Cardiology in the Young

cambridge.org/cty

Single ventricle infants: outcomes and impact of home monitoring programme enrolment

Alice E. Scott[1], Mark J. Johnson[2,5], Tara Bharucha[3] and Luise V. Marino[4,5,6]

[1]Child Health, University Hospitals Southampton NHS Foundation Trust, Southampton, UK; [2]Department of Neonatal Medicine, Princess Anne Hospital, University Southampton Hospital NHS Foundation Trust, Southampton, UK; [3]Department of Paediatric Cardiology, Southampton Children's Hospital, University Southampton Hospital NHS Foundation Trust, Southampton, UK; [4]Paediatric Intensive Care, Southampton Children's Hospital, University Southampton Hospital NHS Foundation Trust, Southampton, UK; [5]NIHR Biomedical Research Centre, University Southampton Hospital NHS Foundation Trust and University of Southampton, Southampton, UK and [6]Research & Development, South West Yorkshire Partnership NHS Foundation Trust, Fieldhead Hospital, Wakefield, UK

Original Article

Cite this article: Scott AE, Johnson MJ, Bharucha T, and Marino LV (2025) Single ventricle infants: outcomes and impact of home monitoring programme enrolment. *Cardiology in the Young* **35**: 568–574. doi: 10.1017/S1047951124036345

Received: 4 March 2024
Revised: 18 October 2024
Accepted: 28 October 2024
First published online: 12 February 2025

Keywords:
single ventricle; home monitoring; CHD; nutrition; growth

Corresponding author:
Mark J. Johnson;
Email: M.Johnson@soton.ac.uk

Abstract

Introduction: Poor weight gain in infants with single ventricle cardiac physiology between stage 1 and stage 2 palliative surgeries is associated with worse outcomes. The growth of infants with single ventricle physiology, enrolled in home monitoring programmes in the United Kingdom, has not been widely described. *Aim:* To explore the growth of infants with single ventricle physiology supported by a home monitoring programme, at a tertiary centre in the South of England. *Methods:* A retrospective review of two cohorts, comparing weight gain amongst infants with single ventricle physiology, before and following the implementation of a home monitoring programme. Inclusion was dependent on a diagnosis compatible with single ventricle physiology during the interstage. *Results:* Enrolment into a home monitoring programme (cohort 2) was associated with 55% more infants being discharged home during the interstage period ($p < 0.05$). Interstage mortality did not differ between cohorts. There were no differences in interstage growth velocity between cohorts (cohort 1 23.98 ± 11.7 g/day and cohort 2 23.82 ± 8.3 g/day); however, infants in cohort 2 experienced less growth deceleration early in life, and achieved catch-up growth at 12-23 months. Interstage nasogastric feeding, regardless of the cohort, was associated with worse growth outcomes. *Conclusion:* A home monitoring programme for infants with single ventricle physiology provides the opportunity for infants to be safely discharged home to their families and cared for at home during the interstage. Infants in the home monitoring programme experienced better growth, achieving weight restoration at 12–23 months.

Introduction

Single ventricle cardiac physiology, as a result of an inadequate right or left ventricle,[1] has a reported prevalence of 0.16 per 1000 live births in the United Kingdom.[2] In efforts to reduce mortality in the surgical perioperative journey, and improve the quality of life for infants and parents, home monitoring programmes were first introduced as part of a paediatric quality improvement initiative in the United States of America (USA). These programmes focussed on monitoring of oxygen saturations, weight gain and hydration status during the shunt dependent period between stage 1 and stage 2 surgical palliation, commonly referred to as the "interstage period."[5] These programmes have generally been accepted to be of benefit in reducing the risk of interstage death.[6–7] The impact and role of the home monitoring programme in reducing associated growth failure (deemed to be modifiable) has been a more recent focus, with some positive findings for its impact on interstage weight gain.[7]

A 2022 systematic review mapped the growth of single ventricle patients, and identified that the most intense somatic growth faltering, with a fall in z score of>1 for both height and weight, occurred from birth until stage 2 palliation, which encompassed the high-risk interstage period.[8] Risk factors for growth failure include inadequate caloric intake, increased metabolic demands due to cardiac dysfunction, and gastrointestinal dysfunction, as well as poor feeding and haemodynamic instability.[6] In addition, impaired somatic growth has been identified as a risk factor for poor surgical outcomes,[9] affected neurodevelopment, and increased risk of mortality.[10–11]

