



Published in final edited form as:

Pediatr Cardiol. 2008 November ; 29(6): 1059–1065. doi:10.1007/s00246-008-9254-8.

Parental Understanding of Neonatal Congenital Heart Disease

Ismee A. Williams, Roxana Shaw, Charles S. Kleinman, Welton M. Gersony, Ashwin Prakash, Stephanie M. Lvasseur, and Julie S. Glickstein

Department of Pediatrics, Division of Pediatric Cardiology and the Center for Prenatal Pediatrics, Columbia University College of Physicians and Surgeons, Morgan Stanley Children's Hospital of New York, 2-North 3959 Broadway, New York, NY 10032, USA

Ismee A. Williams: iib6@columbia.edu

Abstract

Background—This study aimed to evaluate the impact of prenatal diagnosis on parental understanding of congenital heart disease (CHD) in newborns.

Methods—Consenting parents of newborns with CHD answered questions about the cardiac lesion, surgical repair, follow-up management, risk for CHD in future children, and maternal education before neonatal intensive care unit (NICU) discharge. A total understanding score was calculated (0–10) as the sum of five subscores: physician score, CHD score, surgery score, follow-up score, and reproduction score. Each category was scored as 0 (none correct), 1 (some correct), or 2 (all correct). The prenatal and postnatal diagnoses scores were compared.

Results—From June 2006 to November 2006, 50 families completed the questionnaire. Of these 50 families, 26 reported a prenatal diagnosis. The mean infant age when the parents were approached was 17.3 ± 13.3 days. The summary understanding score for the entire group was 6.3 ± 2.4 of 10. Multivariate regression analysis demonstrated a difference in scores between prenatal and postnatal diagnosis groups ($p = 0.02$) when control was used for maternal education. Prenatal diagnosis and maternal education ($p < 0.01$) had independent effects on the score.

Conclusion—Prenatal diagnosis increases parental understanding of neonatal CHD. Nevertheless, parental understanding remains suboptimal.

Keywords

Congenital heart disease; Fetal echocardiography; Parent education; Prenatal diagnosis

Congenital heart disease (CHD) affects up to 1% of infants, most of whom will require a lifetime of medical care. In the current era, prenatal diagnosis of CHD is widely available. Multiple studies have documented the benefits to the newborn of a fetal CHD diagnosis, including prompt delivery of medical care and avoidance of severe cyanosis or low cardiac output by maintenance of ductus arteriosus patency [3, 8, 11, 12]. Another benefit of prenatal diagnosis is improved maternal–infant bonding [9].

The impact of prenatal diagnosis on parental understanding of the neonate's medical condition has not been published previously. Anecdotal experience led us to believe that parents of infants with a prenatal diagnosis of complex CHD had levels of understanding superior to those of parents of infants with a postnatal diagnosis. The primary aim of this study was to test this hypothesis and to establish the baseline level of understanding among

new parents of infants with complex CHD. Baseline information then could be used prospectively to study parent behavior vis-a-vis medical follow-up assessment and later decision making. In addition, the results of this study could help physicians direct educational efforts toward areas most in need.

Materials and Methods

An institutional review board (IRB)-approved pilot study involving a cross-sectional survey of parents who had infants with CHD was conducted at the Morgan Stanley Children's Hospital of New York from May 2006 to November 2006. Parents of infants with all forms of CHD admitted to the neonatal intensive care unit (NICU) were eligible. Inability to read English or Spanish was the only exclusion criteria.

Families were informed about the study in person when the infant was stable cardiovascularly and close to discharge. Parents were not approached on the day of discharge due to concern that study participation might lead to increased parental stress. To avoid influencing parent or physician behavior, advance notice about the study was not given.

Consenting parents filled out a questionnaire (see Appendix) that asked about the infant's heart condition, the parents' perceptions about their own level of understanding, and demographics. Assistance from a medical care provider in filling out the questionnaires was not permitted, although individuals were allowed to take the form home for input from a partner not present. Answers were reviewed immediately after receipt of the questionnaire, and parents whose responses demonstrated lack of understanding received additional education before their child's discharge.

