Cardiology in the Young

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Identifying best practices in interstage care: using a positive deviance approach within the National Pediatric Cardiology Quality Improvement Collaborative

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Abstract

Introduction: To identify interstage best practices associated with lower mortality, we studied National Pediatric Cardiology Quality Improvement Collaborative centres registry using a positive deviance approach. *Methods:* Positive deviant and control centre team members were interviewed to identify potential interstage best practices. Subsequently, all collaborative centres were surveyed on the use of these practices to test their associations with centre mortality. Questionnaires were scored using Likert scales; the overall score was linearly transformed to a 0–100-point scale with higher scores indicating increased use of practices. Mortality was based on patients enrolled after a centre's first year in the collaborative. Centre mortality rates were divided into tertiles. Survey scores for the low mortality tertile were compared with the other tertiles. *Results:* For this study, seven positive deviant and four control teams were interviewed. A total of 20 potential best practices were identified, including team composition, improvement practices, and parent involvement. Questionnaires were completed by 36/43 eligible centres, providing 1504 patients for analysis. Average survey score was 50.2 (SD 13.4). Average mortality was 6.1% (SD 4.1). There was no correlation between survey scores and mortality ($r = 0.14$, $p = 0.41$). The one practice associated with the low mortality tertile was frequency of discussion of interstage results: 58.3% of low mortality teams discussed results at least monthly versus 8.4% of the middle and high tertile centres ($p = 0.02$). *Conclusions:* Low-mortality centres more frequently discuss interstage results than high-mortality centres. Heightened awareness of outcomes may influence practice; however, further study is needed to understand the variation in outcomes across centres.

Background

The National Pediatric Cardiology Quality Improvement Collaborative has succeeded in lowering interstage mortality for infants with hypoplastic left heart syndrome across 60 participating centres.[1] Despite the challenges inherent in comparing rare outcomes in small populations, there is some evidence that mortality outcomes differ across collaborative sites.[2] It remains unknown whether this variation in mortality outcomes is due to implementation of specific practices advocated by the collaborative, such as the formation of single-ventricle clinics or use of a structured discharge conference call. Many such practices have not been recorded in the collaborative registry and, therefore, are unavailable for comparison with mortality rates. However, these centre-level practices may have significant unmeasured effects on outcomes that have not been previously explored across the collaborative.

To explore whether there are best practices for interstage care – in other words, practices that are associated with lower interstage mortality – we started with a positive deviance approach that has been previously used to explore differences in survival after myocardial infarction[3] as well as public health outcomes.[4,5] Positive deviance methodology assumes that knowledge about best practices exists in organisations with consistently exceptional performance. Using both quantitative and qualitative methodology, the positive deviance approach consists of the four steps – identifying "positive deviants" or high-performing organisations; studying these organisations in-depth using qualitative methods to develop hypotheses about best practices; testing these hypotheses in larger samples of organisations; and disseminating evidence about best practices by working in partnership with key stakeholders.[6] Using the

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positive deviance approach to identify best practices used more commonly by collaborative centres with lower mortality rates could inform future collaborative improvement efforts, further reducing interstage mortality.

In previously published work, we identified lower mortality centres (positive deviants) and higher mortality centres (control centres) and compared patient characteristics between these centre groups.[2] The purpose of this study was to complete the qualitative evaluation and hypothesis testing steps of the positive deviance methodology. First, we interviewed positive deviant and control centres to specify their interstage practices, then we analysed results to identify potential best practices that were more commonly used by positive deviant centres. Finally, to answer our main question, we used survey methodology to compare the use of potential interstage best practices to centre mortality rates.

Methods

The National Pediatric Cardiology Quality Improvement Collaborative includes a voluntary registry that receives data from 60 paediatric cardiac programmes who have joined on a rolling basis since its inception in 2008. There is a standard dataset with data definitions, online web-based data entry, and data quality checks. The deidentified data are housed in a secure server at Cincinnati Children's Hospital Medical Centre. Institutional Review Boards of each institution reviewed and approved participation in the registry. Infants followed at participating centres are eligible for enrolment into the registry if they meet the criteria, which are diagnosis of single-ventricle disease requiring Norwood stage 1 procedure or variant; survival to, and discharge from, the hospital before stage 2 procedure or transplant. If required by individual centre Institutional Review Boards, families of each individual patient provide consent before enrolment. This study, including both use of registry data and prospectively collected interview and survey data, was approved by the Institutional Review Board of the University of Michigan.

