Association of Interstage Home Monitoring with Mortality, Readmissions, and Weight Gain: A Multicenter Study from the National Pediatric Cardiology Quality Improvement Collaborative

Running title: Oster et al.; Outcomes of Interstage Home Monitoring

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Abstract

**Background**—Daily home monitoring of oxygen saturation and weight has been reported to improve outcomes for patients with single ventricle heart disease during the period between stage I palliation and stage II palliation. However, these studies have been limited to single institutions and used historical controls. Our objective was to determine the association of various interstage home monitoring strategies with outcomes using a multicenter cohort with contemporary controls.

**Methods and Results**—We performed a retrospective cohort study using prospectively collected data from the National Pediatric Cardiology Quality Improvement Collaborative from 2008 to 2012. We compared interstage mortality, unscheduled readmissions, and change in weight-for-age Z-score for various home monitoring strategies of oxygen saturation (N=494) or weight (N=472), adjusting for sex, syndrome, tricuspid regurgitation, arch obstruction, and shunt type. Overall interstage mortality was 8.1%, and 47% had ≥1 unscheduled readmission. We did not find any associations of home oxygen saturation and/or weight monitoring with mortality or readmission. While there was no difference in weight-for-age Z-score for daily (0.33 ± 0.12) vs. weekly weight monitoring (0.34 ± 0.18, p=0.98), daily home weight monitoring was superior to no home weight monitoring (-0.15 ± 0.18, p<0.01).

**Conclusions**—Home weight monitoring is associated with improved weight gain during the interstage period, but we did not find any benefits in other clinical outcomes for either home oxygen saturation monitoring or home weight monitoring.

**Key words:** heart defects, congenital, mortality, hypoxia, readmission, home care
Introduction

While there have been great improvements in the medical and surgical management of children with single ventricle heart disease over the past 3 decades, the period between stage I palliation (SIP) and stage II palliation (SIIP) remains a time of notable morbidity and mortality. In the Pediatric Heart Network Single Ventricle Reconstruction trial, 97 of 549 patients had in-hospital death or transplant following SIP, and another 50 of the 426 who were discharged to home died during the interstage period prior to SIIP.1

One key effort to improve these interstage outcomes has been the use of home monitoring. Home monitoring of single ventricle infants during the interstage period consists of either home oxygen saturation monitoring, home weight checks, or both, at a given frequency. The type of frequency varies by institution, with the most common frequency being daily. Parents are typically instructed to seek medical attention based on predetermined triggers for low oxygen saturation or poor weight gain. The hope is that home monitoring may identify potential deteriorations in clinical condition sooner, with earlier detection translating to improved outcomes. In some centers, this hope appears to have been realized. In 2003, a study in Wisconsin demonstrated a decrease in interstage mortality from 16% to 0% following the introduction of home monitoring.2 In their follow up study, the interstage mortality was 2% over 10 years of experience with over 150 patients with the use of home monitoring.3 Similarly, multiple other studies have shown decreases in interstage mortality with the use of home monitoring.4-6

These prior studies are limited by the fact that they were retrospective, single-center studies and used historical controls. Our purpose, therefore, was to determine the associations of various home monitoring strategies with interstage outcomes using a multicenter cohort with
contemporary controls. We hypothesized that home monitoring would be associated with improved outcomes and that patients with more frequent home monitoring would have better outcomes than those with less frequent home monitoring.

Methods

Study Design and Data Source

We performed a retrospective cohort study using data prospectively collected through the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC), which has previously been well described. Briefly, the NPC-QIC was formed in 2006 by the Joint Council on Congenital Heart Disease with a goal to improve care and outcomes for children with cardiovascular disease. The aim of the initial quality improvement project of the NPC-QIC is to reduce mortality and improve quality of life during the interstage period (the period between SIP discharge and SIIP) for infants with a univentricular heart who require a Norwood operation. Registry data have been collected prospectively from participating centers beginning in 2008. Individual patient data are collected at the site of surgical care and are entered into a REDCap database by the local NPC-QIC teams. Quarterly enrollment audits are performed to determine the percentage of eligible patients enrolled in the NPC-QIC registry. All patients from 2008-2012 who had complete data for all of our variables of interest were eligible for this study. During the time of this study, the enrollment audit demonstrated that >95% of eligible patients were enrolled in the registry across the collaborative sites. Individual institutional review boards at each participating center approved participation in the registry, and family consent was obtained prior to being included in the registry.