There are ten paediatric cardiac surgical centres in the United Kingdom, and most have developed an individualised approach to a home monitoring service; largely, the service focuses on monitoring oxygen saturations and weight gain, based on the premise of enabling recognition of deterioration and initiating early interventions during the interstage period.[12] The aim of this retrospective evaluation is to describe the growth of infants with single ventricle physiology when supported by a home monitoring programme in the South of England. To date,

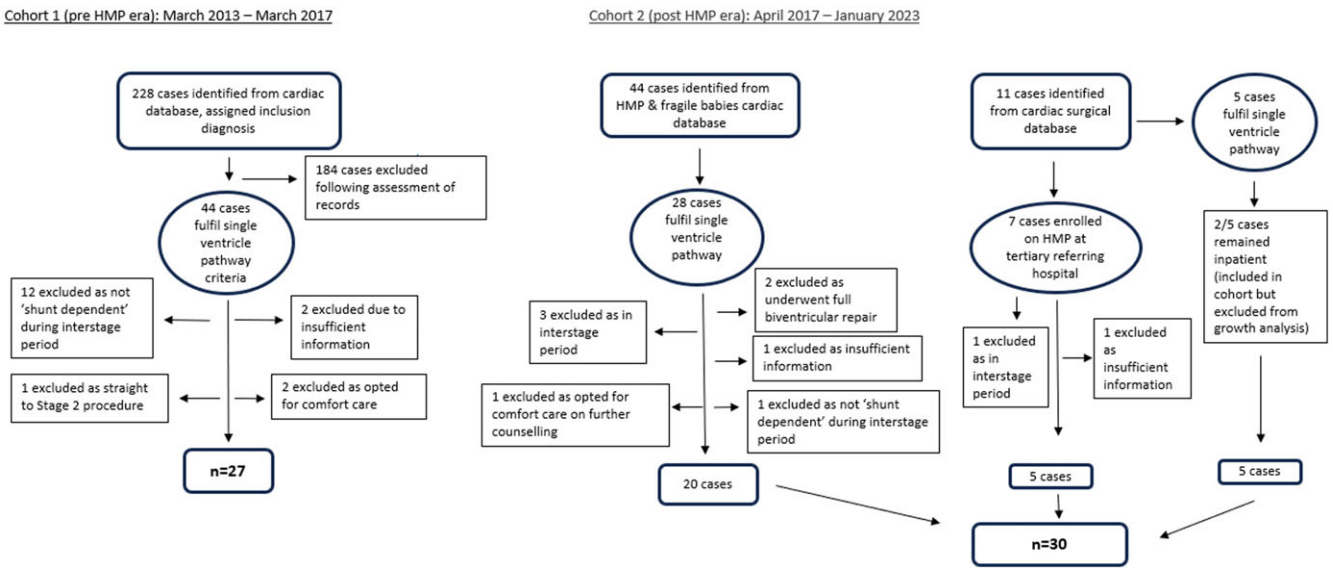

Figure 1. Cohort inclusion/exclusion pathway. HMP = Home Monitoring Programme.

the impact of interstage surveillance via the home monitoring programme has not been widely described in the United Kingdom.

Materials and Method

A retrospective review of two epochs of infants with single ventricle physiology—cohort 1: before, and cohort 2: following the implementation of a home monitoring programme—was carried out. Cohort 1 (pre-home monitoring era): March 2013 – March 2017 and cohort 2 (post-home monitoring programme era): April 2017 to January 2023. Those eligible for inclusion were identified via hospital patient records, with inclusion dependent on a single ventricle diagnosis, and dependence on a systemic to pulmonary shunt during the interstage (Fig 1).

The included diagnoses of single ventricle infants were: *Hypoplastic left heart syndrome, pulmonary valve atresia, double outlet right ventricle, double inlet left ventricle, tricuspid valve atresia, pulmonary and tricuspid valve atresia and unbalanced atrioventricular septal defect.*

Exclusion criteria included: infants currently in the interstage period, infants who were not shunt dependent during the interstage (a pre-requisite for home monitoring enrolment), and infants whose families opted for comfort-focussed care, as opposed to surgical palliation.

