Vulnerable Child Syndrome and Newborn Screening Carrier Results for Cystic Fibrosis or Sickle Cell

Michael H. Farrell, MD[1,2], Alexandra M. Sims, MD[3], Alison La Pean Kirschner, MS, CGC[2], Philip M. Farrell, MD, PhD[4], and Beth A. Tarini, MD, MS[3,5]

Objectives To measure parental perceptions of child vulnerability, as a precursor to developing a population-scale mechanism to mitigate harm after newborn screening.

Study design Participants were parents of infants aged 2-5 months. Parental perceptions of child vulnerability were assessed with an adapted version of the Vulnerable Baby Scale. The scale was included in the script for a larger study of telephone follow-up for 2 newborn blood screening samples (carrier status for cystic fibrosis or sickle cell hemoglobinopathy). A comparison sample was added using a paper survey with well-baby visits to an urban/suburban clinic.

Results Sample sizes consisted of 288 parents in the cystic fibrosis group, 426 in the sickle cell hemoglobinopathy group, and 79 in the clinic comparison group. Parental perceptions of child vulnerability were higher in the sickle cell group than cystic fibrosis group ($P < .0001$), and both were higher than the clinic comparison group ($P < .0001$). Parental perceptions of child vulnerability were inversely correlated with parental age ($P < .002$) and lower health literacy ($P < .015$, sickle cell hemoglobinopathy group only).

Conclusions Increased parental perceptions of child vulnerability seem to be a bona fide complication of incidental newborn blood screening findings, and healthcare professionals should be alert to the possibility. From a public health perspective, we recommend routine follow-up after incidental findings to mitigate psychosocial harm. *(J Pediatr 2020;224:44-50)*.

See editorial, p 22 and related article, p 37

Newborn blood screening (NBS) is one of the best examples of successful bench to bedside research. More than 6000 infants in the US are diagnosed annually with dozens of potentially fatal, relatively rare, conditions.[1] As whole genome sequencing moves toward a reality for disease identification in the newborn period, it has garnered the interest of parents, clinicians, researchers, and industry leaders as a public health screening tool.[2,3] Despite the lives NBS saves and the promise the future holds, there remain concerns about the psychosocial implications of incidental findings, such as false-positive results and carrier statuses, that accompany NBS. These concerns from policy experts and investigators alike do not diminish the value of scientific advancement, but do encourage us to be thoughtful about how new technologies are implemented in NBS policy and practice.

Vulnerable Child Syndrome is a commonly mentioned complication after NBS, although much of the Vulnerable Child Syndrome literature focuses on health conditions rather than test results.[4-8] Originally described by Green and Solnit in 1964, Vulnerable Child Syndrome includes a suite of parental behavioral and psychological issues after a perceived health threat to a child.[9] Despite recovery from illness, Vulnerable Child Syndrome families may develop common symptoms, including parental overprotection, separation difficulties, poor school performance, challenges with limit setting, and preoccupation with somatic complaints like abdominal pain or headaches.[10-13] Vulnerable Child Syndrome and the resulting overconcern contribute to increased use of healthcare services and increased dissatisfaction with health services rendered.[11-16]

The original description referred to a history of life-threatening illness, and risk for Vulnerable Child Syndrome is correlated with severity of the child's original illness.[9,11,12,17-20] However, Vulnerable Child Syndrome has also been

CF	Cystic fibrosis
ELSI	Ethical, legal, and social implication
NBS	Newborn blood screening
SCH	Sickle cell hemoglobinopathy
VB Scale	Adaptation of Kerruish's Vulnerable Baby Scale

From the [1]Department of Pediatrics and Adolescent Medicine, Mayo Clinic, Rochester, MN; [2]Center for Patient Care and Outcomes Research, Medical College of Wisconsin, Milwaukee, WI; [3]Department of Pediatrics, George Washington University, Washington DC; [4]Departments of Pediatrics and Population Health Sciences, University of Wisconsin School of Medicine and Public Health, Madison, WI; and [5]Center for Translational Research, Children's National Hospital, Washington, DC

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associated with relatively benign conditions like feeding difficulties, gastroenteritis, croup, and jaundice.[21-27] Other risk factors for Vulnerable Child Syndrome include the child being the first born, having a history of prematurity, or being a product of a high-risk pregnancy or delivery.[10,12,18,28,29] Vulnerable Child Syndrome is also thought to be partially modulated by other parent and child experiences, including postpartum depression.[13,30,31]