Variables of Interest

Two main exposures of interest were collected at the time of discharge from the SIP
hospitalization: home oxygen saturation monitoring and home weight monitoring. We
categorized each variable according to the planned frequency of monitoring: daily, weekly, or
none. Those with other oxygen or weight monitoring frequencies such as “three times per week”
or “twice weekly” were excluded due their rarity, and those with “as needed” were excluded due
to the ambiguity regarding actual frequency. For both types of home monitoring, our primary
outcome of interest was interstage mortality, and our secondary outcomes of interest included
occurrence of at least one unscheduled readmission for any cause and a composite measure of
interstage mortality or transplant (mortality/transplant). For the home oxygen saturation
monitoring analyses, occurrence of at least one unscheduled readmission for cyanosis was an
additional secondary outcome. For the home weight monitoring analyses, additional secondary
outcome measures included occurrence of at least one unscheduled readmission for poor weight
gain and change in interstage weight-for-age Z-score (ΔWAZ). The weight gain analyses were
limited to those patients who had weights recorded at both the time of discharge after SIP and the
time of SIIP (i.e. interstage ΔWAZ).

In each of our analyses, our target covariates of interest included sex, presence of a

genetic syndrome, institution, degree of tricuspid regurgitation by postoperative echocardiogram
prior to SIP discharge (none/trivial/mild vs. moderate/severe), degree of arch obstruction by
postoperative echocardiogram prior to SIP discharge (0-10mmHg vs. >10mmHg), ventricular
function on postoperative echocardiogram prior to SIP discharge (normal function/low normal
function/mild dysfunction vs. moderate/severe dysfunction) and shunt type (Modified Blalock-
Taussig shunt [MBTS], right ventricle to pulmonary artery shunt [RVPAS], or Hybrid).

However, some covariates could not be included due to lack of variability within the dataset, i.e.
the models would not run properly or there were concerns about collinearity. For institution,
there were some institutions with such small sample sizes that the models would not converge, and most institutions included only one type of monitoring frequency; this covariate was thus not included. For ventricular function, only 4% of patients had ventricular function rated as moderate or severe dysfunction, and all but one of these had daily monitoring for oxygen and weight; this covariate was also not included. For shunt type, almost all infants with shunt type of “Hybrid” had daily home oxygen saturation monitoring and daily home weight monitoring, and we thus excluded those with a “Hybrid” Norwood from our study; those with a shunt type for MBTS or RVPAS remained in the study. We furthermore excluded patients who had no echocardiographic data, who were not candidates for SIIP, who were lost to follow-up, who withdrew from the study, or who had insufficient data for the covariates in our models.

Statistics

Patient demographics and clinical characteristics were summarized using frequency and percent for categorical variables. Age at SIIP was summarized using medians and was compared among the monitoring groups using the Steel-Dwass test for pairwise comparisons. Multivariable logistic regression models were developed for all of our dichotomous outcomes of interest. For our primary outcome of interstage mortality, we further performed proportional hazards models and adjusted survival curves, censoring patients at the time of SIIP or at 9 months following discharge from SIP, whichever occurred earlier. For ΔWAZ, we constructed an analysis of covariance model and report least square means and standard errors from the model. All multivariable models adjusted for sex, presence of a genetic syndrome, degree of tricuspid regurgitation by postoperative echocardiogram prior to SIP discharge, degree of arch obstruction by postoperative echocardiogram prior to SIP discharge, and shunt type. The reference group for each model was the daily home monitoring group, chosen a priori. As we had information
regarding only the planned type and frequency of home monitoring at time of discharge after SIP, all analyses were intent-to-treat analyses. Our exposure variables of interest were considered significant if p<0.05. All analyses were conducted with SAS Version 9.3 (Cary, NC). While this was an observational study in which we used all data available at the time of this study, we anticipated that we would need a total of 250 patients in order to have 80% power to detect a 50% difference in mortality between daily and weekly home monitoring groups at the 0.05 significance level, assuming a 5% mortality in the daily home monitoring groups and 10% mortality in the weekly home monitoring groups.