The local home monitoring programme enlists multi-disciplinary reviews from clinicians, dietitians, and local services, with a cardiology nurse specialist team leading. Compliance with the centre-specific home monitoring protocol begins prior to discharge, with consensus on suitability of infant for interstage home discharge discussed within the cardiac multi-disciplinary team, following the stage 1 procedure. Successful completion of the protocol checklist is mandatory for discharge, which includes a period of solo caregiving whilst on the ward. Upon discharge, parents receive bi-weekly phone call check-ins and are provided with a hotline number to ring if they have any concerns or hit any "red flag" parameters. Parents are expected to take a daily weight and oxygen saturation and record daily fluid intake. All equipment is provided to parents.

As part of each review, parents report the weight of their infant to a member of the multi-disciplinary team, who records the new weight within the child's electronic growth chart. This is completed in real time to provide parents with immediate feedback on the child's growth, including any required changes to the nutrition care plan. Each child will have an acceptable oxygen saturation range and will trigger a "red flag" when outside of this range. "Red flag" weight parameters are triggered if the infant does not gain 20g each day for three days, loses more than 30g in one day, or is feeding less than 100mls/kg/day of fluid. An urgent in-person health assessment by a cardiac specialist and dietitian would then be completed.

Weight and age were identified from electronic patient health records at birth, stage 1 procedure and discharge (where applicable for cohort 1 infants), stage 2 procedure and discharge, and 12–23 months. Secondary variables were collected for the entirety of a cohort to allow for comparison between cohorts and account for confounding variables for growth. These variables included sex, single ventricle diagnosis, age at stage 1 and 2 palliations, procedure type, mean length of paediatric ICU and hospital stays post-procedure, interstage feeding regime, and interstage mortality, defined as death between stage 1 and stage 2 palliation (see Table 1 for complete secondary variables).

World Health Organisation AnthroPlus software version 1.0.4 was used to calculate z-scores for weight. Moderate undernutrition was defined as a z score of < -2.[13] Infants born before <37 weeks gestational age were defined as being preterm with weight-for-age z scores corrected using Intergrowth-21st Preterm Tools.[14] Chi-squared and Fisher's exact tests were used for cohort comparison of secondary variables. Weight-for-age z scores were compared across time points using an independent sample *t*-test for each individual cohort. Unpaired *t*-test was utilised for weight-for-age z-score comparison between cohorts, and multiple linear regression to control for confounding variables in dataset. IBM

https://doi.org/10.1017/S1047951124036345 Published online by Cambridge University Press

Table 1. Infant characterstics: Cohort 1 and Cohort 2. HMP - Home Monitoring Programme. Both subtypes of Double Outlet Right Ventricle = DORV with noncommitted VSD

	Cohort 1 (pre-HMP era) [n = 27]	Cohort 2 (HMP era) [n = 30]	p value
Preoperative characteristics			
Sex			0.54
Male	20/27 (74.1%)	20/30 (66.7%)	
Female	7/27 (25.9%)	10/30 (33.3%)	
Gestational age			0.34
Term	24/27 (88.9%)	29/30 (96.7%)	
Preterm	3/27 (11.1%)	1/30 (3.3%)	
Birthweight, mean	3248 *g* (2110-4210), sd [580]	3249 *g* (2080-4040), sd [420]	0.996
Diagnosis			0.30
Hypoplastic left heart syndrome	16/27 (59.3%)	15/30 (50%)	
Pulmonary valve atresia	5/27 (18.5%)	6/30 (20%)	
Double outlet right ventricle	2/27 (7.4%)		
Double inlet left ventricle	2/27 (7.4%)	5/30 (16.7%)	
Tricuspid valve atresia		3/30 (10%)	
Pulmonary and tricuspid valve atresia	1/27 (3.7%)	1/30 (3.3%)	
Unbalanced Atrioventricular septal defect	1/27 (3.7%)		
Stage 1 operative characteristics			
Age at intervention (days)	Median = 9 (IQR = 9) (25^{th} percentile = 3, 75^{th} percentile = 12)	Median = 8 (IQR = 7) (25^{th} percentile = 6, 75^{th} percentile = 13)	0.89
Stage 1 procedure			0.098
Norwood procedure with Sano modification	16/27 (59.3%)	16/30 (53.4%)	
Norwood procedure with BT shunt	5/27 (18.5%)	3/30 (10%)	
Modified BT shunt (non-Norwood)	4/27 (14.8%)	3/30 (10%)	
PDA stent (non-hybrid)		7/30 (23.3%)	<0.05
Hybrid procedure	2/27 (7.4%)	1/30 (3.3%)	
Mean length of post-procedure PICU stay	8.8 days (n = 26), sd [7.1]	10.9 days (n = 28), sd [10.5]	0.45
Mean no of days to discharge post Stage 1 procedure	21.3 days (n = 18), sd [10.4]	29 days (n = 26), sd [21.0]	0.12
Interstage discharge location			0.029
Home	10/26 (38.4%)	21/28 (75%)	<0.05
Local hospital	8/26 (30.8%)	5/28 (17.9%) [transferred back to referring hospital then discharged onto HMP]	
Remained inpatient	8/26 (30.8%)	2/28 (7.1%)	<0.05
Interstage characteristics			
Feeding regime (NG versus NoNG)			0.55
No Nasogastric nutrition			
Breastfeeding	2/26 (7.7%)		
Breastfeeding + Oral formula	2/26 (7.7%)	7/28 (25%)	
Oral formula	7/26 (27.0%)	4/28 (14.3%)	
EBF + Oral formula	5/26 (19.2%)	4/28 (14.3%)	
Nasogastric/Parenteral Nutrition			
Breastfeeding + NG top ups	2/26 (7.7%)	1/28 (3.6%)	