Identification of positive deviant centres

As previously reported, all collaborative centres with at least 25 patients enrolled in the registry were eligible for inclusion in this analysis. Using individual centre g charts, a statistical process control chart designed for sensitive detection of changes in rates of rare events such as mortalities,[7] we identified those centres with >25 consecutive interstage survivors at the time of the query in March 2015 as positive deviant sites with lower mortality. Based on the historical collaborative mortality rate of 9.5%,[1] those centres with an aggregate mortality rate >10% at the time of the query were selected as higher mortality sites to serve as controls for comparison of qualitative data. This definition created significantly different groups with an interstage mortality rate of 2.7% in the seven positive deviant centres versus 13.3% in the four control centres ($p < 0.0001$).[2]

Qualitative evaluation of positive deviant centres

The semi-structured interview guide was based on a recent collaborative centre practices questionnaire as well as clinical and programmatic knowledge of interstage home monitoring programmes. The interview guide was tested on team members from a site that was not eligible for inclusion in either the lower mortality or higher mortality control group. Based on feedback from interviewees, the script was modified iteratively. The interview guide included questions on team practices, standardisation of inpatient care practices, discharge decision making, and interstage outpatient follow-up (Table 1). Semi-structured group

Table 1. Interview guide outline and sample questions.

Category	Sample questions
Team composition and practices	*Can you please describe for me how a typical interstage team meeting works at your centre?* *How, if at all, do you use National Pediatric Cardiology Quality Improvement Collaborative data?* *How, if at all, are parents involved in your team?*
Surgery/early peri-operative period	*How are your surgeons involved in your interstage team?* *Have there been any changes in your surgeon staffing since you joined the National Pediatric Cardiology Quality Improvement Collaborative?* *How are your intensive care physicians involved in your interstage team?*
Post-operative inpatient care	*Does your centre have an actual written protocol for postoperative care?* *Are there unwritten general guidelines about screening for postop complications?* *How, if at all, is your interstage team involved in inpatient care following the Norwood?*
Decision to discharge home from Norwood admission	*Does your centre have specific or general medical criteria required for discharge?* *How does your centre assess families' ability to care for their child at home?* *Does your centre require parents to "room in" before discharge?*
Outpatient management	*What, if any, standardised evaluations have you added to care of post-Norwood and interstage patients since forming an interstage programme?* *How do you communicate with primary care providers?*
Red flags and interstage mortalities	*How do you typically respond to a red flag alert for low saturations?* *When a child is readmitted for any reason, how do you decide whether he or she can be discharged home for the rest of the interstage?* *How does your team review interstage mortalities?*
Team reflections	*What have you learned as a team over your years of working on this clinical problem?* *Which changes do you think account for your success as a programme?* *Aside from what you have learned through the National Pediatric Cardiology Quality Improvement Collaborative, have there been other resources or changes at your institution that have helped your programme?*

interviews were conducted via telephone between January 2016 and March 2016 by study team members (K.E.B. and K.U.). Key contacts from the 11 positive deviant and control centres were provided with a topic outline and asked to invite as many members as needed to answer the questions, with a minimum of two members required. Transcribed interviews were coded by two researchers (K.E.B. and K.U.) using principles of grounded theory analysis.[8] Discrepancies were resolved via consensus. Interviewers and coders were blinded to the mortality group of participating sites. Additional data were collected via an initial questionnaire sent to centres to collect information on topics that were more amenable to brief written answers, for example professional roles represented on interstage team (Appendix). Results from both the interview and initial questionnaire analysis were compared by two members of the investigative team (K.E.B. and K.U.), to identify potential interstage best practices that were more prevalent in positive deviant centres as compared with the control centres.

