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Use of a Digital Monitoring Platform to Improve Outcomes in Infants With a Single Ventricle

Jeffrey Vergales, MD, MS[1], Leslie Peregoy, MSN, CPNP[1], Jodi Zalewski, MSN, APRN, CPNP-AC[2], and Sarah Tyler Plummer, MD[2]

Abstract

Background: Despite advances, infants with single ventricle heart disease continue to have high morbidity and mortality in the first year of life. Home monitoring programs (HMPs) have reduced mortality and have grown to use integrative digital platforms. The objective was to evaluate how implementation of a digital HMP platform affects nutritional outcomes in infants undergoing staged single ventricle palliation. **Methods:** We conducted a retrospective, multicenter, observational study of all infants who required a neonatal operation as part of staged single ventricle palliation between 2013 and 2018. Patients were excluded if less than 35 weeks' gestation or underwent biventricular repair in the first year of life. Implementation of a digital monitoring platform that allows for secure monitoring of nasogastric feed advancement and oxygen saturation occurred in 2016, creating the two groups in a similar surgical era. **Results:** There were 38 patients who fell under a standard HMP compared to 31 utilizing the digital platform. There was no difference in baseline demographics, anatomy, or preoperative factors between the groups. Use of a digital platform was associated with reduced postoperative length of stay (30.1 vs 33.1 days, $P = .04$). More children in the digital platform monitoring group were able to achieve oral feeding at one year of age (90% vs 68%, $P = .03$). A total of 25% of infants went home with a nasogastric tube, all but one transitioning to full oral feeds. **Conclusions:** Use of a digital, fully electronic medical record (EMR)-integrated, comprehensive HMP was associated with shorter postoperative length of stay in neonates undergoing staged single ventricle palliation and allowed for higher rates of full oral feeding.

Keywords

congenital heart surgery, CHD, univentricular heart, postoperative care, outcomes

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Introduction

The last 20 years has seen a significant improvement in operative mortality for patients with complex congenital heart disease, including those with a single ventricle.[1] As survival to hospital discharge improved, the field's focus has expanded to improving home mortality and overall morbidity in these patients—especially during the first year of life. Home monitoring programs (HMPs) were initially implemented to combat the relatively high mortality rate between stage 1 palliation (S1P) and stage 2 palliation (S2P) by developing comprehensive care coordination teams, maintaining open communication with patients, and gathering patient-derived data.[2-4]

The initial model of HMPs revolved around at-home written documentation, phone calls with care providers to review data from the previous few days, and expectations on parents to recognize and act on various warning signs—or "red flags"—exhibited by their children.[2,5] With the advent of digital remote monitoring platforms, HMPs have moved toward true telehealth solutions by incorporating near real-time secure data transmission and review, multimedia capabilities, improved communication, and shorter delays in care.[6-9] Thus, there is

[1] Division of Pediatric Cardiology, University of Virginia, Charlottesville, VA, USA
[2] Division of Pediatric Cardiology, Case Western Reserve University, Cleveland, OH, USA
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Corresponding Author:
Jeffrey Vergales, Division of Pediatric Cardiology, University of Virginia, Charlottesville, VA 22908, USA.
Email: jvergales@virginia.edu

Abbreviations and Acronyms

ECMO	extracorporeal membrane oxygenation
HLHS	hypoplastic left heart syndrome
HMP	home monitoring program
NG	nasogastric
NPC-QIC	National Pediatric Cardiology Quality Improvement Collaborative
S1P	stage 1 palliation
S2P	stage 2 palliation
WAZ	weight-for-age z-score

now an ability in this high-risk population to provide continued ongoing high-level support while the patient is at home.

Despite the relative success of HMP in reducing mortality before S2P, significant issues remain through the first year of life including growth failure, high rates of supplemental tube feeding, dysphagia, and low rates of exclusive oral feeding.[10-14] While near elimination of these concerns would be challenging, groups including the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) currently endeavor to improve rates of all oral enteral nutrition through the first year. Yet, proven factors and interventions that could contribute to this goal remain sparse.