Vulnerable Child Syndrome has been observed after false-positive NBS for metabolic disorders, newborn hearing screening, and infant screening for type 1 diabetes risk.[5-8] Vulnerable Child Syndrome may also occur after NBS for cystic fibrosis (CF) identifies heterozygous or carrier status, as observed in a modest sample in previous research.[4] We suspect Vulnerable Child Syndrome will continue to be mentioned as a complication in policy discussions, given the expansion of molecular genetic methods in NBS and elsewhere. The chief opportunity for this research is afforded by incidental finding of carrier status for CF or sickle cell hemoglobinopathy (SCH). A Vulnerable Child Syndrome measure was included in the Wisconsin Project on Improvement of Communication Process and Outcomes after Newborn Screening, but the Vulnerable Child Syndrome results were provocative enough that we postponed this report until we had a comparison sample from a more general pediatric population.[32-41]

Methods

A diagnosis of Vulnerable Child Syndrome depends on clinical judgment, but in research there have been a variety of methods to operationalize the concept.[4-7,9-31,42-44] Prior investigations have assessed "parental perception of child vulnerability" as with the Forsyth's Child Vulnerability Scale.[15] The first iteration of this tool asked for 5-point responses to 12 statements, such as "In general my child seems less healthy than other children" and "I often think about calling the doctor about my child." This was revised to 8 items with a 4-point response scale and later validated.[15,21] Kerruish et al developed the Vulnerable Baby Scale (VB Scale) by modifying Forsyth's survey statements to be appropriate for young infants.[25] We made slight modifications to Kerruish's text to fit with our study (**Table I**; available at www.jpeds.com).

The current report compares analyses of VB Scale data from 3 parallel groups of parents of infants between 2 and 5 months of age. In the first 2 groups, the infants had been identified by NBS as carriers for SCH or CF. The third group is referred to as the clinic comparison group, and consisted of parents who presented for a 2- or 4-month well-baby check at a primary care clinic. Institutional review board approvals were obtained separately for the NBS groups and the clinic comparison group.

Participants

The SCH and CF groups were recruited as part of the Wisconsin Project on Improvement of Communication Process and Outcomes after Newborn Screening, which was conducted from 2008 to 2012 in collaboration with Wisconsin's NBS laboratory.[32-41] For the SCH group, infants had an NBS result showing fetal, adult, and sickle hemoglobin (the FAS result). For the CF group, infants' NBS result showed elevated immunoreactive trypsinogen and a single mutation in the *CFTR* gene, followed by a normal result on the infant's sweat chloride testing.

Recruiting procedures have been detailed elsewhere, including design elements meant to mitigate recruitment bias.[32,41] In brief, NBS results were assessed until we identified 1669 infants with SCH carrier status and 800 infants with CF results. Then, 10 types of exclusion criteria were applied from NBS records and a call to the primary care provider: (1) >1 abnormality found on NBS, (2) NBS was a repeat specimen, (3) gestational age of <35 weeks, (4) calendar age at collection was >180 days, (5) a primary care provider could not be identified, (6) the infant spent >5 days in hospital, (7) the infant was rehospitalized after discharge, (8) the infant was being evaluated for another serious medical condition, (9) the parent(s) reportedly needed a language interpreter, and (10) infants in the CF group had a positive sweat chloride test.

As described elsewhere, consent occurred over a 5-stage process that was carefully designed to mitigate distress for parents who had forgotten about the NBS results or were never informed.[32,41] Parents were offered the chance to decline the research aspect of the project but still discuss the NBS result with us.

Clinic Comparison Group

When parental perceptions of child vulnerability data from the NBS groups were higher than expected, we sought permission from a local primary care clinic to gather a comparison sample. The clinic served a diverse population across an urban and suburban region. The clinic's desk staff were given a stack of large envelopes that each contained a printed survey packet (described elsewhere in this article). For an approximately 6-month period in 2012, the desk staff were asked to give the envelope to parents who were presenting to the pediatrics and family medicine groups for a 2- or 4-month well-baby check, as identified on the clinic schedule.

On the cover of the envelope was printed a message describing the research, assuring parents that they were not obligated to participate, and that they could withdraw at any time. All returned envelopes were opened later and abstracted to the study database, regardless of how complete they were.