Results

Of 767 enrollees at 50 centers, 494 met inclusion criteria for the home oxygen saturation monitoring analyses and 472 for the home weight monitoring analyses. (Figure 1) In both portions of the study, the majority of the subjects were male, did not have a genetic syndrome, had a RVPAS, had no/trivial/mild tricuspid regurgitation, and had a residual aortic arch gradient 0-10mmHg. (Table 1) Overall, 8.1% experienced interstage mortality, and 47% had at least 1 unscheduled readmission.

Of the 494 subjects in the home oxygen saturation monitoring analyses, 80% had daily home oxygen saturation monitoring, 12% had weekly, and 7% had none. Median age at SIIP was similar for the daily monitoring group and the weekly monitoring group (141 days vs. 151 days, p=0.83), but those without home oxygen saturation monitoring were more likely to have SIIP at a later date than those with daily monitoring (167 days, p=0.002). In the final multivariable analyses, there were no statistically significant differences between daily home oxygen saturation monitoring and the other groups with regards to interstage mortality, mortality/transplant,
unscheduled readmission, or unscheduled readmission for cyanosis. (Table 2 and Supplemental Table 1) In the adjusted proportional hazards and survival analyses for home oxygen saturation monitoring, there was no significant difference in interstage mortality for weekly monitoring vs. daily monitoring (HR 1.05, 95% CI 0.35-3.17, p=0.94) or for no monitoring vs. daily monitoring (HR 0.73, 95% CI 0.17-3.12, p=0.68). (Figure 2)

Of the 472 subjects in the home weight monitoring analyses, 75% had home daily weight monitoring, 13% had weekly, and 12% had none. Median age at SIIP was similar between the daily monitoring group and the weekly monitoring group (143 days vs. 151 days, p=0.93); however the time to SIIP was significantly longer for the no monitoring group compared to the daily monitoring group (164 days, p=0.004). In the final multivariable analyses, there were no statistically significant differences between daily home monitoring and the other groups with regards to mortality, mortality/transplant, unscheduled readmission, or unscheduled readmission for poor weight gain. (Table 3 and Supplemental Table 2) In the adjusted proportional hazards and survival analyses for home weight monitoring, there was no significant difference in interstage mortality for weekly monitoring vs. daily monitoring (HR 0.98, 95% CI 0.32-3.00, p=0.97) or for no monitoring vs. daily monitoring (HR 0.46, 95% CI 0.11-1.94, p=0.29). (Figure 3) When comparing the ΔWAZ among the 423 infants with sufficient information for weight gain, there was no difference for daily (lsmean±sem) (0.33 ± 0.12) vs. weekly weight monitoring (0.34 ± 0.18, p=0.98), but daily was superior to no home weight monitoring (-0.15 ± 0.18, p<0.01).

There was notable overlap between the oxygen and weight monitoring groups by type of monitoring. That is, those with one type of frequency of home oxygen monitoring were likely to have the same frequency of home weight monitoring. Of those with daily, weekly, or no home
oxygen monitoring, 89%, 98%, and 100% had daily, weekly, or no home weight monitoring, respectively.

Discussion

In this large, multicenter cohort study, 80% of infants with single ventricle physiology received daily home oxygen saturation monitoring during the interstage period between SIP and SIIP and 75% received daily home weight monitoring. For oxygen home monitoring, we did not find any association of daily home monitoring with mortality, mortality/transplant, or readmission as compared to those with weekly or no home oxygen saturation monitoring. In our analyses of home weight monitoring, we likewise did not find any differences in mortality, mortality/transplant, readmission or weight gain between the daily and weekly weight monitoring groups, but we did find that those patients with daily home weight monitoring had improved interstage weight gain compared to those without any home weight monitoring.