(*Continued*)

https://doi.org/10.1017/S1047951124036345 Published online by Cambridge University Press

Table 1. (*Continued*)

	Cohort 1 (pre-HMP era) [n = 27]	Cohort 2 (HMP era) [n = 30]	p value
Oral formula with NG top ups	1/26 (3.8%)	5/28 (17.8%)	
NG feeding	6/26 (23.1%)	7/28 (25%)	
Parenteral feeding	1/26 (3.8%)		
Number of HMP breaches			
Number of babies who breached	n/a	15 (n = 21)	
Total number of HMP breaches	n/a	27	
Number of ED attendances / unplanned admissions			
Total infants readmitted to tertiary service during interstage period (admission from home or local hospital)	10/18 (55.6%)	16/26 (61.5%)	0.46
Unplanned interstage admissions to tertiary service	15 (n = 10)	29 (n = 16)	
Unplanned admission relating to HMP breach	n/a	21/29 (n = 16)	
Interstage mortality	3/27 (11.1%)	4/30 (13.3%)	1
Survival at 1 year	22/27 (81.5%)	26/30 (86.6%)	0.72
Stage 2 operative characteristics	**Pre-HMP era, [n = 24]**	**HMP era, [n = 26]**	
Age at intervention (weeks)	Median = 17.9 (IQR = 8.6) (25^{th} percentile = 14.9, 75^{th} percentile = 23.5)	Median = 20.0 (IQR = 8.0) (25^{th} percentile = 16.0, 75^{th} percentile = 24.0)	0.22
Stage 2 procedure			0.60
Bidirectional cavopulmonary anastomosis (BCPS) / Glenn procedure	22/24 (91.7%)	25/26 (96.1%)	
Hybrid procedure Stage 2	2/24 (8.3%)	1/26 (3.9%)	
Mean Length of post operative PICU stay	9.1 days (n = 23), sd [13.8]	8.5 days (n = 26), sd [8.1]	0.85
Number of days to discharge post-procedure	25 (n = 22), sd [22.5]	21.3 (n = 26), sd [14.4]	0.57

SPSS Statistics, (Version 29.0.2.0 (2023) Armonk, NY: IBM Corp.) was used for the analysis of this data, with statistical significance defined as a p-value of<0.05.

Results

Infant characteristics

Demographic characteristics were collected for all infants in cohort 1 and cohort 2 (Table 1). Hypoplastic left heart syndrome was the most common single-ventricle diagnosis, occuring in 59.3% (n = 16/27) of cohort 1 and 50% (n = 15/30) of cohort 2, with no significant differences in the prevalence of diagnosis between cohorts. For both cohorts, the Norwood with Sano modification was the most common procedure for stage 1, and Bidirectional Glenn for stage 2. The introduction of the patent ductus arteriosus stent as a stage 1 procedure from 2017 onwards for seven infants was responsible for the significant difference in procedure types between cohorts ($p < 0.05$).

Number of infants discharged home

In cohort 1, 38% (n = 10/26) infants were discharged home with outpatient medical follow up during the interstage in the pre-home monitoring programme era, compared to cohort 2, where 75% (n = 21/28) discharged home in the home monitoring programme era ($p < 0.05$). Five additional infants in cohort 2 were also initially transferred to a local hospital and were also discharged onto a home monitoring programme, resulting in 93% (n = 26/28) infants being discharged home.