Data Collection

NBS Groups. Trained nurses or a genetic counselor were scheduled to telephone the parents when their infants were between 3 and 5 months old, to allow for ≥1 well-baby visit.

As detailed elsewhere, callers followed a standardized script that was initially designed for clinical follow-up, and then structured to facilitate research data collection.[32,41] The core clinical topics in the script were verifying receipt of the NBS result, checking for misunderstandings, and providing initial counseling. Embedded in the script was an adapted version

of the VB Scale (Table I).[25] Health literacy was evaluated with a 3-item screening tool adapted from Chew et al.[45]

To ensure that the dataset reflected multiracial diversity, we asked an open-ended question, "How would you describe your race or ethnicity?" We then abstracted responses as closely as possible into one or more binary fields for each of the standard National Institutes of Health categories.[46] For example, if a parent described his or her ethnicity as "mixed Latino and white" then the database fields for Hispanic and white were flagged (per National Institutes of Health protocol, Spaniards were classified as Hispanic, and Brazilians as white).

Calls were digitally audio-recorded and transcribed without names or other identifying information. Interviewers kept written notes during the call, and both notes and transcripts were abstracted for fixed answers and other fields in the project database.

Clinic Comparison Group. The paper survey instrument included our adapted version of the VB Scale[25] (Table I). Also included were the open-ended race/ethnicity questions and the Chew health literacy questions.[45] Several other questions were added to confirm the diverse nature of the sample, because we knew in advance that the clinic comparison sample size would be smaller than the SCH and CF groups.

Statistical Analyses

Analyses were done as applicable for the nature of each variable (*t* test, correlation, the Wilcoxon rank-sum test, or logistic and ordinal modeling) using JMP software (SAS Institute, Cary, North Carolina).

Missing data were addressed with 2 approaches. For the main analysis, records were excluded if a VB Scale item was missing. However, in the NBS study we were aware of anecdotes where the VB Scale would be interrupted because the parent was growing impatient to get back to the NBS result. We therefore conducted a secondary analysis with prorated scores from any parent who answered ≥7 of the 10 VB Scale items. A third analytic approach was added post hoc, as described in the Results.

Results

As reported elsewhere, the NBS study's final sample consisted of 426 in the SCH group and 288 in the CF group (respective participation rates 34.8% and 49.6% of eligible parents).[41] For the primary care clinic sample it unfortunately is not possible to know how many parents were approached by the desk staff, but based on the printed supply and the clinic schedule we estimated a ratio of about 20% of eligible parents were approached and one-half of those envelopes were returned. Of these surveys, 7.1% were returned too incomplete for analysis, and there was no way to discern if the parent chose to stop or if the survey had been interrupted by the arrival of the clinic provider. The final sample size for the comparison group was 79.

The characteristics of the 3 groups are given in Table II, with the CF and SCH columns adapted from previous reports.[41]

VB Scale Scores

The distributions of parental perceptions of child vulnerability data are depicted in the Figure (available at www.jpeds.com), with histogram columns connected into lines for ease of comparison.

The means for parental perceptions of child vulnerability data are shown in Table III, for 3 parallel analyses. The top row depicts the main analysis of parents who completed the entire VB Scale. Parental perceptions of child vulnerability were significantly greater for the SCH group than the CF group, which in turn was greater than for the clinic comparison group (both $P < .0001$ on a *t* test). The second row depicts the ≥7 items completed analysis described in the Methods section, prorated for comparison with the 10-item data in the top row. The significant differences were maintained (SCH group > CF group > clinic comparison group; both $P < .0001$ on a *t* test).

The bottom row of Table III presents an ad hoc analysis that was added within the first few weeks of the NBS study, when we realized from many parent comments that there was an applicability problem with question #9: "If you left the baby with someone else, how likely would you be to make contact with that person while you were away?" In their responses, many parents mentioned that they would use their mobile phone to text or telephone the babysitter. We inferred that the increased availability of mobile phones might lead to a secular trend that would artefactually seem like an increase in Vulnerable Child Syndrome since earlier studies.[15,21,25-27,43] Nevertheless, we decided to continue asking the question and analyze the parental perceptions of child vulnerability data both with and without the babysitter question. We also carried forward this analytic approach for the clinic comparison group. Removal of item #9 did not change the significant differences (SCH group > CF group > clinic comparison group; both $P < .0001$ on a *t* test).