Parent Understanding Questionnaire

The Parent Understanding Questionnaire, developed by the investigators, was based on information deemed necessary for parents to understand before hospital discharge of their child. The Parent Understanding Questionnaire was modeled after the Leuven Knowledge Questionnaire for Congenital Heart Diseases, which tests adults with CHD about knowledge in four domains: disease and treatment, measures to prevent complications, physical activities, and reproductive issues [10]. Modifications to the Leuven questionnaire were necessary given the different target population, and five knowledge domains were constructed. The questionnaires were scored according to a predetermined algorithm, and a total understanding score was calculated based on the sum of scores from five separate domains. These five domains included information about the infant's doctors, CHD description, surgery, reproductive issues, and follow-up care. Although questions about medications were included on the questionnaire, information regarding medication usage was not used for score calculation because most parents had not received discharge instructions from the nurse at the time of questionnaire administration.

Each of the five domains was scored 0 (no answers correct), 1 (some answers correct), or 2 (all answers correct). The total understanding score ranged from 0 to 10 points. Answers left blank were coded as incorrect. The total understanding score of parents who had obtained a prenatal diagnosis was compared with the score of those who had received a postnatal diagnosis. In addition, the association of the score with other factors known to influence parental understanding, such as maternal education level, was evaluated [2].

Statistical Analysis

Basic descriptive characteristics were calculated and reported using means and standard deviations for normally distributed data or medians and ranges for nonparametric

distributions. To evaluate the association between prenatal diagnosis and the understanding score, a two-sided Student's *t* test comparing the mean summary understanding scores between families with prenatal and postnatal diagnoses was conducted. Multivariate regression analysis was used to evaluate the aforementioned relationship, with control used for maternal education level. Differences in proportions were evaluated using two-by-two tables and reported using a two-sided Pearson's *p* value or a two-sided Fisher's exact *p* value when expected cell counts were less than 5. Measures of association are reported using odds ratios (OR) and 95% confidence intervals (CI). Because this was a pilot study to assess the baseline level of understanding among our patient population, a power analysis was not conducted.

Results

Of the 81 families screened between June 2006 and November 2006, 50 provided written informed consent and completed the questionnaire. Of the 31 families not included in the study, 3 were ineligible because they could not read English or Spanish, and 28 did not visit the NICU during the study eligibility period and therefore could not be enrolled. Families were approached at a mean infant age of 17.3 ± 13.3 days. The CHD diagnoses of the study subjects are listed in Table 1.

Additional medical problems were found for 14 (28%) of the 50 subjects. Half of the families (25/50) involved first-time parents. The average birth order of the infant with CHD was 1.72.

Understanding Scores

The summary understanding score for the entire study population was 6.3 ± 2.4 of a possible score of 10. The average doctor score was 1.24 ± 0.74 of a total possible score of 2 for the entire group. The surgeon's name was the most frequently accurate (35/50, 70%), followed by the name of any cardiologist caring for the child (31/50, 62%) and that of the pediatrician who would care for the child after discharge (29/50, 58%). Less than half of the study group (21/50, 42%) reported the names of all three physicians correctly.

The mean CHD score was 1.49 ± 0.66 . Most families (37/50, 74%) could name the condition, and 36/50 (72%) could describe the condition accurately. Two additional subjects received partial credit for each of these questions. Correct location of the condition on a diagram was seen for 35 (70%) of the 50 subjects. Slightly more than half of the families (29/50, 58%) were able to answer all three questions accurately.

The mean surgery score was 1.6 ± 0.67 . Correct description of the surgery was provided by 35 (70%) of the 50 families. Among the 50 infants, 44 (88%) had undergone surgery at the time of questionnaire administration, and 35 (70%) of the 50 families were able to answer all three surgical questions accurately.

The study group understood the least about reproduction, as demonstrated by the mean reproduction score of 0.64 ± 0.77 . Both questions were answered correctly by 9 (18%) of the 50 parents. The mean follow-up score was 1.37 ± 0.61 . Of the 50 parents, 34 (68%) knew that lifetime cardiology follow-up care would be required for their child, 39 (78%) listed at least one sign that their baby was not doing well, and 23 (46%) accurately answered questions regarding exercise limitations and the potential need for special schooling in later life.