The goal of this study is to ascertain whether utilizing a secure, digital remote monitoring platform as part of a single ventricle HMP can contribute to increased oral enteral nutrition, thereby reducing known morbidity, in this very vulnerable population.

Methods

We conducted a retrospective, two-center, observational study of all infants who required a neonatal operation—under 30 days of life—as part of staged single ventricle palliation between 2013 and 2018 at the University of Virginia Children's Hospital and Rainbow Babies and Children's Hospital. The study was approved by the institutional review boards of both institutions with waiver of consent as all data were gathered retrospectively via the electronic medical record (EMR). Patients were only included if they were followed in the institution's HMP by their care coordination team and survived to discharge from S1P with further plans for cardiac intervention. Patients were excluded from analysis, though not the HMP, if born less than 35 weeks' gestation or had presented in extremis as a newborn requiring extracorporeal membrane oxygenation (ECMO) prior to their initial operation. The reason for this was to minimize potential confounding that prematurity and preoperative ECMO had on the ability to feed by mouth early in the patient's life. Patients were also excluded if they underwent biventricular repair in the first year of life.

The NPC-QIC rolled out collaborative-wide initiatives surrounding nutrition and advancement of full oral feeds, as well as improvements to perioperative care bundles at the end of 2017. The study period for our investigation was selected to minimize any potential effects that these or other extrinsically directed quality initiatives might have on our outcomes of interest. Furthermore, over this time interval, neither center implemented any major or widespread changes with respect to feeding algorithms, perioperative care, key personnel, or preoperative feeding as best as could be studied.

The structure of the HMP was the same across both institutions, involving daily monitoring of oxygen saturations, weights, intake, and output. Data were reviewed and acted on by a heart center care coordination team, thus creating an open line of communication between the families and the institution. The historical HMP structure included use of a notebook with daily data recordings. Information was transmitted by phone to the care team once per week, with decision-making about non-life-threatening information frequently being made based on potentially out-of-date data.

In 2016, both programs instituted a digital monitoring platform providing families with a secured, locked-down iPad directly connected to the institution's electronic medical record. Families were able to input daily data digitally using a patient-facing interface customized to the individual (Figure 1). Information was now reviewed daily utilizing the electronic medical record of the institution and the HMP-specific views. Families were contacted as clinically appropriate to necessitate interventions and changes to feeding plans, provide assessments, answer questions, or address any other concerns. Furthermore, digital face-to-face care was provided, when needed, by directly connecting speech therapy or nutrition services via a secure video link through the interface.

With the ease of real-time data collection and viewing, an institutional push at both centers was made to attempt to utilize more home nasogastric (NG) feeding for children who were slow to orally feed as daily interventions could be implemented in coordination with the care team. Thus, oral feed advances at home, in the setting of an HMP with full support, was encouraged for infants who required more time to achieve this goal. At-home graphical trends of NG feeds versus oral feeds were reviewed daily by the care team and, with the families, to continue advancement of oral feeds and obviate the need for tube-assisted nutrition. Patients requiring continued feeding support even after S2P were continued in the HMP as long as necessary.

Consequently, this created two distinct groups for comparison, one using a standard, nondigital HMP versus an integrated digital platform with an emphasis on continuing oral feed advances at home. During the whole study period, there were no changes in the personnel on the home monitoring team, no change in nutrition or speech therapy services through the hospital, and no change in how postoperative feeding was managed.

Baseline demographics for both groups were collected and were available for comparison. Outcome and nutrition variables were gathered to assess how the use of an expanded digital HMP would affect feeding outcomes and hospital course. Preoperative oral feeding was defined as by-mouth enteral nutrition at a rate greater than 20 mL/kg/d or any breastfeeding. Growth failure during the interstage was defined as any negative change in the weight-for-age *z*-score (WAZ)