Single ventricle infant growth

Weight-for-age z-score initially faltered in both cohorts when compared to birthweight (Table 2). The peak fall in weight-for-age z-score for both cohorts was at stage 1 discharge. Cohort 1 had the largest deceleration and crossing down of centile lines. Weight-for-age z-scores started to recover subsequent to stage 1 discharge. Cohort 1 did not reach its baseline weight-for-age z-score by 12–23 months. In cohort 2, weight-for-age z score is higher at 12–23 months than at birthweight: 0.18 ± 1.63 indicating achievement of catch-up growth.

Pre-home monitoring versus home monitoring

Both cohorts of infants with single ventricle physiology experienced weight faltering post-birth. Fig 2 shows decelerations and accelerations in weight-for-age across the surgical journey. Comparison of weight changes between the cohort 1 and cohort 2 showed no statistically significant differences. Interstage growth velocity, calculated as [(S2P weight – S1P discharge weight)/(age at S2P – age at S1P discharge)], was 23.98 ± 11.7 g/day in the pre-home monitoring cohort (n = 17) and 23.82 ± 8.3 g/day in the home monitoring cohort (n = 21) (p = 0.964).

https://doi.org/10.1017/S1047951124036345 Published online by Cambridge University Press

Table 2. Cohort comparison, change in mean WAZ score. Cohort 1: pre-home monitoring programme. Cohort 2: home monitoring programme enrolment. *Significant falter from baseline WAZ, $p < 0.05$. ~ only discharged infants contribute to this data point. WAZ = weight-for-age z-score

	Mean weight-for-age z-score delta change compared to initial birth weight	
Palliation stage	**Cohort 1**	**Cohort 2**
Stage 1 Palliation	−0.52 ± 0.78*	−0.40 ± 0.52*
Stage 1 Discharge	−1.85 ± 0.70*~	−1.33 ± 0.89*
Stage 2 Palliation	−1.36 ± 0.90 *	−1.14 ± 0.94*
Stage 2 Discharge	−0.98 ± 1.22 *	−1.14 ± 1.06*
12–23 months	−0.7 ± 1.13	0.18 ± 1.63

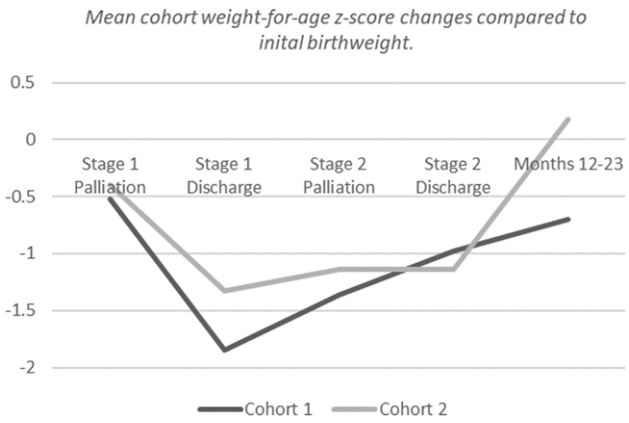

Figure 2. Mean cohort weight-for-age z-score changes compared to initial birth weight.

Although cohorts had comparable growth velocity during the interstage, cohort 2 infants maintained growth velocity closer to original centile line. This weight consistency contributed to the finding that only cohort 2 achieved catch-up growth at 12–23 months.

Nasogastric feeding and growth

Within the pre-home monitoring cohort, 10 infants had a feeding regime that included nasogastric feeding (38%) during the interstage period. In the home monitoring cohort, a total of 13 infants had equivalent nasogastric interventions (46%), $p = 0.55$.

Linear regression was utilised to adjust for the independent factors of cohort and nasogastric feeding with regard to growth. At stage 1 discharge, once adjusting for cohort, the requirement for an interstage nasogastric tube was associated with a deceleration in growth and fall in weight-for-age z-score of −0.57, 95% CI [−1.14, 0.001] compared to those who did not require one (p=<0.05). At stage 2 palliation, when controlling for these above variables, there was no significant impact on growth. At stage 2 discharge, the presence of a nasogastric feeding tube during the interstage was associated with a reduction in weight-for-age z-score of −0.57, 95% CI [−1.16, 0.018] (p = 0.057). This relationship continues; the presence of a nasogastric tube during the interstage was associated with a significant, persistent fall in weight-for-age z-score of −0.97, 95% CI [−1.75,−0.19](p = 0.17) at 12–23 months.