Maternal Education Level

Demographic information for the study cohort is listed in Table 2. The summary scores differed significantly between the women who completed no more than high school ($n = 18$; 5.16 ± 2.3) and those who completed college or postgraduate studies ($n = 29$; 7.1 ± 1.9 ; $p = 0.003$), indicating that a higher level of maternal education was associated with better understanding of the neonate's CHD at NICU discharge. There was no significant association between maternal education level and prenatal diagnosis ($p = 0.23$), indicating no bias because of differential access to prenatal medical care.

Postnatal Diagnosis

The median age at CHD diagnosis in the postnatal group was 1 day (range, 1–13 days). The diagnosis for one patient with total anomalous pulmonary venous return was not made until day 13 of life. Using a scale of 1 (no understanding) to 10 (complete understanding), parents reported a slightly higher understanding of the child's current medical condition (7.7 ± 2.5) compared with their understanding about what would happen to their child in the future (6.8 ± 2.7). No significant difference in the subjective reporting of parental comprehension of the child's future was observed between parents with a prenatal diagnosis and those with a postnatal diagnosis ($p = 0.14$). Compared with 24 (92%) of the 26 families who had a prenatal diagnosis, 18 (72%) of the 25 families with a postnatal diagnosis thought that they could describe their child's heart condition to a friend ($p = 0.13$).

Prenatal Diagnosis

Approximately half of the families (26/50) had a prenatal diagnosis. Eight of the diagnoses were received before 5 months of pregnancy, whereas 18 diagnoses were received at 5 to 7 months, and none were received later than 7 months. The average number of prenatal visits with a cardiologist was 4 ± 2 . Trisomy 21 with an atrioventricular canal was diagnosed by an obstetrician for one patient who did not see a cardiologist prenatally. This family was scored as receiving a nonprenatal diagnosis for the purposes of this study.

On a scale of 1 (no understanding) to 10 (complete understanding), the average self-reported understanding of the child's heart condition before birth was 7.2 ± 2.2 . Using the same scale, parents reported how much they understood prenatally about what would happen during the first few weeks of the child's life (7.3 ± 1.9) and in the future (6.5 ± 2). Self-reported parental understanding of the child's future increased slightly after the birth of the baby (7.7 ± 1). Most of the parents (24/26, 92%) reported that they would be able to describe their child's heart condition to a friend.

Prenatal diagnosis was associated with increased parental concern after the child's birth. Approximately half of the families (24/50, 48%) reported worry about taking their baby home. Of these 24 families, 17 (71%) had received a prenatal diagnosis (OR, 4.6; 95% CI, 1.2–18.1; $p = 0.01$).

A trend toward a difference in total understanding score between prenatal diagnosis (6.9 ± 2.2) and postnatal diagnosis (5.8 ± 2.5 ; $p = 0.09$) was shown by *t* test analysis. Multivariate regression used to control for maternal education level showed that a prenatal diagnosis was associated with a higher understanding score ($p = 0.02$) (Fig. 1). Both prenatal diagnosis and maternal education ($p < 0.01$) had independent effects on the score, and no significant interaction effect was found, indicating that a significant association between prenatal diagnosis and increased parental understanding exists at each level of maternal education.

The effects of maternal education and prenatal diagnosis were seen across all subsets of the understanding score. However, *t* test analysis demonstrated statistical significance only for

maternal education in the CHD score ($p = 0.04$) and the follow-up score ($p = 0.001$) (Figs. 2 and 3).

Discussion

The results of this study indicate that a prenatal diagnosis of CHD is associated with increased parental understanding at NICU discharge. The positive association between prenatal diagnosis and increased parental understanding existed across different levels of maternal education, such that families with both low and high educational backgrounds benefited from prenatal diagnosis. A possible explanation for this finding includes increased time for parent education. Prenatal diagnosis of CHD often leads to multiple visits with care providers before birth, including the pediatric cardiologist, the pediatric cardiothoracic surgeon, geneticists, and high-risk obstetricians, allowing the parents repeated opportunities for discussion about their future child's condition. It also could be argued that parents are more receptive to education during the prenatal period, which is likely to be less stressful than the neonatal period, when parents must devote a significant portion of their mental and emotional capacity to the critically ill infant and mothers are faced with the challenges of the postpartum period.

