

Research Explained

The Journal of the American College of Cardiology published a study in April 2014: "Association of Home Monitoring with Interstage Mortality, Readmissions, and Weight Gain: A Multicenter Study from the National Pediatric Cardiology Quality Improvement Collaborative."

The abstract can be found here: http://content.onlinejacc.org/article.aspx?articleid=1856818

The NPC-QIC Research and Publication Committee reviewed this article, and a summary of the findings can be found below.

Key Findings:

Although home monitoring (measuring oxygen saturations and weight) has been an important part of interstage care programs at many hospitals, this study found that home monitoring in and of itself may help babies to gain weight better but does not necessarily prevent interstage death or hospital readmissions.

Main Finding from this Study:

The time between the Norwood and Glenn surgeries for Hypoplastic Left Heart Syndrome and other similar congenital heart disease is called the interstage period. In an effort to reduce interstage death many hospitals have instituted home monitoring programs. These programs take a variety of forms, with variations in what is monitored (oxygen saturation, weight gain) and how frequently (daily, weekly, other).

Much of the evidence to support home monitoring comes from small, single center studies. But these studies are not perfect. In these studies:

- 1) Home monitoring was often one part of an overall change in interstage care coordination at a single center and
- 2) the effects of home monitoring were compared to the outcomes that happened historically.

This study attempted to overcome those limitations by using information from many hospitals and comparing information from the same time period.

This study describes the outcomes of interstage survival, readmissions, and weight gain depending on the type and frequency of home monitoring. The types of monitoring done at home were oxygen saturations and/or weights on home scale. How often families were asked to monitor these things was either daily, weekly, or not at all.

The authors found that weight gain significantly improved with daily or weekly monitoring, but they did not find any differences with regards to survival or readmissions. In other words, monitoring weight helps babies to gain weight but does not necessarily impact their survival or prevent them from going back into the hospital.

About this Study:

Why is this study important?

This study is important because it is the first study to use information from many hospitals to evaluate home monitoring. Because NPC-QIC collects information from many centers with different home monitoring practices, our data can be used to study the variation between centers. Doing this allows us to learn from the contrasting experiences and evaluate what truly happens in a "real world" setting.

How was this study performed?

The authors used NPC QIC information from 2008-2012, which includes babies from over 50 centers. The authors looked at how often mortality (either death or transplant) and unscheduled readmission occurred for each type of monitoring. They also looked at how weight gain monitoring impacted readmission for poor weight gain and how oxygen saturation monitoring impacted readmission for low oxygen saturations (cyanosis). Patients were excluded if there were missing data, if the type of Norwood procedure was a Hybrid, or if the home monitoring frequency was other than daily, weekly, or none. Because certain risk factors are known to affect death and readmission rates, the authors made statistical adjustments for those risk factors, including sex, presence of a genetic syndrome, degree of tricuspid regurgitation, degree of arch obstruction, and shunt type.

The researchers for this study were at Children's Healthcare of Atlanta/Emory University and Cincinnati Children's Medical Center.

What were the findings from the research?

Oxygen Saturation Monitoring

494 patients with information recorded: 80% with daily monitoring, 12% weekly, 7% none

- No significant differences between groups for:
 - Interstage mortality
 - Requiring transplant or mortality
 - At least one unscheduled readmission for any cause
 - At least one unscheduled readmission for low saturations

Weight Monitoring

472 patients with information recorded: 75% with daily monitoring, 13% weekly, 12% none

- No significant difference between groups in:
 - Interstage mortality
 - Requiring transplant or mortality
 - At least one unscheduled readmission for any cause
 - At least one unscheduled readmission for poor weight gain

 Weight gain: No difference in weight gain between infants with daily vs weekly home monitoring, <u>BUT infants with daily weight monitoring had significantly better weight gain</u> than those without any home weight monitoring

• What were the limitations of this study?

- o The authors cannot tell if parents were actually doing the home monitoring as directed
- Each hospital is different and does things a little differently. The authors could not factor these differences between centers into the study. These non-included differences may be more important than whether patients have home monitoring or not.
- o Most of the babies in the study were monitored daily so the other monitoring types we studied had a smaller group of patients in them, which might skew the results.
- o The authors did not have all information for all patients

What are the takeaway messages considering the results and limitations of this study?

Interstage mortality has improved over time at all centers. Although most centers use some form of home monitoring, this study suggests that home monitoring is not a standalone solution for preventing interstage death. It is one of many care improvements that NPC-QIC centers have implemented and continue to work on, such as building dedicated interstage teams and teaching parents how to identify and react to "red flags." However, this study also suggests that home weight monitoring may be a good tool to keep babies growing during the interstage. We think this may be important because some studies have shown better Glenn outcomes in babies who have better interstage growth.

Many centers and parents believe that home monitoring has made a big difference for them, which may include improved support and comfort for families. But other centers have accomplished these goals without asking parents to measure oxygen saturations and weights at home. Because each center is different, just as each child and family is different, individual centers, in conjunction with parent input, should decide whether home monitoring is beneficial for their patients and families.