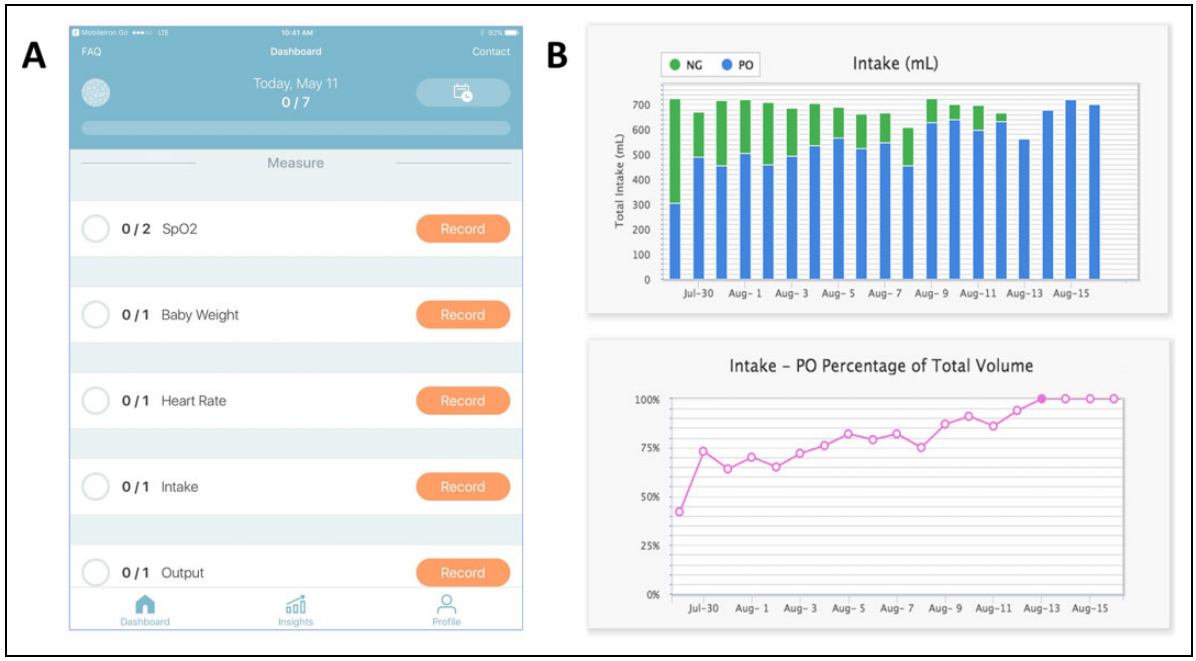

Figure 1. A, Patient-facing integrated application utilized at each center allowing patient-derived input. B, Provider view dashboard allowing daily advancement of oral feeds. Color image is available in the online version of the article.

using the weight at the time of S2P or weight at the time of death. Patients were analyzed in the type of HMP they were discharged into, regardless of adherence, to reduce ascertainment bias.

Continuous, normally distributed data are reported as mean $\pm$ SD, while non-normal data are presented as medians with interquartile ranges, where appropriate. Categorical variables are reported as frequencies (%). Comparisons were made using appropriate parametric and nonparametric hypothesis testing for both continuous (including *t* tests) and categorical variables including extension to the χ^2 test for multiple categories or Fisher test for lower total numbers. To assess outcomes over the first year of life, Kaplan-Meier analysis was performed and censored to last known status if patient had died prior to 12 months of age or at 12 months of age if the event had not occurred. Curves were compared using the log-rank test. A *P* value of less than .05 was considered significant. All statistical analysis was performed using SPSS.

Results

A total of 69 patients were identified during the study period, with 38 in the historical standard monitoring program compared to 31 who utilized the current digital platform. Daily weights, oxygen saturations, and intake and output were transmitted in the digital group 93.2% of the time, with 24 of the patients having 100% adherence to daily monitoring prior to S2P. Baseline demographics, anatomic, and surgical variables comparing the two groups are displayed in Table 1. There was no observed difference in the background demographics including birth weight, age at surgery, and proportion of patients who were fed orally prior to initial palliation. The majority of patients in both groups had hypoplastic left heart syndrome (HLHS) and its variants with an overall equal distribution of other single ventricle anomalies. The Norwood procedure with Sano modification remained the most frequently performed intervention followed by a systemic to pulmonary artery shunt.