This study also found a significant association between prenatal diagnosis and increased parental concern about taking the baby home. Parents whose child had a prenatal diagnosis were four times more likely to report worry about taking the infant home than parents who received a postnatal diagnosis. We hypothesize that this is due to increased knowledge about the cardiac condition, including increased awareness of potential problems that could develop at home. It also is possible that parents who have had longer to dwell on their child's congenital anomaly are more likely to develop anxiety and express concern than those who have had less time to think about it. However, Hoehn et al. [7], in a study designed primarily to evaluate the validity of informed consent for neonatal cardiothoracic surgery, found no difference in anxiety or stress levels between the parents who knew about their child's CHD before birth and those who found out about it after the birth. Further investigation into the impact of prenatal CHD diagnosis on parental stress and anxiety is necessary for a clearer definition of this potential relationship.

This study also demonstrated that even with prenatal diagnosis, gaps in parental understanding exist. Cheuk et al. [6] similarly reported parental understanding deficits in a population of older children with less complex CHD in Hong Kong. Other groups have shown a parental lack in understanding endocarditis prophylaxis recommendations [1, 4, 5]. Beerl et al. [2] demonstrated that higher levels of parent education were associated with improved parental understanding of CHD. However, these investigators still considered parental knowledge to be suboptimal. Improvements in family education by health care providers, during both the prenatal and postnatal periods, including investigation into potential interventions to maximize these efforts, are needed.

This study had certain limitations. As a pilot study, it enrolled only a small number of subjects, and thus had limited power to detect multiple associations, including analysis of the different question domains and the effect of primary language spoken. Another potential limitation was ascertainment bias. The study investigator approached and enrolled only parents physically present in the NICU 1 or 2 days before discharge. Finally, because the idea to assess parental understanding of CHD in the newborn period is novel, a standardized assessment tool was not available. The questionnaire and scoring system used were developed by the investigators and had not been used previously.

Conclusions

This study aimed to assess the baseline level of parental understanding at NICU discharge and to explore whether prenatal diagnosis influences this understanding. This is the first published study to demonstrate the association between prenatal diagnosis and parent understanding of the child's CHD. We conclude that prenatal diagnosis improves parental understanding of neonatal CHD at NICU discharge and that efforts to support timely prenatal diagnosis of CHD should be pursued. Future studies are needed to investigate the impact that improved parental understanding of CHD in the neonatal period has on parental behavior and clinical outcomes over the first year of life. Axiomatically, it is better for parents to know than not to know. However, the practical benefits of improved parental understanding require documentation.

Acknowledgments

Ismee Williams reports support from a K12 National Institutes of Health (NIH) grant. This publication was made possible by grant no. KL2 RR024157 from the National Center for Research Resources (NCRR), a component of the NIH, and the NIH Roadmap for Medical Research. The contents of this report are solely the responsibility of the authors and do not necessarily represent the official view of NCRR or NIH. Information on NCRR is available at <http://www.ncrr.nih.gov/>. Information on reengineering of the Clinical Research Enterprise can be obtained from <http://www.nihroadmap.nih.gov/clinicalresearch/overview-translational.asp>.

Appendix

Parent Understanding Questionnaire (partial)

Doctor Score

Who is your baby's pediatrician?

Who will be your baby's cardiologist when you go home?

Who operated on your baby's heart (surgeon's name)?

CHD Description Score

What is the name of your baby's heart condition?

Can you describe your baby's heart condition?

Can you circle on a diagram where your baby's heart problem is? (see diagram)

Surgery Score

Has your baby had heart surgery yet? Yes No

If yes, can you describe what the surgery was for?

Will your baby need another surgery in the future?

Yes No Maybe Don't know

If yes, how many surgeries will your baby need in total?

1 2 3 Don't know

Reproduction Score

Do you know your chances of having another baby with a heart condition? (circle one)

Don't know <5% 10% 50% 100%

Does your baby have a higher chance of bearing children with his/her own with heart conditions?

Yes No Don't know

Follow-up Score

What type of follow-up medical care will your child need? (circle one)

No further follow-up needed

Follow-up until 18 years of age

Lifetime care by a cardiologist

Will your child have exercise limitations later in life?

Yes No Don't know

Will your child be able to attend regular school?

Yes No Don't know

What are signs that you should look for that your baby is not doing well?