Characteristics Associated with Perception of Vulnerability

Inferential analyses were conducted in aggregate and for each of the 3 groups. In the SCH group, the screen for health literacy problems was associated with slightly higher parental perceptions of child vulnerability (28.8 vs 27.7; $P < .015$ on a *t* test). Parental perceptions of child vulnerability data in both groups were correlated with younger parental age (for SCH group, $r = -0.17$, $P < .002$; for the CF group, $r = -0.20$, $P < .002$).

Race/ethnicity factors had a variety of associations with parental perceptions of child vulnerability, but many factors co-varied. With stepwise regression, parental perceptions of child vulnerability data in the CF group were inversely associated with black race only for the infant (OR, 0.23; $P < .001$).

Table II. Participant characteristics

Characteristics	SCH carrier group Mean	SD	CF carrier group Mean	SD	Clinic comparison group Mean	SD
Numeric data						
Gestational age at birth (weeks)	38.9	1.3	39.1*	1.2	39.1	(1.8)
Baby's age at interview (days)	107.1	23.9	110.8	25.8	101	(16.3)
Parent's age (years)	25.8	(5.9)	28.7	(5.6)	30	(5.3)
Categorical data	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**
Screen positive for health literacy problem	150	(37.7)	104	(36.5)	35	(44.3)
Parent race data*						
Race-included						
Black-included	280	(65.7)	20	(6.9)	5	6.3
White-included	87	(20.4)	250	(86.8)	56	70.9
Hispanic-included	29	(6.8)	8	(2.8)	13	16.5
Other-included	14	(3.3)	7	(2.4)	7	8.9
Race-only						
Black-only	265	(62.2)	16	(5.6)	3	3.8
White-only	72	(16.9)	246	(85.4)	49	62
Hispanic-only	19	(4.5)	5	(1.7)	10	12.7
Other-only	7	(16.4)	4	(1.4)	5	6.3
Multiracial unspecified	5	(1.2)	1	(0.4)	1	1.3
Not asked or answered	36	(8.4)	9	(3.1)	4	5.1
Infant race data*						
Race-included						
Black-included	330	(77.5)	24	(8.3)	9	11.4
White-included	82	(19.3)	255	(88.5)	54	68.4
Hispanic-included	38	(8.9)	14	(4.9)	10	12.7
Other-included	23	(5.4)	11	(3.8)	6	7.6
Race-only						
Black-only	249	(58.5)	14	(4.9)	3	3.8
White-only	13	(3.1)	235	(81.6)	48	60.8
Hispanic-only	15	(3.5)	4	(1.4)	7	8.9
Other-only	2	(0.5)	4	(1.4)	5	6.3
Multiracial unspecified	52	(12.0)	7	(2.4)	1	1.3
Not asked or answered	14	(3.2)	6	(2.1)	8	10.1

*Columns for race data do not sum to 100% because data are not mutually exclusive.

For the SCH group, VB Scale data were inversely associated with white race only for the parent (OR, 0.33; $P < .001$).

Within the clinic comparison group, no significant associations were detected.

Individual Items from the VB Scale

As mentioned elsewhere in this article, our anecdotal experiences with item #9 led us to analyze data with and without that item. We then decided to report responses to all of the individual items, to document the individual attitudes within the parental perceptions of child vulnerability construct. The resulting analyses are listed in Table IV. Although the data are nonparametric, the intergroup differences are qualitatively analogous to those of the summary scores.

Discussion

Many child health professionals encounter families with high parental perceptions of child vulnerability. These families often improve, but some family members develop persistent Vulnerable Child Syndrome symptoms or long-term issues with the healthcare system. Vulnerable Child Syndrome is especially regrettable when NBS identifies carrier status, because carrier results are incidental findings during the effort to decrease disease morbidity and mortality, and have limited health implications. When we evaluated parents of carrier infants, the parental perceptions of child vulnerability data were considerably worse than we were expecting based on previous samples.[21,25] Our clinic

Table III. Vulnerable baby scores*

Analytic approaches	SCH carrier group Mean	SD	CF carrier group Mean	SD	Clinic comparison group Mean	SD
Entire survey completed	38.4	(4.8)	36.5	(3.5)	31.8	(2.9)
At least 7 items completed (prorated)	38.3	(3.9)	36.3	(3.7)	31.8	(2.9)
Without item 9 (prorated)	37.4	(3.7)	35.8	(3.2)	33.7	(2.5)

Values are mean (SD).
*Each mean is significantly different from the other 2 means in its row ($P < .0001$).