Outcomes involving feeding are depicted in Table 2. There was no appreciable difference in initiation of feeds postoperatively among both groups. A total of eight patients (21%) underwent gastrostomy tube placement prior to S1P discharge in the standard HMP compared to three (10%) in the digital platform ($P = .32$). Use of the digital platform, along with the mentioned push to utilize temporary tube feeding more as an outpatient, resulted in eight patients (26%) being discharged home with NG tubes compared to one (3%) in the standard HMP ($P = .03$) and a reduction in the postoperative length of stay (33 vs 30 days, $P = .04$).

Weight parameters between S1P and S2P, the interstage period, are further represented in Table 2. Although patients were younger at the time of S2P in the digital group (4.6 vs 5.4 months, $P < .001$), they demonstrated a higher increase in their WAZ at the time of S2P compared to the standard HMP (0.71 vs 0.33, $P = .02$). This translated to better age-adjusted growth during the interstage for patients utilizing the digital platform. There were two deaths on the standard HMP and none using the digital platform. There were no adverse events associated with NG tube feeds in either population.

Of patients who were sent home with any type of tube feeds in the standard HMP, only two of them (22%) were successfully transitioned to oral feeds by age 1 compared to 72% of

Table 1. Baseline Demographics of Standard HMP Compared to Digitally Integrated HMP.[a]

	Standard HMP (n = 38)	Digitally integrated HMP (n = 31)	*P* value
Birth weight (kg)	3.14 ± 0.49	3.15 ± 0.54	.91
Gestational age (completed weeks)	38.2 ± 1.44	37.8 ± 1.70	.27
Age at initial surgery (days)	8.2 ± 4.9	7.5 ± 4.2	.60
Male gender	20 (53%)	21 (68%)	.20
Oral feeding prior to surgery	18 (47%)	20 (65%)	.10
Heterotaxy	4 (11%)	2 (6%)	.34
Major chromosomal anomaly	3 (8%)	0 (0%)	.11
Congenital gut anomaly	2 (5%)	1 (3%)	.65
Cardiac anatomy			.56
Hypoplastic left heart syndrome	18	23	
Tricuspid atresia	6	3	
Double outlet right ventricle	6	0	
Pulmonary atresia/intact ventricular septum	1	4	
Ebstein's anomaly	0	1	
Double inlet left ventricle	1	0	
Unbalanced AVSD	6	0	
Type of initial surgery			.44
Norwood/Sano	19	23	
Norwood/BT shunt	3	1	
Systemic to pulmonary shunt	11	6	
Hybrid procedure	5	1	

Abbreviations: AVSD, atrioventricular septal defect; BT shunt, Blalock-Taussig shunt; HMP, home monitoring program.
[a]Values are reported as mean ± SD and frequency (%) where appropriate.

Table 2. Descriptive Outcomes of Standard HMP Compared to Digitally Integrated HMP.

	Standard HMP (n = 38)	Digitally integrated HMP (n = 31)	*P* value
Postoperative day of first enteral feed	4.6 ± 3.3	5.3 ± 3.3	.69
Postoperative day of first oral feed	12.3 ± 8.0	13.2 ± 9.1	.67
Gastrostomy tube placed prior to S1P discharge	8 (21%)	3 (10%)	.32
Discharged with home NG feeds	1 (3%)	8 (26%)	.03
Postoperative length of stay (days)	33.0 ± 10.2	30.0 ± 12.5	.04
Age at S1P discharge (days)	41.2 ± 26	37.6 ± 16.5	.53
Weight at S1P discharge (kg)	3.18 ± 1.05	3.46 ± 0.71	.22
WAZ at S1P discharge	−1.48 ± 0.9	−1.67 ± 1.0	.48
Age at S2P (months)	5.4 ± 1.1	4.6 ± 0.6	<.001
Total home monitoring time (days)	122 ± 39.9	101 ± 25.1	.01
Weight gain during interstage (g/d)	20.0 ± 6.9	23.1 ± 4.8	.10
Change in WAZ at S2P admission	0.33 ± 0.9	0.71 ± 0.9	.02
Growth failure during interstage	8 (21%)	5 (16%)	.34
Successful transition to all oral feeds at 1 year	26 (68%)	28 (90%)	.03