References

1. Al-Jarallah AS, Lardhi AA, Hassan AA. Endocarditis prophylaxis in children with congenital heart disease: a parent's awareness. *Saudi Med J.* 2004; 25:182–185. [PubMed: 14968214]
2. Beeri M, Haramati Z, Rein JJ, Nir A. Parental knowledge and views of pediatric congenital heart disease. *Isr Med Assoc J.* 2001; 3:194–197. [PubMed: 11303378]
3. Bonnet D, Coltri A, Butera G, et al. Detection of transposition of the great arteries in fetuses reduces neonatal morbidity and mortality. *Circulation.* 1999; 99:916–918. [PubMed: 10027815]
4. Bulat DC, Kantoch MJ. How much do parents know about their children's heart condition and prophylaxis against endocarditis? *Can J Cardiol.* 2003; 19:501–506. [PubMed: 12717485]
5. Cetta F, Bell TJ, Podlecki DD, Ros SP. Parental knowledge of bacterial endocarditis prophylaxis. *Pediatr Cardiol.* 1993; 14:220–222. [PubMed: 8255795]
6. Cheuk DK, Wong SM, Choi YP, et al. Parents' understanding of their child's congenital heart disease. *Heart.* 2004; 90:435–439. [PubMed: 15020523]
7. Hoehn KS, Wernovsky G, Rychik J, et al. Parental decision making in congenital heart disease. *Cardiol Young.* 2004; 14:309–314. [PubMed: 15680025]
8. Mahle WT, Clancy RR, McGaurn SP, et al. Impact of prenatal diagnosis on survival and early neurologic morbidity in neonates with the hypoplastic left heart syndrome. *Pediatrics.* 2001; 107:1277–1282. [PubMed: 11389243]
9. Menahem S, Grimwade J. Effective counselling of prenatal diagnosis of serious heart disease: an aid to maternal bonding? *Fetal Diagn Ther.* 2004; 19:470–474. [PubMed: 15539868]
10. Moons P, De Volder E, Budts W, et al. What do adult patients with congenital heart disease know about their disease, treatment, and prevention of complications? A call for structured patient education. *Heart.* 2001; 86:74–80. [PubMed: 11410567]
11. Satomi G, Yasukochi S, Shimizu T, et al. Has fetal echocardiography improved the prognosis of congenital heart disease? Comparison of patients with hypoplastic left heart syndrome with and without prenatal diagnosis. *Pediatr Int.* 1999; 41:728–732. [PubMed: 10618902]
12. Tworetzky W, McElhinney DB, Reddy VM, et al. Improved surgical outcome after fetal diagnosis of hypoplastic left heart syndrome. *Circulation.* 2001; 103:1269–1273. [PubMed: 11238272]