Mortality

Interstage death, death between stage 1 and stage 2 palliative procedures was 11.1% (n = 3) in the pre-home monitoring cohort, and 13.3% (n = 4) in the home monitoring cohort (Table 1). Mortality at 1 year was also comparable between both cohorts.

Discussion

This retrospective review assesses safety and impact of a home monitoring programme on the growth of infants with single ventricle physiology. The results suggest that enrolment in a home monitoring programme—using oxygen saturation, daily weights, and early nutrition support—significantly increases the number of infants safely discharged to their families during the interstage period. Home monitoring programmes are offered as a standard of care by some paediatric surgical centres in the United Kingdom, during the interstage period for infants with single ventricle physiology. However, evidence on the impact of these programmes with regard to growth, mortality, and quality of life measures for families remains limited.[7]

A key finding, especially given the considerable burden on single ventricle patients and their families, is the significant difference in discharge location for infants during the interstage period, following the introduction of the home monitoring programme.[15] The majority of infants with single ventricle physiology were able to be discharged home into the care of their family or caregiver during the interstage period when enrolled on the home monitoring programme, compared to around one-third of infants before its introduction. This shift in discharge location was not associated with a change in interstage mortality. From the families' perspective, qualitative research involving single ventricle families has shown that medicalisation of caring tasks for these infants whilst in hospital limits parental bonding and impairs parent identity.[16–17] Benefits from the National Health Service perspective may include reduction in cost and capacity burden.

In terms of growth from birth, both cohorts had their peak weight faltering at stage 1 discharge, with the pre-home monitoring cohort having a greater degree of faltering than the home-monitoring cohort. Previous research has identified this period as high risk for growth failure,[8–18] associated with adverse outcomes in the single ventricle population.[19] However, the present findings suggest that the severity of weight faltering from birth to stage one discharge is modifiable, as the home monitoring cohort had a reduction in this falter compared to prior to its implementation. This finding, however, cannot be attributed to the home monitoring programme, given infants were yet to be enrolled; these improvements could reflect wider centre advancement, including the impact of a pre-surgical nutrition pathway implemented across a similar time frame. The nutrition pathway sought to support normal growth in the context of greater demand for infants with a range of CHD diagnoses, not solely single ventricle physiology. Pathway evaluations have shown improved growth outcomes following this implementation.

The results show that the home monitoring cohort was the only group to surpass their initial birthweight growth centile and that growth was surpassed at 12–23 months. This suggests that infants were able to achieve catch-up growth after their first two surgical interventions when enrolled on the home monitoring programme, compared to before its introduction. Further work is required to

https://doi.org/10.1017/S1047951124036345 Published online by Cambridge University Press

understand whether accelerated weight gain during the first two years of life increases the risk of overweight and obesity later in childhood in this vulnerable cohort of children, or whether it supports improved linear growth outcomes over time.[20-22]

When focusing on growth solely during the interstage period, irrespective of prior growth falter, the mean growth velocity of each cohort is almost identical. Interstage growth velocity was within the considered normal daily weight gain of 20 to 30g/day for this age group.[12] The home monitoring cohort observed fewer extreme values for interstage growth velocity and maintained growth velocity on a centile closer to original birthweight.

Interstage feeding modalities between the cohorts were comparable. Interpretation of the impact of nasogastric feeding regimens on infant growth is challenging, given that poor weight gain would be an indicator for the placement of a feeding tube; and not achieving sufficient oral intake and growth may be markers of more severe illness.[23] A nasogastric interstage feeding regime at stage 1 discharge was associated with a more significant growth falter. This likely identifies that we are correctly intervening in feeding regimes. Positively, this falter did not persist at stage 2 palliation, which suggests a nasogastric regime improved growth during the interstage, consistent with findings in larger studies.[23–24] An important finding when looking at the growth of these infants at 12–23 months was that those who had a nasogastric feeding tube during the interstage remained significantly faltered in their growth compared to their counterparts. This suggests that the need for an interstage nasogastric tube is a positive predictor of poor growth, which persists to 23 months of age.

This review adds to the literature describing United Kingdom home monitoring programmes, and contributes to transparency in care nationally.

