Parents' Preferences Regarding Public Reporting of Outcomes in Congenital Heart Surgery

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Background. **Calls for public reporting of outcomes in congenital heart surgery have led to several different reporting schemes, including a star rating system and benchmark procedure-specific mortality data tables. Important unanswered questions remain about the optimal format and content of public reporting of congenital heart surgery outcomes.**

Methods. **In conjunction with three parent advocacy groups, we developed a questionnaire to gauge parents' attitudes regarding the format and content of an "optimal" public reporting scheme. Parents were solicited for participation through email lists of members of parent advocacy groups and from a cohort of parents whose children had undergone an STS benchmark procedure of the Society of Thoracic Surgeons at the Children's Hospital of Philadelphia after January 1, 2007.**

Results. **The 1,297 responses received provided complete data for analysis. Nearly all the participants were mothers of children with congenital heart disease, and most were white. About half of the children were diagnosed prenatally, and 63% underwent initial repair of the defect in the neonatal period. Parents identified survival statistics, surgeon-specific experience, and complication rates as most important. Presented with three display formats for mortality rates, most parents (89%) identified a numeric procedure-based approach as the best format, and more than half identified the hospital star rating system as the worst format.**

Conclusions. **Parents of children with congenital heart disease identify survival statistics, surgeon-specific experience, and complication rates as the most important outcome measures to report publicly. Additionally, parents preferred mortality data to be presented in a procedure-specific format using a numeric procedure-based approach, as opposed to the star rating system.**

(Ann Thorac Surg 2017;■:■–■)
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Nearly 40,000 children are born in the United States each year with congenital heart disease (CHD), and one third of those children will require surgical intervention during the first year of life. Parents of children diagnosed with CHD must make decisions regarding the surgeon and the medical center to provide medical and surgical care for their child's specific heart defect. For many of these parents, these decisions may be among the most challenging they face during pregnancy or after the birth of their child. In part to better inform these decisions, public reporting of outcomes in pediatric heart surgery is becoming more common. Despite the use of several different reporting schemes, however, unanswered questions remain about the optimal format and content of public reporting for pediatric heart surgery outcomes. Without doubt, how data are presented may be more important than the data themselves; the type of visual display used affects the degree to which patients correctly interpret the data presented [1, 2].

In response to our growing appreciation for the importance of how data are presented to patients, some experts have advocated a "less is more" approach and argue that doing so improves comprehension among patients with lower numeric literacy [3]. In the realm of pediatric congenital heart surgery, the star ratings system, used by The Society of Thoracic Surgeons (STS) (Fig 1) [4], adheres to the "less is more" philosophy by assigning one, two, or three stars to hospitals performing pediatric heart surgery on the basis of the overall risk-adjusted observed-to-expected operative mortality ratio for all

The Supplemental Figures can be viewed in the online version of this article [http://dx.doi.org/10.1016/j.athoracsur.2017.05.043] on http://www.annalsthoracicsurgery.org.

Accepted for publication May 15, 2017.

Presented at the Fifty-third Annual Meeting of the Society of Thoracic Surgeons, Houston, TX, Jan 21–25, 2017.

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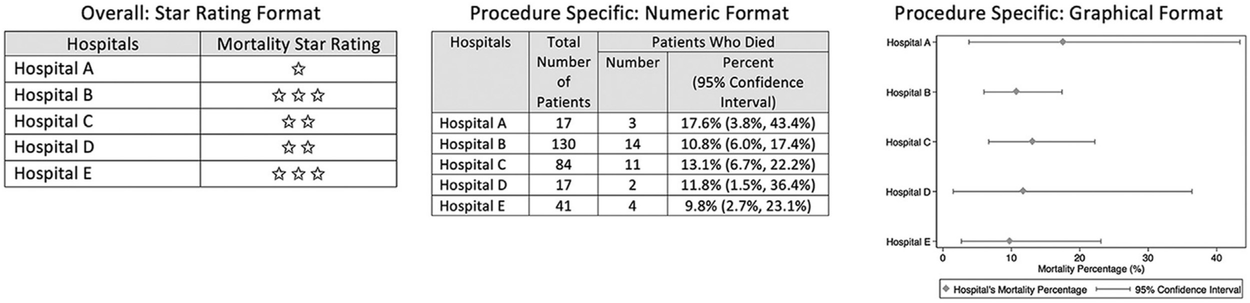
Published by Elsevier Inc.