Table IV. Responses to individual questions in the VB Scale

	SCH carrier group		CF carrier group		Clinic comparison group	
Individual items	Median	*P* vs CF carrier	Median	*P* vs clinic comparison group	Median	*P* vs SCH carrier
1. Check while asleep	4	<.0001	3	NS	3	<.0001
2. Leave out of earshot	5	NS	5	<.0001	1	<.0001
3. Friend with a cold	3	<.0001	3	NS	3	<.0001
4. Stomach pains	1	<.0001	2	.0002	4	<.0001
5. Concern not healthy	1	NS	1	<.0001	5	<.0001
6. Worse than others	2	<.006	2	<.0001	4	<.0001
7. Worry will become ill	2	NS	2	<.0001	4	<.0001
8. Think about SIDS	2	NS	2	<.0001	4	<.0001
9. Contact babysitter	5	<.0001	5	<.0001	1	<.0001
10. Contact doctor/nurse	1	<.03	1	<.0001	2	<.0001

NS, not significant; *SIDS*, sudden infant death syndrome.

comparison group also had worse parental perceptions of child vulnerability than previous reports, but significantly less so than our 2 NBS groups. Thus, increased parental perceptions of child vulnerability (and likely some cases of Vulnerable Child Syndrome) seem to be a bona fide complication of carrier identification after NBS.

Telephone and paper methods were used in the NBS and comparison groups, respectively, but both approaches have also been reported in the literature.[4,7,15-28,42-44] The comparison group was smaller than the 2 NBS groups because this ad hoc collection was not budgeted in our grants, but there were enough participants to allow statistical significance. The NBS groups' recruiting methods were designed to mitigate bias,[32,35,41] but we recognize that some parents' voices may not have been represented. Even so, the effect sizes were strong enough that significance would have been maintained despite substantial increases in response rate with limited parental perceptions of child vulnerability. Further study may be needed to discern how modest numeric differences in parental perceptions of child vulnerability relate to the number of children with clinical differences in Vulnerable Child Syndrome.

Our experience with this analysis has convinced us of a serious need for more research into parental perceptions of child vulnerability and Vulnerable Child Syndrome in the general population. Previous reports suggest that parental perceptions of child vulnerability may be elevated in between 3% and 10% of parents in the general community.[15,21,25,43,44] If parental perceptions of child vulnerability have increased broadly (as suggested by our small comparison group), there may be society-scale effects on child development, healthcare, and expenditures. Further research may also help clinicians and health systems to identify families where parental perceptions of child vulnerability have increased to worrisome levels, and has actually led to psychological problems and unnecessary use. In contrast, we may need to recalibrate the parental perceptions of child vulnerability construct. For example, the convenience of mobile phones may have influenced VB Scale item #9, and it is difficult for us to judge whether texting a babysitter reflects unnecessary anxiety. The significant differences for item #9 seemed to parallel the overall differences, including items such as perception of health or desire for healthcare visits.

However, this report was not originally intended to address the ongoing debate about Vulnerable Child Syndrome and measurement. Instead, we intended to implement a straightforward set of questions in a real-world public health setting. Given that success, the next step is to consider the implications for clinical care and NBS policy.

The clinical implication is that healthcare providers should be aware of the possibility for increased parental perceptions of child vulnerability and Vulnerable Child Syndrome after NBS. Some parents may be at greater risk. Younger parents in both NBS groups had higher parental perceptions of child vulnerability. Lower health literacy may also be a risk factor, although we are unsure why this association was limited to our SCH group. Racial/ethnic disparities in parental perceptions of child vulnerability were difficult to interpret succinctly and call for further investigation.

Clinical awareness may not be enough, because there may be problems with providers' communication after NBS.[37] We therefore recommend that NBS programs conduct follow-up and provide skilled counseling as a public health measure for families of infants with incidental and false-positive findings.

Routine follow-up after incidental findings would be consistent with what we have called a "safety approach" to ethical, legal, and social implication (ELSI).[37,41] In a safety approach to ELSIs, NBS programs assume responsibility for incidental findings and the resulting psychosocial complications. A safety approach contrasts with ELSI scholarship grounded in questions about whether certain screening tests should be implemented. We anticipate continued expansion regardless of ELSIs, because NBS is so dominated by disease advocacy groups and attractive technological advances. We believe that the next step for NBS and bioethicists is to collaborate on mitigating Vulnerable Child Syndrome and other psychosocial complications. Anyone worried about the cost of follow-up programs should consider how the cost-benefits of expanding NBS outweigh the modest personnel costs of telephone counselors.