Limitations

This was a single-centre service evaluation, so the results identified may not be generalisable to all home monitoring programmes, especially given the heterogeneity in the setup of services. For example, interstage shunt dependence is a pre-requisite for enrolment in this home monitoring programme. The two cohorts (pre-home monitoring versus home monitoring) were treated across different timeframes, no control group could be identified for this evaluation due to a universal change in practice.

As this was a retrospective review, limitations surrounding missing data and the quality of data available impacted the conclusions drawn; in terms of growth data handling the entirety of the pre-home monitoring cohort were analysed; however, the growth data for stage 1 discharge only reflects those in the cohort who was discharged, as a pre-requisite for completion of data point. The analysis aimed to maximise data points that could be included, with the dataset impacted by missing data, but recognises that infants who were not discharged during the interstage may have been at higher risk of morbidity and mortality impacting on growth observed at this stage. As the growth of the pre-home monitoring cohort was compared to the growth of those only enrolled on the home monitoring programme, this limits the validity of the comparison that can be made across the cohorts.

Identification of the single ventricle cohort was reliant on the correct coding of the individual in the paediatric cardiac database. Growth analyses were reliant on the availability of this retrospective data. Due to insufficient data points available on height, these were excluded from the final analysis.

Conclusion

The introduction of a home monitoring programme enabled a significant increase in the number of infants who were safely able to be discharged home to caregivers during the interstage period. Infants enrolled on the home monitoring programme did not have any worse outcomes and achieved catch-up growth at 12–23 months. Interstage nasogastric feeding remains a positive predictor of poor growth at 23 months of age.

Acknowledgements. We would like to acknowledge the specialist cardiac nurses for their input and insight into the workings of the home monitoring programme. In addition, Research Dietitian Catarina Fandinga, and Mr Antoinio Ravaglioli, Paediatric and Adult congenital cardiac surgery for their assistance with the project.

Financial support. MJJ's salary is support by the National Institue for Health and Care Research, Biomedical Research Centre Southampton. LM is supported by Southampton Academy of Research Leaders programme, University Hospital Southampton NHS Foundation Trust.

Competing interests. None.

Ethical Standard. The home monitoring programme for infants with single ventricle cardiac physiology was applied to all infants who met the criteria as part of a change in practice brought about by a National Health Service Commissioning for Quality and Innovation in 2017. It was therefore the study of a clinical practice change using clinical audit as part of a service evaluation and not an interventional study, with no ethical approval required.

Growth data were collected as part of a registered service evaluation of the new practice. Opinion regarding ethical review was sought from a local ethics committee regarding the use of growth data and felt to be unnecessary in the context of service evaluation. The project was registered on University Hospital Southampton NHS Foundation Trust clinical governance system Ulysess as a service evaluation [Number 7784].

References

1. Rao PS. Single ventricle—a comprehensive review. Children 2021; 8 *(6)*: 441. DOI: 10.3390/children8060441.
2. Coats L, O'Connor S, Wren C, O'Sullivan J. The single-ventricle patient population: a current and future concern a population-based study in the north of England. Heart 2014; 100 *(17)*: 1348–1353. DOI: 10.1136/HEARTJNL-2013-305336.
3. Haller C, Barron DJ. Surgical strategies in single ventricle management of neonates and infants. Can J Cardiol 2022; 38 *(7)*: 909–920. DOI: 10.1016/j.cjca.2022.04.021.
4. Oster ME, Ehrlich A, King E, et al. Association of interstage home monitoring with mortality, readmissions, and weight gain: a multicenter study from the national pediatric cardiology quality improvement collaborative. Circulation 2015; 132 *(6)*: 502–508. DOI: 10.1161/CIRCULATIONAHA.114.014107.
5. Ghanayem NS, Hoffman GM, Mussatto KA, et al. Home surveillance program prevents interstage mortality after the norwood procedure. J Thorac Cardiovasc Surg 2003; 126 *(5)*: 1367–1375. DOI: 10.1016/S0022-5223(03)00071-0.
6. Rudd NA, Ghanayem NS, Hill GD, et al. Interstage home monitoring for infants with single ventricle heart disease: education and management: a scientific statement from the American heart association. J Am Heart Assoc 2020 Aug 18; 9 (16): e014548. DOI: 10.1161/JAHA.119.014548.
7. Hehir DA, Ghanayem NS. Single-ventricle infant home monitoring programs: outcomes and impact. Curr Opin Cardiol 2013; 28 *(2)*: 97–102. DOI: 10.1097/HCO.0b013e32835dceaf.
8. Van den Eynde J, Bartelse S, Rijnberg FM, et al. Somatic growth in single ventricle patients: a systematic review and meta-analysis. Acta Paediatrica, International Journal of Paediatrics 2023; 112 *(2)*: 186–199. DOI: 10.1111/apa.16562.

