme and environment.

KEY POINTS

- Rehabilitation post paediatric cardiac transplant results in improved exercise capacity, strength, balance and gross motor skill acquisition.
- Where literature is emergent and thus insufficient to guide practice, benchmarking with internationally renowned centres helps to inform practice.
- Post paediatric cardiac transplant rehabilitation programmes should be age and environment appropriate.

ADDRESS FOR CORRESPONDENCE

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