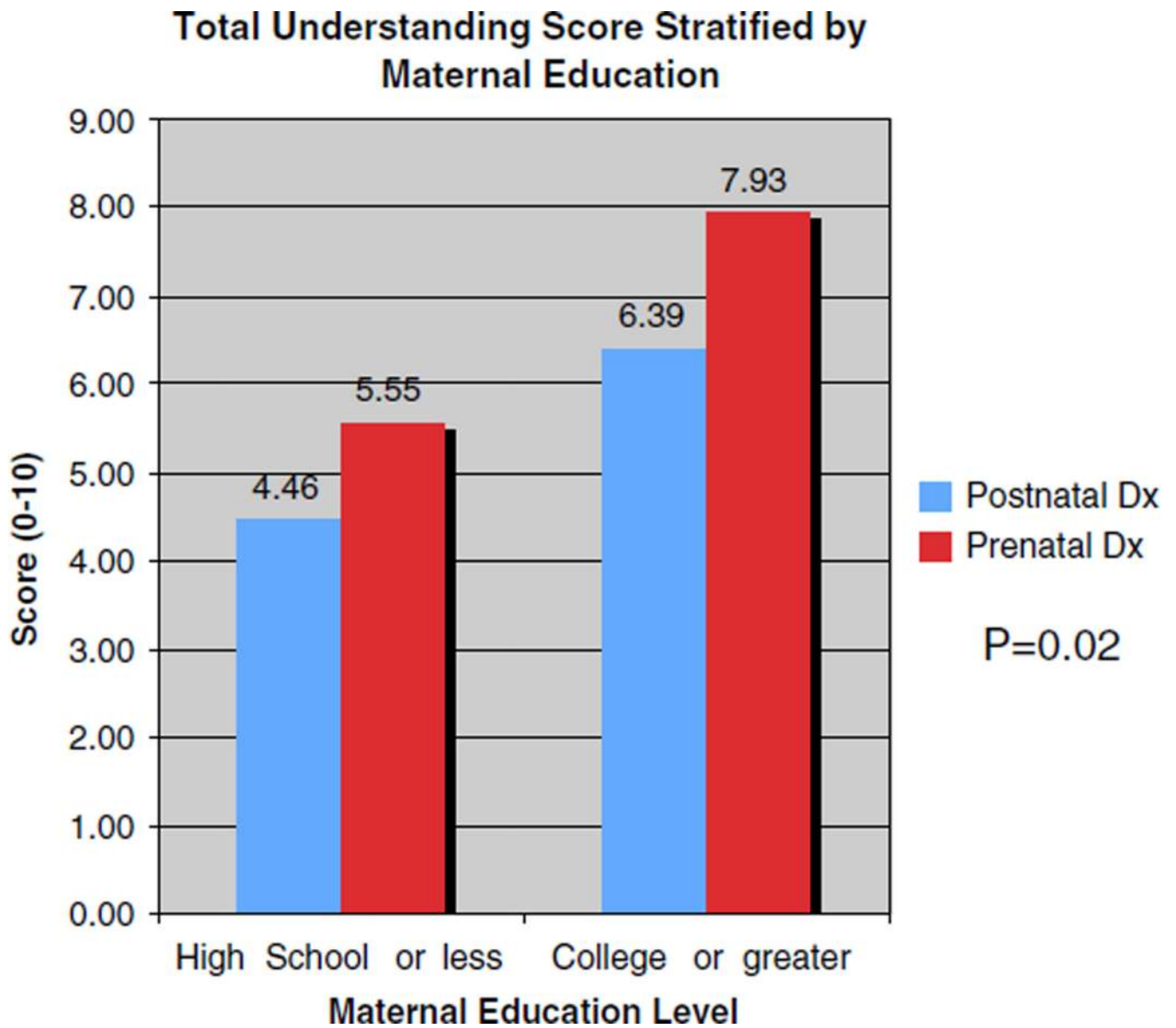