9. Hehir DA, Cooper DS, Walters EM, Ghanayem NS. Feeding, growth, nutrition, and optimal interstage surveillance for infants with hypoplastic left heart syndrome. Cardiol Young 2011; 21 *(S2)*: 59–64. DOI: 10.1017/S1047951111001600.
10. Murni IK, Patmasari L, Wirawan MT, et al. Outcome and factors associated with undernutrition among children with congenital heart disease. PLoS ONE 2023; 18 *(2)*: e0281753. DOI: 10.1371/journal.pone.0281753.
11. Trivedi A, Carmo KBrowning, James-Nunez K, Jatana V, Gordon A. Growth and risk of adverse neuro-developmental outcome in newborns with congenital heart disease: a single-centre retrospective study. Early Hum Dev 2023; 183: 105798. DOI: 10.1016/j.earlhumdev.2023.105798.
12. Hehir DA, Rudd N, Slicker J, et al. Normal interstage growth after the norwood operation associated with interstage home monitoring HHS public access. PediatrCardiol 2012; 33 *(8)*: 1315–1322. DOI: 10.1007/s00246-012-0320-x.
13. World Health Organization (WHO). WHO AnthroPlus for Personal Computers Manual: Software for Assessing Growth of the World's Children and Adolescents. WHO, Geneva, 2009.
14. The Global Health Network. Intergrowth - standard and tools. 2023.
15. Drury NE, Stoll VM, Bond CJ, Patel AJ, Hutchinson S, Clift PF. Research priorities in single-ventricle heart conditions: a United Kingdom national study. Cardiol Young 2019; 29 *(3)*: 303–309. DOI: 10.1017/S104795111800224X.
16. Mery CM, Well A, Taylor K, et al. Examining the real-life journey of individuals and families affected by single-ventricle congenital heart disease. J Am Heart Assoc 2023 Mar 7; 12 (5): e027556. DOI: 10.1161/JAHA.122.027556.
17. Elliott M, Erickson L, Russell CL, Chrisman M, Toalson JGross, Emerson A. Defining a new normal: a qualitative exploration of the parent experience during the single ventricle congenital heart disease interstage period. J Adv Nurs 2021; 77 *(5)*: 2437–2446. DOI: 10.1111/jan.14785.
18. Shine AM, Foyle L, Gentles E, Ward F, McMahon CJ. Growth and nutritional intake of infants with univentricular circulation. J Pediatr 2021; 237: 79–86.e2. DOI: 10.1016/j.jpeds.2021.06.037.
19. Gardner MM, Mercer-Rosa L, Faerber J, et al. Association of a home monitoring program with interstage and Stage 2 outcomes. J Am Heart Assoc 2019 May 21; 8 (10): e010783. DOI: 10.1161/JAHA.118.010783.
20. Aguilar DC, Raff GW, Tancredi DJ, Griffin IJ. Childhood growth patterns following congenital heart disease. Cardiol Young 2015; 25 *(6)*: 1044–1053. DOI: 10.1017/S104795111400153X.
21. Smith AE, Bharucha T, Marino LV. Making every contact count: recognising obesity in paediatric and young adult cardiology. Cardiol Young 2022; 32 *(1)*: 77–82.
22. Marino LV, Johnson MJ, Davies NJ, et al. Improving growth of infants with congenital heart disease using a consensus-based nutritional pathway. Clin Nutr 2020; 39 *(8)*: 2455–2462.
23. Hill GD, Hehir DA, Bartz PJ, et al. Effect of feeding modality on interstage growth after stage I palliation: a report from the national pediatric cardiology quality improvement collaborative. J Thorac Cardiovasc Surg 2014; 148 *(4)*: 1534–1539. DOI: 10.1016/j.jtcvs.2014.02.025.
24. Medoff-Cooper B, Irving SY, Marino BS, et al. Weight change in infants with a functionally univentricular heart: from surgical intervention to hospital discharge. Cardiol Young 2011; 21 *(2)*: 136–144. DOI: 10.1017/S104795111000154X.

https://doi.org/10.1017/S1047951124036345 Published online by Cambridge University Press