Our results may be relevant for the longstanding debate about withholding carrier results from parents, as has been explored in literature too extensive to cite here. We acknowledge that commentators who favor withholding may cite our data in their arguments. However, we have argued for a population-scale mechanism for follow-up after carrier identification to ensure "more good than harm."[41,47,48]

Some critics might argue that NBS policy does not need to be concerned about Vulnerable Child Syndrome, because our analysis only measured parental perceptions of child vulnerability. In our view, however, the precise incidence of Vulnerable Child Syndrome is not so relevant as the fact that Vulnerable Child Syndrome is at least partially iatrogenic. Families at risk for Vulnerable Child Syndrome after incidental NBS findings are paying part of the price for other infants' early identification.

In summary, increased parental perceptions of child vulnerability and risk for Vulnerable Child Syndrome are bona fide risks of incidental findings after NBS identifies carrier status for CF or SCH. Healthcare professionals should be aware of this risk, but we also recommend public health follow-up for safety reasons. There is a need for re-investigation of parental perceptions of child vulnerability, Vulnerable Child Syndrome, healthcare, and child development. ■

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Reprint requests: Michael H. Farrell, MD, Mayo Clinic Department of Pediatrics and Adolescent Medicine, 200 First Street SW, Rochester, MN 55905. E-mail: Farrell.Michael1@mayo.edu

Data Statement

Data sharing statement available at www.jpeds.com.

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50 Years Ago in *THE JOURNAL OF PEDIATRICS*

Impact of Technology and Innovation on Congenital Heart Disease Survival

Hurwitz RA, Simmons RL, Girod DA. Survival of infants with severe congenital heart disease. J Pediatr 1970; 77:412-6.

In the 1950s, the availability of cardiac catheterization and cardiopulmonary bypass revolutionized the diagnosis and treatment of congenital heart disease (CHD). During the 1960s, repair of tetralogy of Fallot, left-to-right shunts, and the atrial switch procedure for transposition of the great arteries (dTGA) were routinely performed in older infants and children; however, surgery for severely ill neonates with CHD did not become a reality until the 1970s.

This report by Hurwitz et al, written on the cusp of the availability of neonatal cardiac surgery, describes survival in 170 infants born between 1963 and 1968 with severe CHD. Overall survival was 44%, and most deaths occurred before 3 months of age. Survival improved over time from 27% to 51%, due to the availability of balloon atrial septostomy and improvements in surgical approach. No infants with hypoplastic left heart syndrome (HLHS) or total anomalous pulmonary venous return survived. The authors concluded that survival would continue to rise and that 59% of the survivors could expect to have definitive surgery with acceptable risk.

In the ensuing 50 years, the management of infants with severe CHD progressed far beyond the predictions of Hurwitz et al. In the late 1970s, transthoracic echocardiography quickly supplanted diagnostic cardiac catheterization, and at present, fetal echocardiography can detect up to 90% of severe CHD. Prophylactic use of prostaglandin E1 prevents the negative consequences of hypoxia and poor perfusion in ductal-dependent CHD, and neonatal cardiac surgery is routinely performed for the most complex lesions. The anatomically correct arterial switch procedure has supplanted the atrial switch in dTGA with outstanding results, and staged palliation of HLHS has resulted in 1-year survival of 69%. Current estimates predict that 90% of children born with CHD will survive beyond 18 years of age.

We are now in an era where more adults are living with CHD than children. The oldest survivors of open-heart CHD surgery are in their 70s, receiving care from board-certified adult CHD subspecialists. The care of patients with CHD has evolved beyond improving operative survival to addressing the challenges of long-term cardiac, medical, psychosocial, and neurodevelopmental outcomes and optimizing quality of life.