Association of home monitoring with mortality

Our findings of no improvement in mortality for either home oxygen saturation monitoring or home weight monitoring differ from the findings of prior single center studies. In the studies from Wisconsin and Stanford, interstage mortality was 0% following the introduction of daily home oxygen and weight monitoring, down from 16% and 7%, respectively. In Wisconsin this improvement was sustained over a ten year period with overall interstage mortality of 2%. In our study, interstage mortality was approximately 8% overall, with no significant differences between the daily, weekly, and no home monitoring groups. Aside from a potential type II error in our study, which is always a possibility in a negative study, there are two possible explanations for these differences in findings. First is the possibility of general improvements
over time, unrelated to home monitoring strategies. In the studies from Wisconsin and Stanford, the home monitoring group cohort and the non-home monitoring group cohort were not concurrent. General changes that occurred over time independent of home monitoring, such as improved interstage care (e.g. a dedicated team), improved prenatal diagnosis rates, changes in surgeons or surgical practices, earlier timing of SIIP, or improvements in postoperative care, could have confounded the findings. When we compare our multicenter cohort, which enrolled subjects from 2008 to 2012, to that of the Pediatric Heart Network Single Ventricle Reconstruction (SVR) Trial,¹ which enrolled subjects from 2005 to 2008 at 15 centers to compare MBTS to RVPAS, we see a similar effect. In the SVR trial, there was an overall estimated interstage mortality of 12%, a rate that is notably higher than the overall mortality of 8% in our more recent study. It is of interest to note that the majority of SVR centers also participated in NPC-QIC and thus contributed data to the more recent cohort reported in this study. Similar temporal findings are reported in a large single-center study from Houston, a program that participates in NPC-QIC.⁵ In that study, from January 2002 to August 2007, prior to initiation of a coordinated single ventricle program that included daily home oxygen and weight monitoring, interstage mortality was 12%; in the period from September 2007 to February 2010 following the introduction of the single ventricle program, interstage mortality was 8%, although this difference did not meet statistical significance.

A second possible explanation for the findings in our study is that, while home monitoring is the presumed driver of improvements in earlier reports, it could be the case that home monitoring is but one component of an overall coordinated interstage care plan, and that it is the coordination of care that is helping effect change. In the studies reported from Stanford and Houston (both NPC-QIC participants), home monitoring was just one part of a standardized
coordination of care that also included elements of pre-discharge planning, coordinated outpatient follow-up, and tentatively scheduled SIIP and pre-SIIP catheterization. In our study, although not all centers utilized home monitoring, all centers were participants in a national quality improvement collaborative that aimed to improve interstage care through standardized care and care coordination that, in many centers, included focused interstage clinics and teams. Institutional participation in a quality improvement effort has been shown to improve outcomes.

8 For instance, in NPC-QIC the use of a standardized nutrition bundle is associated with improved weight gain during the interstage period.9 We believe that having orchestrated coordination of care may be the key driver of improved outcomes during the interstage period over time. For some centers, this coordinated care plan includes home monitoring; for others it does not.

Association of home monitoring with weight gain

While we did not find any difference with regards to mortality by type of home monitoring, we did show important benefits with regards to weight gain for patients who had home weight monitoring. As our study shows, subjects with either daily or weekly home weight monitoring on average gained percentiles in weight (net positive ΔWAZ), whereas those without home weight monitoring lost percentiles. This is consistent with prior studies. In both Wisconsin and Houston, home weight monitoring has been associated with improved WAZ at time of SIIP.5,10 One theory for this improved weight gain is that frequent home monitoring allows a greater opportunity for care coordinators to intervene.6 Indeed, in a recent single-center study in Atlanta, the greatest predictor of improved growth during the interstage period was the number of nutritional interventions by the infant’s cardiologist.11 Appropriate weight gain and nutrition during the interstage period has been shown to be associated with a myriad of important
outcomes in this population. During the SIIP, lower WAZ has been shown to be associated with a higher rate of complications.12 Furthermore, lower WAZ at the time of SIIP is associated with a higher risk of death or cardiac transplantation before stage III palliation.13