Testing the use of hypothesised interstage best practices across the National Pediatric Cardiology Quality Improvement Collaborative

To assess the use of potential interstage best practices identified in the interviews, a follow-up best practices questionnaire assessing the use of each best practice was written and refined iteratively. The final best practices questionnaire was then distributed electronically to one key contact at each of the 60 collaborative centres in April 2017. To focus attention on the effect of collaborative participation on centre mortality, we analysed questionnaire results from only those centres who had enrolled at least 10 patients after their first year of participation. Questionnaire answers were scored using Likert scales and the overall score was linearly transformed to a 0–100-point scale with higher scores indicating more frequent use of potential best practices. For questions where respondents could select "Other" and write in details, responses were reviewed and scored relative to the provided answers.

To assess for bias in results, centre characteristics, including years in the collaborative, total number of patients enrolled after the first year of participation, and mortality rate were compared between centres who completed the best practices questionnaire versus those who did not, using Wilcoxon rank-sum test. Pearson correlation coefficient was used for continuous variables to examine the correlation between the overall questionnaire result and individual centre mortality rates after a centre's first year in the collaborative. Centre mortality rates were also divided into tertiles and the use of individual best practices for the low mortality tertile were compared with the other tertiles combined using χ^2-test, Fisher's exact test, or χ^2-test for trend, as appropriate. All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC, USA). A p-value <0.05 considered statistically significant.

Results

Seven positive deviant centres and four control centres were identified for inclusion in the qualitative data collection. A total of 11 group interviews were conducted via phone with 2–6 participants per site. All 11 sites also returned the initial questionnaire. A total of 20 potential best practices identified through qualitative analysis of the interviews and questionnaires were included in the follow-up best practices questionnaire, which was completed by 36/43 (83.7%) eligible centres. The average survey score was 50.2 (SD 13.4) and the median survey score was 50.4, indicating a near-normal distribution of scores. There were 1504 patients included in the analysis (Fig 1). The average centre mortality was 6.1% (SD 4.1). There were no differences in length of collaborative participation or mortality rate between responding and non-responding centres; however, non-responding centres had lower total enrolment numbers after the first year of participation compared to responding centres (Table 2).

Centres varied widely in their use of the potential best practices, illustrating the variability in interstage programme structure and practice (Table 3). Most centres recommended at least two clinic visits per month, monthly multidisciplinary discussion of patients, and at least weekly contact with interstage families. Over 90% of responding centres reported using some interventions recommended or highlighted by the collaborative, including home weight and oxygen saturation monitoring, a stage 1 hospitalisation discharge checklist, and a Red Flag response protocol. Other interventions had lower rates of use. Inclusion of social work and intensive care physicians into the teams was variable, as was the type of parent involvement, although most centres reported having some parent participation. Team practices around quality

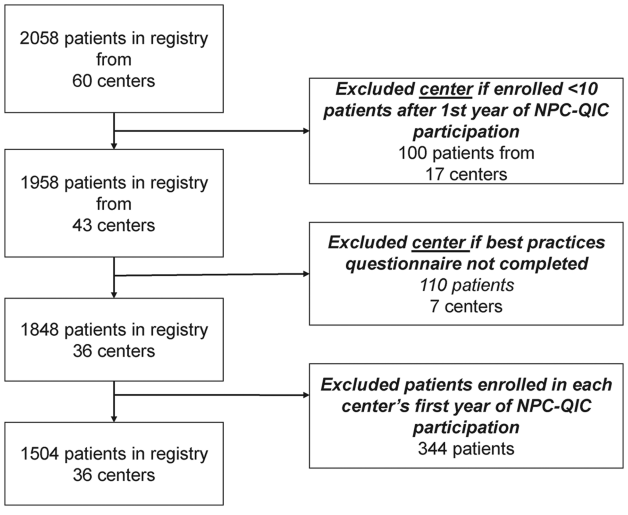

Figure 1. Patient flow diagram.

Table 2. Characteristics of responding versus non-responding centres in potential best practices survey.