Erin A. Paul, MD
Daphne T. Hsu, MD
Division of Pediatric Cardiology
Children's Hospital at Montefiore
Albert Einstein College of Medicine
Bronx, New York

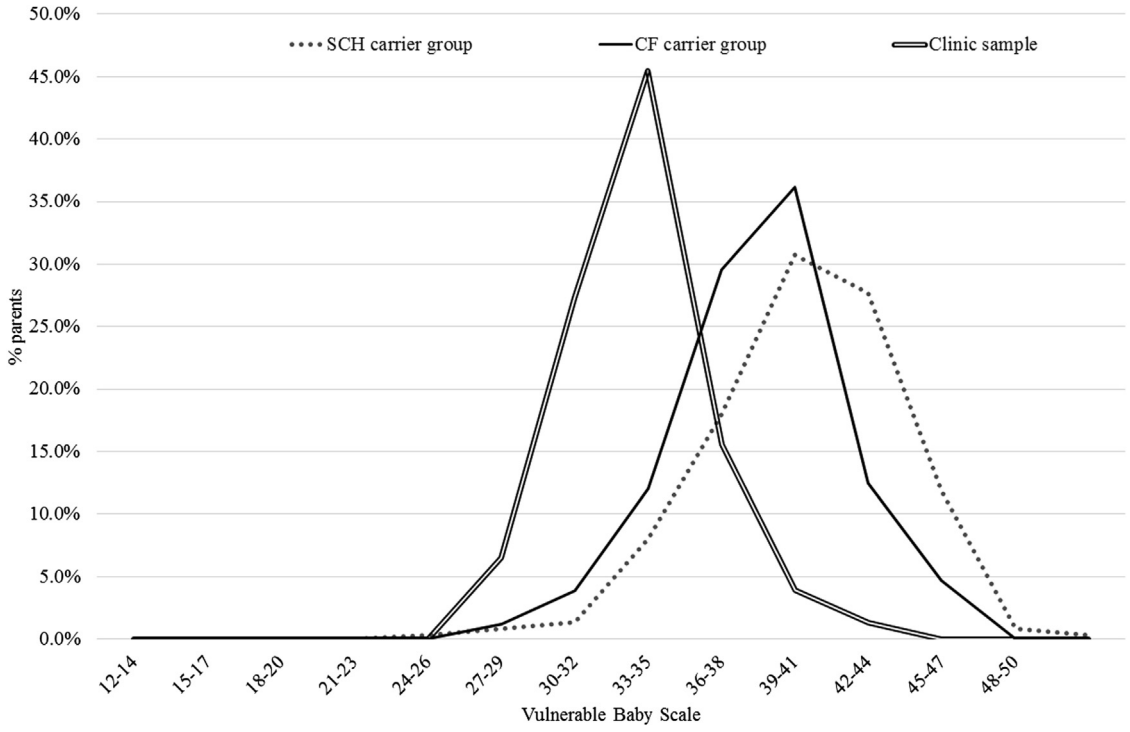

Figure. Distributions of scores for the VB Scale.

Table I. VB scale*

Questions	Options for reply
1. How often do you check on baby while he/she is asleep at night?	Not at all/Rarely/1-2 times each night/Several times each night/Every half hour or so
2. If baby was awake and playing, what's the longest you would leave baby alone without being able to hear him/her?	Not at all/5 minutes/15 minutes/half an hour/an hour or longer
3. If a friend came over to visit and they had a cold, would you…	Not allow them in the house/Not allow them in the same room as the baby/Allow them in the same room but ask them not to hold the baby/Make them wash their hands before picking up baby/Allow them to pick up the baby as they are
4. How often does baby seem to get stomach pains or other pains?	On a scale of 1 to 5, 5 being "All of the time," 1 being "Not at all."
5. How concerned are you that baby is not as healthy as he/she should be?	On a scale of 1 to 5, 5 being "I think of it all of the time," 1 being "Not concerned at all."
6. When you compare baby 's health to that of other babies do you think he/she is …	On a scale of 1 to 5, 5 being "A lot less healthy," 1 being "a lot more healthy."
7. How often do you find yourself worrying that your baby may become seriously ill?	On a scale of 1 to 5, 5 being "I think of it all the time," 1 being "Not concerned at all"
8. How often do you find yourself worrying about crib death or SIDS?	On a scale of 1 to 5, 5 being "I think of it all the time," 1 being "Not concerned at all"
9. If you left the baby with someone else how likely would you be to make contact with that person while you were away?	On a scale of 1 to 5, 5 being "Yes, definitely," 1 being "No, not at all"
10. In the last 2 weeks how often have been in contact with a doctor or nurse about baby, not including well-baby checks or shots?	Not at all/Once/Once each week/Twice per week/Daily or more

*Adapted from Kerruish.[25]