Other potential benefits of home monitoring

There may be benefits to home monitoring of infants with single ventricle beyond those measured in this study, particularly the psychological effect of home monitoring on parents. Unfortunately, data on such effects are quite limited. In one presented abstract, researchers found that parental stress and anxiety levels decreased after one month of home monitoring, but this study lacked a control group to compare changes in such levels that may occur without home monitoring.14 In an informal survey of parents who participated in the NPC-QIC, there were mixed results regarding the psychological impact of home monitoring.15 Most, but not all, families had very positive experiences with the use of home monitoring. One mother commented in the survey that it was a “blessing” to have pulse oximetry at home, but it was a “curse” for her husband who “focuses on numbers and not the overall picture of our child.” Indeed, constant monitoring leading to alarm fatigue is a well-recognized problem in intensive care units,16 and it is now being seen with some home monitoring devices such as continuous glucose monitors worn by patients with diabetes.17 It is likely that home monitoring for infants with single ventricle may reduce anxiety for some families but not for others. Like all therapies in medicine, the balance of the benefits and side effects for each patient (and the family) must be considered. More studies are needed to better understand family stresses and the impact of different care practices on the families of these fragile infants.

To shed light on the balance of benefits and risks of home monitoring for infants with single ventricle, lessons may be learned from the experience of home apnea monitoring for
premature infants. Available as a treatment option since the 1970’s, home apnea monitoring has been endorsed by both the American Academy of Pediatrics in 1978 \(^{18}\) and the National Institutes of Health in 1986 \(^{19}\) for the prevention of sudden infant death syndrome. However, four decades of research have not shown such monitoring to be effective in preventing mortality in infants believed to be at risk for sudden infant death.\(^{20}\) Home monitoring for children in this population is not believed to reduce parental stress levels, and may even slightly increase them.\(^{21}\)

As a result, the use of home monitoring to prevent sudden infant death remains controversial, with its use guided predominantly by physician preference.\(^{22,\,23}\)

**Strengths and limitations**

This study has several strengths. First, it is a multi-center cohort study with varying types of home monitoring. Second, all members of the cohort were enrolled prospectively and during the same period. Finally, the NPC-QIC has a high enrollment rate, with over 95% of eligible patients consenting for enrollment during the period of this study. As a result of these strengths, this is the largest study to date on home monitoring of infants with single ventricle physiology, and the results are not biased by institutional changes that may have occurred at one center with the advent of home monitoring.

This study, however, is not without its limitations. First, we were not able to include all covariates that we wished to include in our models. Because there were very small sample sizes at some institutions and because almost all institutions used only one type of monitoring as part of the standard practice at their institution, we could not control for institution in our analyses. For a similar reason we excluded those with a shunt type of “Hybrid.” Given that almost all of those with a “Hybrid” Norwood had daily home monitoring for oxygen and weight, it was not possible to control for this shunt type in our analyses and we thus limited our analyses to those
with a RVPAS or MBTS. With the lack of variability in the ventricular function variable, this variable was dropped as well. While we did not wish to drop variables or observations, the lack of variability in these variables did provide reassurance that the use of home monitoring was not used discriminately, i.e. home monitoring did not seem to be offered only to the highest risk patients. Second, we had reliable information regarding the planned home monitoring strategy at the time of discharge after SIP, but we do not know whether families were actually implementing the planned strategies. If families were performing home monitoring at some frequency other than that which was planned for them, our findings would be subject to misclassification bias and may have potentially contributed to our null findings. However, we believe that this most closely resembles real-world scenarios and makes our findings more generalizable. Healthcare personnel can recommend a monitoring option to the family, but whether they follow that plan is up to them. Families with monitoring equipment can choose not to use it, and those without such equipment can choose to obtain it on their own through various third parties. Finally, a potential limitation of any negative study is the lack of power, typically as a result of low numbers. This may be an issue in our study even though it is the largest study to date to examine the issue of home monitoring. While we far exceeded our target enrollment numbers for this study, the study was limited by the fact that enrollment in the groups was heavily skewed toward the daily home monitoring arm, a reflection of current practice. A randomized controlled trial would be one approach to overcoming this limitation. Alternatively, if practice patterns were to change, particularly with regard to the use of home oxygen saturation monitoring, this study could be replicated but with a more even distribution of monitoring frequencies in each study arm.