	Respondents (n = 36)	Non-respondents (n = 7)	p-value
Years in the National Pediatric Cardiology Quality Improvement Collaborative	7.4 (5.7–8.0)	6.1 (5.4–7.6)	0.31
Total patients enrolled after first year	35 (23–57.5)	14 (12–14)	0.0004
Mortality rate after first year	6.3 (3.3–9.4)	7.1 (0–8.3)	0.97

Data are presented as median (interquartile range). p-value from Wilcoxon rank-sum test

Table 3. Use of hypothesised best practices across centres

	n (%)
Interstage centre practices and use of interventions	
Recommended frequency of clinic visits (cardiologist and PCP)	
Weekly	16 (44.4)
Weekly to every other week	5 (13.9)
⩾2 per month	12 (33.3)
Monthly	3 (8.3)
Frequency of multi-disciplinary discussion (⩾2 professional roles) about each patient	
Weekly	12 (33.3)
⩾2 per month	8 (22.2)
Monthly	14 (38.9)
Other	2 (5.6)
Frequency of direct contact with each family (including clinic visits and phone calls)	
>1 per week	13 (36.1)
Weekly	20 (55.6)
⩾2 per month	1 (2.8)
Other	2 (5.6)
Interventions used	
Discharge conference call	16 (44.4)
Parent journey board	21 (58.3)
Required rooming in prior to S1 discharge	32 (88.9)
Standard involvement of dietician with interstage patients	33 (91.7)
Home weight monitoring	34 (94.4)
Home oxygen saturation monitoring	35 (97.2)
Stage 1 hospitalisation discharge checklist	35 (97.2)
Red Flag response protocol	36 (100.0)
Interstage team members and processes	
Roles represented on interstage team during phase 1	
Social work	22 (61.1)
ICU physician	15 (41.7)
Neither	10 (27.8)
Parents and family involvement with team	
Parents/families help develop PDSAs to test improvements	6 (16.7)
Parents/families regularly attend or call into team meetings	9 (25.0)
Parents/families generate ideas for programme improvements	15 (41.7)
Contact as needed as resource or to review new interventions	30 (83.3)
Frequency of team discussion of specific improvement projects	
Rarely	4 (11.1)
Sometimes	15 (41.7)

Table 3. (*Continued*)

	n (%)
Almost always	10 (27.8)
Always	7 (19.4)
Frequency of using written PDSA cycles	
Never	5 (13.9)
Rarely	13 (36.1)
Sometimes	14 (38.9)
Almost always	3 (8.3)
Always	1 (2.8)
Frequency of team discussion about content for quarterly National Pediatric Cardiology Quality Improvement Collaborative reports	
Never	4 (11.1)
Rarely	7 (19.4)
Sometimes	15 (41.7)
Almost always	8 (22.2)
Always	2 (5.6)
Frequency of team discussion of centre's interstage results	
Weekly	1 (2.8)
⩾2 per month	1 (2.8)
Monthly	7 (19.4)
Quarterly	24 (66.7)
Other	3 (8.3)
Engagement with heart centre	
Regularity of sharing centre's interstage results with centre leadership or surgeons	
Monthly	2 (5.6)
Quarterly	8 (22.2)
Semi-annually	4 (11.1)
Annually	17 (47.2)
Other	4 (11.1)
Not reported	1 (2.8)
Regularity of sharing centre's interstage results with centre faculty and staff	
Quarterly	5 (13.9)
Semi-annually	2 (5.6)
Annually	23 (63.9)
Other	6 (16.7)

PDSA = Plan-Do-Study-Act cycle

improvement, preparation of collaborative reports, review of data, and sharing of data within their heart centres were also variable.

When potential best practices survey results and centre mortality were compared, there was no significant association between the overall best practice questionnaire score and mortality as a continuous variable ($r = 0.14$, $p = 0.41$). When the lowest mortality tertile with cumulative mortality <4.1% was compared with the other two tertiles, there was a significant difference in the frequency of interstage team discussion of centre results. Over half of lowest mortality tertile centres discussed results at least monthly, as compared to 8.4% of the other tertiles ($p = 0.02$, Table 4).

Table 4. Use of hypothesised best practices in lowest mortality tertile versus middle and highest mortality tertiles.