0003-4975/$36.00
http://dx.doi.org/10.1016/j.athoracsur.2017.05.043



Overall: Star Rating Format

Hospitals	Mortality Star Rating
Hospital A	☆
Hospital B	☆ ☆ ☆
Hospital C	☆ ☆
Hospital D	☆ ☆
Hospital E	☆ ☆ ☆

Procedure Specific: Numeric Format

Hospitals	Total Number of Patients	Patients Who Died	
		Number	Percent (95% Confidence Interval)
Hospital A	17	3	17.6% (3.8%, 43.4%)
Hospital B	130	14	10.8% (6.0%, 17.4%)
Hospital C	84	11	13.1% (6.7%, 22.2%)
Hospital D	17	2	11.8% (1.5%, 36.4%)
Hospital E	41	4	9.8% (2.7%, 23.1%)

Procedure Specific: Graphical Format

Fig 1. Three different formats for displaying outcomes information for public reporting.

patients undergoing pediatric or congenital heart surgical procedures at that institution. STS does not provide procedure-specific outcomes, but it does provide tabular hospital-specific discharge mortality data for categories of congenital heart procedures (STAT categories), which are thought to represent similar operative risk. In contrast, the Pennsylvania Health Care Cost Containment Council (PHC4) has taken an alternative approach with its Pediatric and Congenital Heart Surgery Report [5], which provides tabular hospital-specific discharge mortality data on the nine STS Benchmark Operations (arterial switch, ventricular septal defect (VSD) repair, arterial switch and VSD repair, Norwood procedure, Glenn/Hemi-Fontan procedure, Fontan procedure, truncus arteriosus repair, complete atrioventricular canal repair, Tetralogy of Fallot repair). In an extremely diverse field with more than 200 types of operations, these procedures have been determined by STS to represent a more homogenous patient population, thus allowing for better comparison of outcomes across centers (almost are performed by $\geq$90% of centers) [6] (Fig 1). The PHC4 report uses a "numerator-denominator" approach to present mortality data, by indicating the total number of children undergoing a specific procedure in addition to the number of children who died after that procedure, and the hospital's calculated operative mortality rate.

Noticeably absent from the STS and PHC4 frameworks is parental input regarding the information that they, as the decision makers, deem necessary to make an informed choice about the surgeon and medical center and about how this information should be presented. Lack of input from parents hampers our ability to improve the design of public reporting systems to best meet their needs. Accordingly, the aim of our project was to identify parents' preferences regarding content of pediatric heart surgery outcomes reports, specifically regarding the types of data that are included; and the optimal format for presentation of these data.

Patients and Methods

Study Design and Survey Implementation

We collaborated with three parent advocacy groups (Mended Little Hearts, the Pediatric Congenital Heart Association, and Sisters by Heart) and members of the cardiothoracic surgical team at the Children's Hospital of Philadelphia (CHOP) to develop a 43-item questionnaire (the CHD Public Reporting Survey) to assess parents' attitudes about public reporting of congenital heart surgery outcomes. The questionnaire collected information regarding demographic and clinical characteristics of the parents' children with CHD, demographic and socioeconomic characteristics of the parents and their families, parents' ratings regarding the relative importance of various potential surgical outcome measures, and parents' votes regarding best and worst information display formats among three options (Fig 1). The survey concluded with an assessment of three different graphic formats for displaying outcomes data, as well as a free-response section for parents to provide comments about the questionnaire and public reporting more generally. The questionnaire was pilot tested among clinical and nonclinical staff members in the Department of Cardiothoracic Surgery at CHOP for readability and was revised accordingly before implementation. The questionnaire was available in English only, and it was implemented through REDCap (Vanderbilt University, Nashville, TN), which anonymously recorded responses in a database. This study was exempted by the Institutional Review Board at CHOP because of the anonymous nature of data collection from adults.

Parents were solicited for participation in the survey either if they were members of one of three parent advocacy groups (Mended Little Hearts, the Pediatric Congenital Heart Association, or Sisters by Heart; collectively, the "Parent Groups") and elected to receive electronic communications from their respective group or if their child had undergone an STS benchmark procedure at CHOP after January 1, 2007. The survey was distributed by email to Parent Group members and CHOP parents on April 21, 2016 and remained open for responses until May 20, 2016.

Statistical Analysis

Survey data were extracted from REDCap and analyzed in Stata 14.2 (StataCorp LP, College Station, TX). We calculated descriptive statistics (percentages, means, medians, distributions) regarding parent participant and child demographics and parents' preferences regarding reporting of outcomes data.

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