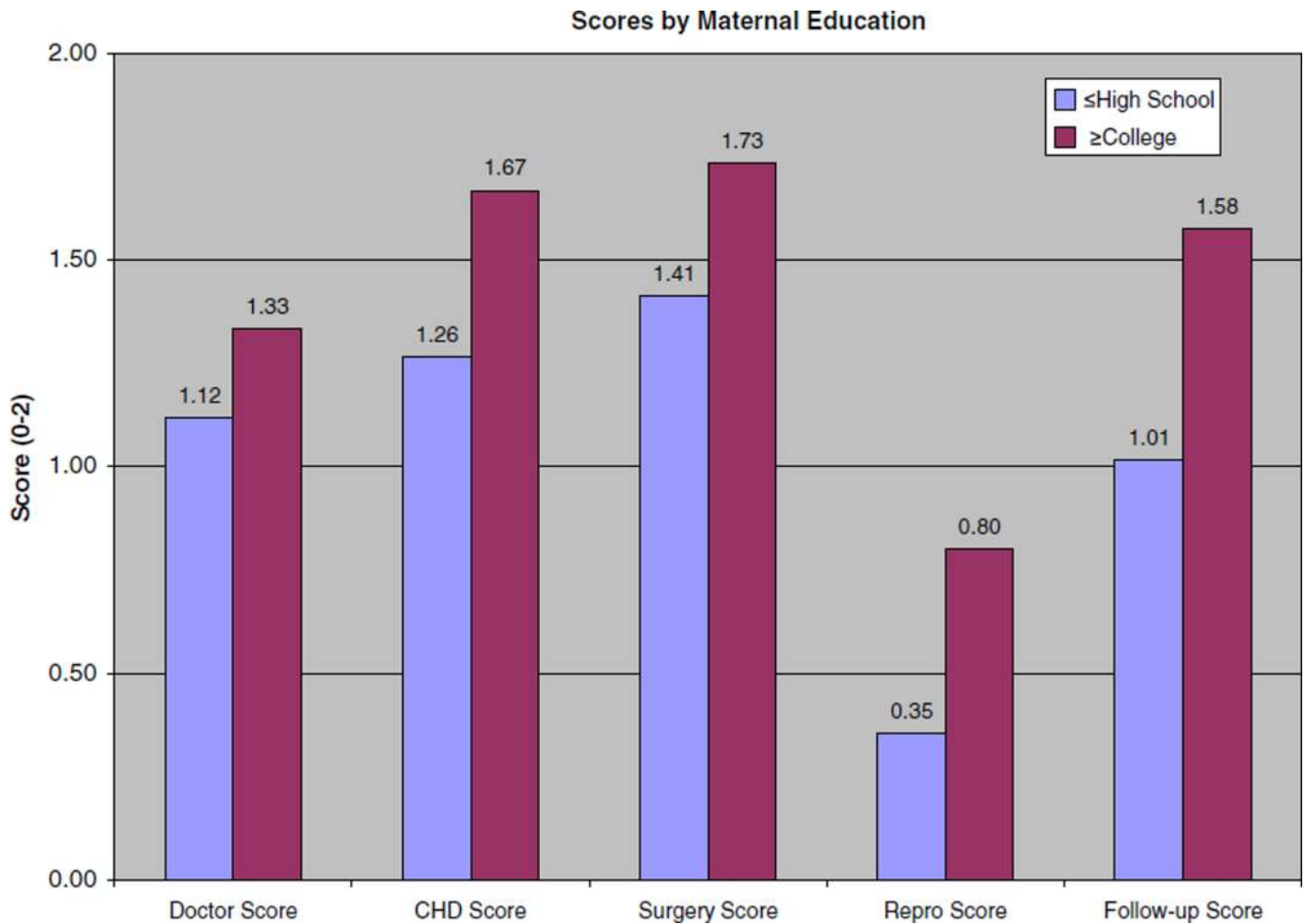