	Interstage mortality		
	< 4.1% (n = 12)	⩾ 4.1% (n = 24)	p-value
Interstage centre practices and use of interventions			
Recommended frequency of clinic visits (cardiologist and PCP)			0.38
Weekly	8 (66.7)	8 (33.3)	
Weekly to every other week	0 (0.0)	5 (20.8)	
⩾ 2 per month	2 (16.7)	10 (41.7)	
Monthly	2 (16.7)	1 (4.2)	
Frequency of multi-disciplinary discussion (⩾2 professional roles) about each patient			0.15
Weekly	6 (50.0)	6 (25.0)	
⩾ 2 per month	2 (16.7)	6 (25.0)	
Monthly	4 (33.3)	10 (41.7)	
Other	0 (0.0)	2 (8.3)	
Frequency of direct contact with each family (including clinic visits and phone calls)			0.45
> 1 per week	4 (33.3)	9 (37.5)	
Weekly	8 (66.7)	12 (50.0)	
⩾ 2 per month	0 (0.0)	1 (4.2)	
Other	0 (0.0)	2 (8.3)	
Intervention(s) used/added after joining the collaborative			
Discharge conference call	6 (50.0)	10 (41.7)	0.64
Parent journey board	6 (50.0)	15 (62.5)	0.47
Required rooming in prior to S1 discharge	11 (91.7)	21 (87.5)	1.00
Standard involvement of dietician with interstage patient	12 (100.0)	21 (87.5)	0.54
Home weight monitoring	12 (100.0)	22 (91.7)	0.54
Home oxygen saturation monitoring	12 (100.0)	23 (95.8)	1.00
Stage 1 hospitalisation discharge checklist	12 (100.0)	23 (95.8)	1.00
Red flag response protocol	12 (100.0)	24 (100.0)	1.00
Interstage team members and processes			
Roles represented on interstage team during phase 1			
Social work	10 (83.3)	12 (50.0)	0.08
ICU physician	4 (33.3)	11 (45.8)	0.47
Parents and family involvement with team			
Contact as needed as resource or to review new interventions	10 (83.3)	20 (83.3)	1.00
Parents/families regularly attend or call into team meetings	3 (25.0)	6 (25.0)	1.00
Parents/families generate ideas for program improvements	6 (50.0)	9 (37.5)	0.47
Parents/families help develop PDSAs to test improvements	1 (8.3)	5 (20.8)	0.64
Frequency of team discussion of specific improvement projects			0.32
Never	0 (0.0)	0 (0.0)	

Table 4. (*Continued*)

	Interstage mortality		
	< 4.1% (n = 12)	⩾ 4.1% (n = 24)	p-value
Rarely	2 (16.7)	2 (8.3)	
Sometimes	5 (41.7)	10 (41.7)	
Almost always	4 (33.3)	6 (25.0)	
Always	1 (8.3)	6 (25.0)	
Frequency of using written PDSA cycles			0.26
Never	1 (8.3)	4 (16.7)	
Rarely	8 (66.7)	5 (20.8)	
Sometimes	2 (16.7)	12 (50.0)	
Almost always	1 (8.3)	2 (8.3)	
Always	0 (0.0)	1 (4.2)	
Frequency of team discussion about content for quarterly collaborative reports			0.74
Never	0 (0.0)	4 (16.7)	
Rarely	4 (33.3)	3 (12.5)	
Sometimes	5 (41.7)	10 (41.7)	
Almost always	2 (16.7)	6 (25.0)	
Always	1 (8.3)	1 (4.2)	
Frequency of team discussion of centre's interstage results			**0.02**
Weekly	0 (0.0)	1 (4.2)	
Twice a month or every other week	1 (8.3)	0 (0.0)	
Monthly	6 (50.0)	1 (4.2)	
Quarterly	5 (41.7)	19 (79.2)	
Other	0 (0.0)	3 (12.5)	
Engagement with heart centre			
Regularity of sharing centre's interstage results with centre leadership or surgeons			0.54
Monthly	1 (8.3)	1 (4.2)	
Quarterly	2 (16.7)	6 (25.0)	
Semi-annually	1 (8.3)	3 (12.5)	
Annually	4 (33.3)	13 (54.2)	
Other	3 (25.0)	1 (4.2)	
Not reported	1 (8.3)	0 (0.0)	
Regularity of sharing centre's interstage results with centre faculty and staff			0.69
Monthly	0 (0.0)	0 (0.0)	
Quarterly	1 (8.3)	4 (16.7)	
Semi-annually	2 (16.7)	0 (0.0)	
Annually	6 (50.0)	17 (70.8)	
Other	3 (25.0)	3 (12.5)	