Abbreviations: HMP, home monitoring program; NG, nasogastric; S1P, stage 1 palliation; S2P, stage 2 palliation; WAZ, weight-for-age z score.
[a]Values are reported as mean ± SD and frequency (%) where appropriate. Growth failure during interstage defined as negative change in weight-for-age z score.

patients sent home with tube feeds in the digital program ($P = .01$). The proportion of patients achieving all oral feeds at age 1 was 68% in the standard program compared to 90% in the digital program ($P = .03$). There were five patients in the digital group who were monitored even after S2P to continue feeding support, compared to none in the standard HMP. There were five patients, all using supplemental tube feeding, who had at least one virtual speech therapy encounter (range: 1-4 encounters) during the interstage period as part of their continued push to full oral feeds.

Freedom from gastrostomy tube placement and achievement of full oral feeds over time is depicted in the Kaplan-Meier analysis in Figure 2. There was a significantly lower amount of gastrostomy tubes placed in the digital group, as predicted, due to a push to utilize home NG tubes. Similarly, there was a higher rate of achieving full oral feeds in the digital group by the time the child turned one. In assessing both Kaplan-Meier curves, patients in the standard group who were slow to orally feed had gastrostomy tubes placed prior to discharge. This differs from the subsequent patients who were

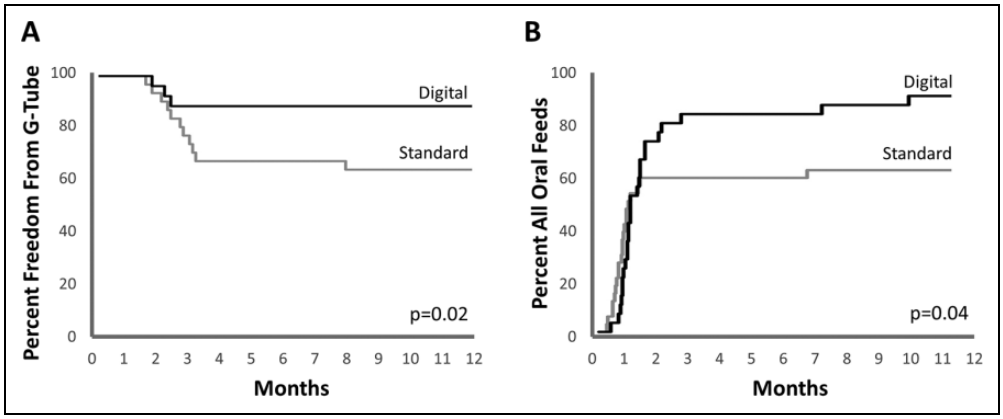

Figure 2. A, Kaplan-Meier curves demonstrating cumulative freedom from gastrostomy (G-tube) placement through the first year of life. B, Kaplan-Meier cumulative 1 − survival curves showing the proportion of patients achieving full oral feeds without tube supplementation through the first year of life.

slow to achieve oral feeds and, supported at home with NG tubes and the digital platform, who were able to achieve full oral feeding eventually at a much higher rate.

Comment

Our findings suggest that infants with shunt-dependent single ventricle heart disease can feed and grow better utilizing a more comprehensive digital remote monitoring platform as part of a coordinated HMP. Furthermore, they were also much more likely to advance to entirely oral enteral nutrition by one year of age, supplanting the need for surgically placed gastrostomy tubes. This was accomplished through the use of home NG feeds coupled with careful daily review of data, demonstrating the need for a more prolonged feed advance for children who may be slow to achieve good oral skills.