Fig. 1. Mean total understanding score stratified by maternal education level and prenatal versus postnatal diagnosis. Multivariable regression analysis demonstrates independent effects with prenatal diagnosis ($p = 0.02$) and maternal education level of college or greater ($p < 0.01$) associated with a higher total understanding score

**Fig. 2.**

Mean scores for each subcategory of parental understanding for the different maternal education groups. Although women with a college education or more scored higher in each subcategory than women who had a high school education or less, *p* values were significant only for the congenital heart disease (CHD) ($p = 0.04$) and follow-up scores ($p = 0.001$)

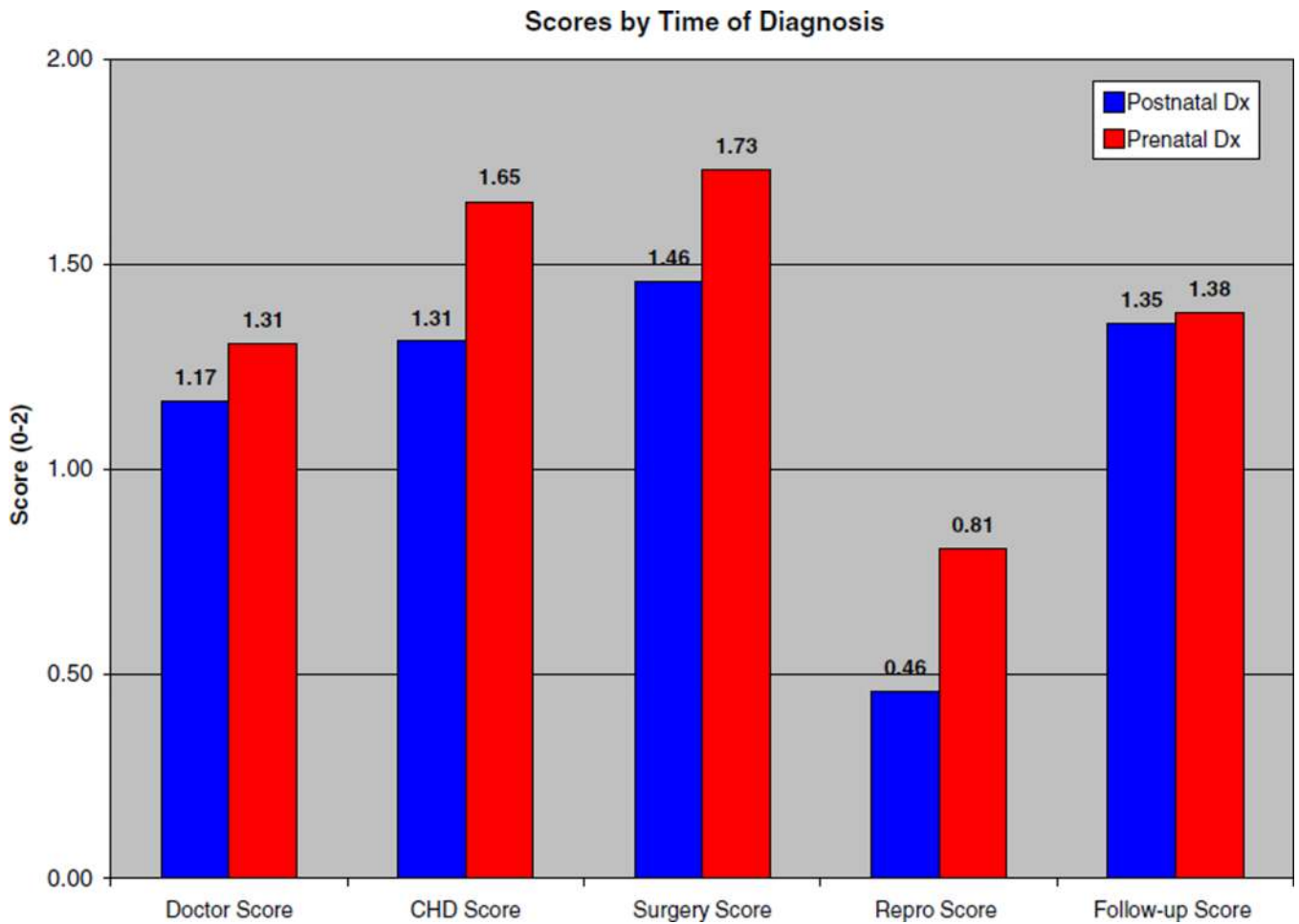


Fig. 3. Mean scores for each subcategory of parental understanding for the prenatal and postnatal diagnosis groups. Although the prenatal diagnosis group scored higher in each subcategory than the postnatal diagnosis group, these differences were not significant according to *t* test analysis

Table 1

Cardiac diagnoses

Diagnosis	Prenatal	Postnatal
Atrioventricular canal (AVC)		3
Right ventricular-dominant AVC	1	1
Valvar pulmonary stenosis	2	
Tetralogy of Fallot (TOF)	3	
TOF/pulmonary atresia	1	
TOF/absent pulmonary valve	1	
Double-outlet right ventricle (DORV)/Taussig-Bing	1	1
DORV/pulmonary atresia	2	
Ventricular septal defect (VSD)		1
VSD/coarctation of aorta or interrupted aortic arch	1	2
Hypoplastic left heart syndrome	6	1
Small left ventricle/hypoplastic aorta	1	1
Coarctation of the aorta		3
Transposition of the great vessels (TGA)	3	5
TGA/VSD		1
TGA/VSD/pulmonary stenosis		1
TGA/coarctation of the aorta		1
TGA/interrupted aortic arch/tricuspid stenosis/hypoplastic right ventricle	1	
L-TGA/double-inlet left ventricle/interrupted aortic arch	2	
Total anomalous pulmonary venous return		2
Left ventricular aneurysm	1	
Obstructive eustachian valve		1

Table 2Study subject characteristics^a

	All (n = 50)	Prenatal Dx (n = 26)	Postnatal Dx (n = 24)
Mean infant age (days)	17.3 ± 13.3	18 ± 16.4	16.4 ± 9
Mean birth order of subject	1.72 ± 1.18	1.58 ± 0.95	1.88 ± 1.39
Mean maternal age (years)	30.7 ± 6.8	30.7 ± 7	30.7 ± 6.7
Highest level of completed maternal education			
Grade school	1	0	1
High school	16	11	5
College	23	11	12
Graduate school	7	3	4
Primary language spoken at home			
English	40	19	21
Spanish	6	4	2
Other	2	2	0
Reported money worries	13	6	7

Dx, diagnosis

^aAll *p* values are nonsignificant