**Conclusion**

In this large, multicenter study using contemporary controls, we were unable to detect any
benefit of interstage daily home oxygen or weight monitoring with regards to mortality, mortality/transplant, unscheduled clinic visits, or unscheduled readmissions, but we did find a benefit with home weight monitoring with regards to weight gain. Importantly, overall mortality was lower in this cohort than in previous cohorts, suggesting that improved overall care coordination, of which home monitoring is one component at most centers, may be a key driver in improved interstage outcomes. While it is promising to see that overall interstage mortality may be decreasing over time for this vulnerable population, further efforts are needed if the goal of 0% interstage mortality rate is to be realized.

Conflict of Interest Disclosures: None.

References:


**Table 1.** Baseline Characteristics of Infants Meeting Inclusion Criteria for the Oxygen Saturation Monitoring and Weight Monitoring Analyses.

<table>
<thead>
<tr>
<th></th>
<th>Oxygen Saturation Monitoring (N=494)</th>
<th>Weight Monitoring (N=472)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>309 (63%)</td>
<td>296 (63%)</td>
</tr>
<tr>
<td>Female</td>
<td>185 (37%)</td>
<td>176 (37%)</td>
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<tr>
<td><strong>Presence of a Genetic Syndrome</strong></td>
<td></td>
<td></td>
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<tr>
<td>Yes</td>
<td>44 (9%)</td>
<td>42 (9%)</td>
</tr>
<tr>
<td>No</td>
<td>450 (91%)</td>
<td>430 (91%)</td>
</tr>
<tr>
<td><strong>Shunt Type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Modified Blalock-Taussig shunt</td>
<td>207 (42%)</td>
<td>202 (43%)</td>
</tr>
<tr>
<td>Right ventricle to pulmonary artery shunt</td>
<td>287 (58%)</td>
<td>270 (57%)</td>
</tr>
<tr>
<td><strong>Tricuspid Regurgitation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None/Trivial/Mild</td>
<td>384 (78%)</td>
<td>367 (78%)</td>
</tr>
<tr>
<td>Mod/Severe</td>
<td>110 (22%)</td>
<td>105 (22%)</td>
</tr>
<tr>
<td><strong>Arch Obstruction</strong></td>
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<td></td>
</tr>
<tr>
<td>0-10 mmHg</td>
<td>408 (83%)</td>
<td>385 (82%)</td>
</tr>
<tr>
<td>&gt; 10 mmHg</td>
<td>86 (17%)</td>
<td>87 (18%)</td>
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</table>
Table 2. Association of Interstage Home Oxygen Saturation Monitoring Frequency with Outcomes for Infants with Single Ventricle Heart Disease.

<table>
<thead>
<tr>
<th></th>
<th>Daily (referent)</th>
<th>Weekly</th>
<th>Adjusted OR* (95% CI)</th>
<th>P-Value</th>
<th>None</th>
<th>Adjusted OR* (95% CI)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
<td></td>
<td>n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interstage Mortality</td>
<td>N = 397</td>
<td>N = 61</td>
<td>1.10 (0.35-3.50)</td>
<td>0.87</td>
<td>2 (6%)</td>
<td>0.85 (0.19-3.79)</td>
<td>0.83</td>
</tr>
<tr>
<td>Interstage Mortality or</td>
<td></td>
<td></td>
<td>0.97 (0.31-3.04)</td>
<td>0.96</td>
<td>5 (14%)</td>
<td>2.12 (0.75-6.00)</td>
<td>0.16</td>
</tr>
<tr>
<td>Transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥1 Unscheduled Readmission (any cause)</td>
<td>190 (48%)</td>
<td>25 (41%)</td>
<td>0.87 (0.49-1.54)</td>
<td>0.63</td>
<td>17 (47%)</td>
<td>1.02 (0.51-2.05)</td>
<td>0.95</td>
</tr>
<tr>
<td>≥1 Unscheduled Readmission for Cyanosis</td>
<td>47 (12%)</td>
<td>6 (10%)</td>
<td>0.91 (0.36-2.31)</td>
<td>0.84</td>
<td>4 (11%)</td>
<td>1.02 (0.34-3.05)</td>
<td>0.97</td>
</tr>
</tbody>
</table>