PDSA, plan-do-study-act

Discussion

We used a positive deviance approach to explore best practices for interstage care in National Pediatric Cardiology Quality Improvement Collaborative centres. Although many potential best practices were identified through centre interviews and questionnaires, neither the summary questionnaire score nor any individual practice had a significant association with mortality rates as a continuous outcome when tested across all centres with a representative sample responding. When the lowest mortality tertile was compared with the other two tertiles, the one practice that differed significantly was the frequency of interstage team discussion of centre results, which was more common in the lowest mortality group. In contrast, there was no difference in the frequency of team discussions about improvement projects, which most centres reported doing at least sometimes. Although it is somewhat surprising that discussion of centre results was the only significant difference identified, it is possible that centre teams that regularly review outcome data in addition to discussing efforts to improve care processes achieve better results than centres that focus only on improvement processes. Indeed, in a review of successful teams participating in a collaborative, Lannon and Peterson highlighted attention to key processes and outcomes as a key characteristic, along with reliable data and measurement, support of senior leadership, and alignment of institutional and collaborative goals.[9]

One possible explanation for why we did not find more associations between interstage practices and mortality rates is that there are statistical challenges inherent in comparing small but variable numbers of interstage outcomes across dozens of centres.[2,10,11] Furthermore, given the focus of the National Pediatric Cardiology Quality Improvement Collaborative on reducing variation in practice across centres,[12] it is perhaps to be expected that few significant differences in the fundamentals of interstage team and care processes were identified. For example, each centre we interviewed had a multi-disciplinary team focussed on interstage care, a fundamental practice encouraged by National Pediatric Cardiology Quality Improvement Collaborative. There was variation in the specific professional roles represented on each multi-disciplinary team in the best practices questionnaire, but there was no association between those roles and centre mortality rates.

Another possible reason for the lack of associations with mortality is that our methodology may not have been sufficiently precise to identify key differences in practices between programmes. We relied on self-reporting of interventions and interactions, which may be inaccurate as individual teams may not have sufficient awareness of the field to identify unique or critical facets of their programs. Moreover, interstage team members may underestimate practice variation within their own clinical sites, which may have obscured real differences between groups. In addition, centre responses likely reflected current practices, some of which may have been implemented recently and therefore would not have affected mortality outcomes over the full study period. Finally, we were only able to assess the use of an intervention, not the quality of its application. Given the importance of social processes to quality improvement work,[13] observational methods used in anthropology might more effectively identify key differences between centres.

Considering these results in conjunction with our earlier comparison of patient characteristics at the seven positive deviant and four control centres,[2] it is possible that interstage outpatient care practices have less impact on interstage outcome than inpatient care practices. In our previous study, we found no significant differences in patient characteristics on admission between lower and higher mortality National Pediatric Cardiology Quality Improvement Collaborative centres.[2] Interestingly, multiple differences between populations, such as need for preoperative mechanical ventilation and type of stage 1 performed, developed in the peri-operative period, raising the possibility that variation in peri-operative care practices across centres might contribute to differences in interstage outcome.[2] However, neither study was designed to assess the association between inpatient care practices and outcomes.

On the contrary, the fact that we did not identify specific interstage best practices suggest that there is likely no single formula for providing high-quality interstage care. In the absence of proven best practices, each centre should perhaps examine its own practice patterns, resources, and culture when evaluating potential new interstage practices to determine whether the practice will add value to their programme. For example, creating a dedicated single-ventricle clinic for all interstage outpatient visits may not be feasible for a centre with a broad geographic referral base, but that centre may benefit from improving care coordination across settings by establishing a rigorous process for multi-disciplinary discharge conference calls between inpatient and outpatient providers and families. In short, effective variation in interstage care may be at the level of the centre in addition to at the level of the patient.