With the recent profound improvement in mortality in this population, focus has shifted to improving morbidity in young children with single ventricle heart disease. Growth failure between S1P and S2P is common and is a frequent target for outcomes-based initiatives. Numerous studies have demonstrated patients with an actual lower WAZ at the time of S2P than was present right after discharge from S1P.[10,13-17] The reason for growth failure along with poor oral feeding is surely multifactorial. Laryngopharyngeal dysfunction, an ongoing catabolic state, and the potential for significantly altered hemodynamics have all been implicated.[11,18,19]

Because of the clear need to maximize growth during this time, use of prolonged supplemental tube feeding is frequent in most programs following staged surgical palliation. Rates of supplemental tube feeding (either via NG tube or surgical gastrostomy tube) at the time of discharge range from 20% to 68% in various series.[13,14,20-23] Yet, placement of a surgical tube does not ensure improved growth, and infants who develop good oral feeding skills have a higher WAZ prior to S2P.[24,25] Some programs have implemented routine gastrostomy placement in all infants with HLHS but do not find that patients grow any better with this feeding method compared to their historical controls.[26] Furthermore, while potentially not causative, need for supplemental tube feedings in the interstage is also associated with higher mortality.[4]

Prolonged supplemental tube feeding has a further negative association with neurodevelopmental outcomes and overall quality of life. Children who require tube feeding years after initial palliation have higher rates of developmental delay, mealtime aggression, resistance to eating, and parental aversion to mealtime.[12,27] Even in younger children, longer than three months of tube feeding is associated with poorer Psychomotor Developmental Index and lower Mental Developmental Index on the Bayley at six months of age.[23]

The data from this study would suggest that a continued push to full oral feeding early in life could lead to a higher proportion of infants who are entirely fed by mouth at one year of age. This is evident in examining the Kaplan-Meier curves in our study, showing that infants who had a gastrostomy tube placed early on tended to stay with tube feeds in the first year and patients who were supported for a longer period of time at home with NG tubes could achieve higher rates of full oral nutrition. These results are similar to other high-risk preterm infants where an earlier push toward oral feeding leads to less prolonged tube feeding and tube dependence.[28] Even in patients with single ventricle physiology, an early move toward exclusive oral feeding has been linked to significantly better growth.[16,24]

The results from this study suggest that there is a subset of infants with single ventricle physiology who may benefit from more time in a structured environment to achieve full oral skills. Inpatient feeding programs are intensive but have the effective benefit of bringing together highly skilled allied health professionals with continuous assessment of oral feed advancement to wean from an indwelling tube.[29,30]

Digital remote monitoring platforms, such as the one utilized in this study, can mimic certain aspects of these programs by providing real-time tube and oral feeding data, weight assessment, secure video connection to allied health professionals regardless of the patient location, and streamlined

communication between providers and families. Our study was clearly underpowered to truly assess the effect of the video, telehealth option, yet continues to demonstrate how we can leverage emerging technologies to connect with these patients in ways we never were able to before.

There has been clear precedent for platforms such as these in improving outcomes in adult patients with congestive heart failure and in diabetes management.[31,32] Furthermore, telehealth platforms have been integrated into single ventricle teams previously with some moderate success.[7-9] Modern comprehensive platforms have also demonstrated reduction in delays in care, lower resource utilization, and a lower incidence of growth failure.[6] Despite early success, widespread adoption of remote monitoring platforms in patients with complex congenital heart disease has yet to occur.[33]

Limitations

Secondary to the smaller numbers and retrospective nature of this study, it is challenging to assign complete causation to the digital platform as the sole variable affecting outcomes. Yet, teams at both institutions did not feel comfortable in discharging infants with congenital heart disease who were still working on oral feed advance without a system in place to ensure timely and accurate data transmission, ease of use for families, and continued access to resources available at the main surgical center. Furthermore, utilizing an historical cohort means that there could have been other differences between the two groups rather than just the use of a digital platform. Timing of the study was chosen to minimize this type of selection bias as it was felt that the structure of the HMP at both institutions differed only by addition of the remote monitoring platform, including similar personnel, no other new major quality initiatives, no new feeding algorithms, and no center-wide changes in perioperative care.

Conclusions

Use of a digital, fully EMR-integrated, virtual HMP focusing on continuing feeding support at home reduced postoperative length of stay in neonates undergoing staged single ventricle palliation. It also allowed infants who were slow to achieve full oral feeds to be cared for at home using similar data fidelity and preserved access to resources as if they had remained admitted. Nasogastric tube feeding in all patients was safe, without reported adverse events, and led to higher rates of full oral feeding at one year of age than patients who underwent historical standard interstage monitoring.

Declaration of Conflicting Interests

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