*Adjusted for sex, presence of a genetic syndrome, degree of tricuspid regurgitation, degree of arch obstruction, and shunt type

Table 3. Association of Interstage Home Weight Monitoring Frequency with Outcomes for Infants with Single Ventricle Heart Disease.

<table>
<thead>
<tr>
<th></th>
<th>Daily (referent)</th>
<th>Weekly</th>
<th>Adjusted OR* (95% CI)</th>
<th>P-Value</th>
<th>None</th>
<th>Adjusted OR* (95% CI)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
<td></td>
<td>n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interstage Mortality</td>
<td>N = 355</td>
<td>N = 60</td>
<td>1.09 (0.34-3.53)</td>
<td>0.89</td>
<td>3 (5%)</td>
<td>0.79 (0.23-2.78)</td>
<td>0.72</td>
</tr>
<tr>
<td>Interstage Mortality or</td>
<td></td>
<td></td>
<td>0.95 (0.30-3.03)</td>
<td>0.93</td>
<td>6 (11%)</td>
<td>1.51 (0.58-3.92)</td>
<td>0.40</td>
</tr>
<tr>
<td>Transplant</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥1 Unscheduled Readmission (any cause)</td>
<td>170 (48%)</td>
<td>24 (40%)</td>
<td>0.85 (0.47-1.54)</td>
<td>0.59</td>
<td>27 (47%)</td>
<td>1.04 (0.59-1.85)</td>
<td>0.88</td>
</tr>
<tr>
<td>≥1 Unscheduled Readmission for Poor Weight Gain</td>
<td>21 (6%)</td>
<td>4 (7%)</td>
<td>1.24 (0.38-4.09)</td>
<td>0.72</td>
<td>1 (2%)</td>
<td>0.32 (0.04-2.47)</td>
<td>0.27</td>
</tr>
<tr>
<td>Change in weight-for-age Z-score ≤0 (in those with weights recorded)</td>
<td>110 (35%)</td>
<td>18 (32%)</td>
<td>1.05 (0.55-2.01)</td>
<td>0.88</td>
<td>23 (45%)</td>
<td>1.34 (0.98-3.36)</td>
<td>0.06</td>
</tr>
</tbody>
</table>

*Adjusted for sex, presence of a genetic syndrome, degree of tricuspid regurgitation, degree of arch obstruction, and shunt type
Figure Legends:

Figure 1. Selection criteria for inclusion in the oxygen and weight monitoring analyses.

Figure 2. Adjusted survival for home oxygen saturation monitoring. Those with weekly or no home oxygen saturation monitoring had similar interstage mortality as compared to those with daily home oxygen saturation monitoring (p=0.98 and 0.84, respectively). Results are adjusted for sex, presence of a genetic syndrome, degree of tricuspid regurgitation, degree of arch obstruction, and shunt type.