Limitations

Our method for choosing positive deviant and control sites is limited by small numbers and the continuous nature of practice improvement. Centres with only one death may have been disqualified from inclusion in the positive deviant group despite having excellent practices. Similarly, control sites were chosen based on an aggregate mortality rate, which may have obscured recent improvements in mortality at an individual centre. Collecting qualitative data at a specific time point may not allow for changes in programmes over time. Answers to the best practices survey may not accurately reflect variation in practice within a given centre and therefore may be misleading. Importantly, because the National Pediatric Cardiology Quality Improvement Collaborative previously enrolled only those patients who were discharged alive during the interstage period,[12] it has not been possible to fully evaluate hospital outcomes as well as outpatient interstage outcomes using this registry. This comparison will be possible in future studies since the National Pediatric Cardiology Quality Improvement Collaborative expanded its eligibility in August 2016 to include all infants with hypoplastic left heart syndrome who are anticipated to undergo a stage 1 procedure.

Conclusion

Low mortality centres more frequently discuss their interstage results than higher mortality centres. Although we identified no interstage best practices associated with mortality as a continuous variable and no additional practices associated with the lowest mortality tertile, heightened awareness of outcomes may be an important contributor to quality improvement. Without clearly identified best practices, individual centres should consider how

potential interventions would work in the context of local resources and culture. Further study is needed to explore variation in process and outcomes across the National Pediatric Cardiology Quality Improvement Collaborative.

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Conflicts of interest. None.

Appendix

INTERSTAGE TEAM COMPOSITION AND PRACTICES

Please indicate how many of the following providers are a part of your interstage team:

Role	*Number*
Cardiologist	
Nurse	
Nurse practitioner	
Dietician	
Social worker	
Surgeon	
Occupational therapist	
Quality improvement expert	
Parent/family representative	
Other (specify):	
Other (specify):	

Who typically joins in for National Paediatric Cardiology Quality Improvement Collaborative (NPC-QIC) action period calls? Please specify roles rather than names (i.e., nurse practitioner rather than Susan).

How are updates from NPC-QIC shared with the rest of the group?

SURGEONS/PERI-OPERATIVE PERIOD

How would you describe your surgical referral base for Norwood or stage 1 procedures?

For example, do you have a certain regional area where you are the dominant centre?

Do you get a lot of referrals from different states, regions, or countries?

Describe any local factors that affect your centre's fetal diagnosis rates. For example, centres with large rural areas nearby may have lower rates, etc.

For the last 2–3 years, please complete the table below. This may require accessing local STS data or other surgical databases at your centre

Time period (i.e. 2012–2015)
Total number of all Norwood stages performed (includes hybrids)
Number of in-hospital mortalities before discharge from Norwood hospitalisation
Number of patients discharged home after Norwood and before stage 2 procedure (i.e., NPC-QIC eligible)

How does your team decide what type of surgical Norwood an individual patient should get? That is, is it based on individual surgeon preference or patient characteristics? If patient characteristics are considered, which ones influence the decision?

INPATIENT CARE

How many physicians are on staff in your intensive care unit?

How long is a typical service period for an intensivist?

a. > 2 weeks
b. 2 weeks
c. 1 week
d. < 1 week

Are interstage patients transferred out of the ICU before discharge?

IF YES: How many physicians are on staff in your cardiology ward?
How long is a typical service period for a ward attending?

a. > 2 weeks
b. 2 weeks
c. 1 week
d. <1 week

How does your team screen for vocal cord paralysis?

How does your team screen for neurologic deficits or seizures?

OUTPATIENT MANAGEMENT

How does your team use home health care or visiting nurses?

a. For all patients
    1. How often does the nurse visit the home?
    2. What activities does the home nurse perform?
b. For selected patients (please specify criteria)
    1. How often does the nurse visit the home?
    2. What activities does the home nurse perform?

If applicable, describe the feeding team at your centre.

When does your centre perform the stage 2 procedure scheduling process?

a. Before Norwood discharge
b. At a specific time point after discharge: (please specify)
c. After pre-stage 2 cath.
d. Other: (please specify)

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