Figure 3. Adjusted survival for home weight monitoring. Those with weekly or no home weight monitoring had similar interstage mortality as compared to those with daily home weight monitoring (p=0.97 and 0.60, respectively). Results are adjusted for sex, presence of a genetic syndrome, degree of tricuspid regurgitation, degree of arch obstruction, and shunt type.
Patients discharged home after Stage I Palliation (n=767)

- Excluded patients with no echocardiographic data (n=111)

n=656

- Excluded patients who were not a candidate for stage II palliation, lost to follow-up, or withdrew from study for other reasons (n=7)

n=649

- Excluded patients with shunt types “hybrid” and “other” (n=55)

n=594

- Excluded patients with insufficient data for model covariates (n=85)

n=509

Other or missing frequencies of weight monitoring (n=37)

Weight monitoring daily, weekly, or none (n=472)

Other or missing frequencies of oxygen monitoring (n=15)

Oxygen monitoring daily, weekly, or none (n=494)
Figure 2

Survival Probability vs. Months Following Discharge After Stage I Palliation for different oxygen monitoring frequencies: Daily, Weekly, and None.
Association of Interstage Home Monitoring with Mortality, Readmissions, and Weight Gain: A Multicenter Study from the National Pediatric Cardiology Quality Improvement Collaborative

Matthew Oster, Alexandra Ehrlich, Eileen King, Christopher J. Petit, Martha Clabby, Sherry Smith, Michelle Glanville, Jeffrey Anderson, Lynn Darbie and Robert H. Beekman III

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### Supplemental Table 1. Reasons for readmission among those with home oxygen saturation monitoring

<table>
<thead>
<tr>
<th>Reason</th>
<th>Daily N(%)</th>
<th>Weekly N(%)</th>
<th>None N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of total readmissions*</td>
<td>278</td>
<td>39</td>
<td>23</td>
</tr>
<tr>
<td>Increased cyanosis</td>
<td>63 (23%)</td>
<td>8 (21%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Poor weight gain</td>
<td>22 (8%)</td>
<td>4 (10%)</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>Feeding problems</td>
<td>58 (21%)</td>
<td>5 (13%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Breathing problems</td>
<td>58 (21%)</td>
<td>9 (23%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Vomiting or diarrhea</td>
<td>48 (17%)</td>
<td>9 (23%)</td>
<td>2 (9%)</td>
</tr>
<tr>
<td>Fever</td>
<td>15 (5%)</td>
<td>2 (5%)</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>Fussiness</td>
<td>9 (3%)</td>
<td>1 (3%)</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>Other</td>
<td>112 (40%)</td>
<td>13 (33%)</td>
<td>12 (52%)</td>
</tr>
</tbody>
</table>

*The numbers represent readmissions, not patients, and the percentages represent percent of all readmissions with that particular reason listed. Patients may have had multiple readmissions, and each readmission may have had multiple indications. As a result, the sum of the individual reasons for readmissions exceeds the number of total readmissions, and the total percentages exceed 100%.
Supplemental Table 2. Reasons for readmission among those with home weight monitoring

<table>
<thead>
<tr>
<th>Reason</th>
<th>Daily N(%)</th>
<th>Weekly N(%)</th>
<th>None N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of total readmissions*</td>
<td>252</td>
<td>38</td>
<td>37</td>
</tr>
<tr>
<td>Increased cyanosis</td>
<td>61 (24%)</td>
<td>8 (21%)</td>
<td>6 (16%)</td>
</tr>
<tr>
<td>Poor weight gain</td>
<td>22 (9%)</td>
<td>4 (11%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Feeding problems</td>
<td>56 (22%)</td>
<td>5 (13%)</td>
<td>4 (11%)</td>
</tr>
<tr>
<td>Breathing problems</td>
<td>50 (20%)</td>
<td>9 (24%)</td>
<td>7 (19%)</td>
</tr>
<tr>
<td>Vomiting or diarrhea</td>
<td>48 (19%)</td>
<td>9 (24%)</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Fever</td>
<td>13 (5%)</td>
<td>2 (5%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Fussiness</td>
<td>8 (3%)</td>
<td>1 (3%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Other</td>
<td>101 (40%)</td>
<td>12 (32%)</td>
<td>21 (57%)</td>
</tr>
</tbody>
</table>

*The numbers represent readmissions, not patients, and the percentages represent percent of all readmissions with that particular reason listed. Patients may have had multiple readmissions, and each readmission may have had multiple indications. As a result, the sum of the individual reasons for readmissions exceeds the number of total readmissions, and the total percentages exceed 100%.*