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Screening for Critical Congenital Heart Disease: The Newest Member of the Recommended Uniform Screening Panel

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LEARNING OBJECTIVES

Upon completion of this article the reader will be able to:

- Describe the importance of pulse oximetry in the newborn nursery as a screening tool for critical congenital heart disease.
- Discuss the recommended screening protocol, as well as implications for nursing care.
- Refer to the history of screening for critical congenital heart disease, and know the current national recommendations for such screening.
- Make recommendations for implementing a screening program, including program planning, necessary equipment, training of providers and education of parents and guardians.

On a Sunday evening a 7-day-old infant is brought to the emergency department of your hospital by her parents. They report that she sometimes turns blue, falls asleep during feedings and has been losing weight since birth. You examine her, noting weak pulses and tachypnea. You and your team begin efforts to stabilize her and a blood gas and chest x-ray are ordered.

The blood gas reveals that she is acidotic and the chest x-ray shows an enlarged heart. A consulting cardiologist performs an echocardiogram and confirms that the infant has hypoplastic left heart syndrome, a form of critical congenital heart disease (CCHD). Her parents are shocked. The mother had state-of-the-art prenatal care and there were no complications during the baby's stay in the newborn nursery. The parents ask why this condition was not detected on the prenatal ultrasound, or immediately after birth. You wonder yourself: how did the physicians and nurses miss this? What could have been done differently for this infant?

Incidence

Congenital heart disease (CHD) is the most common birth defect. Current estimates are that 8 of every 1,000 infants born each

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1 **Screening for Critical Congenital Heart Disease**
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Large, population-based studies conducted in Sweden, Germany and England have provided evaluation of the sensitivity and specificity of pulse oximetry and have shown more complete identification of CCHD in nurseries utilizing this technology.[7,8,9,10]

year in the United States have some form of CHD.[1] CCHD, more severe types of CHD that affect the infant's oxygenation status and require intervention in the first year of life, account for approximately one quarter of all infants born with CHD.[2] A significant risk of morbidity and mortality is associated with CCHD.[3] Fortunately, over the past decade, there have been numerous advances in the repair of CCHD, which have improved outcomes for affected infants.

Screening for CHD: Early Research

Physical examination may miss more than half of all infants born with CCHD. This is mainly due to the fact that not all neonates present with the typical signs and/or symptoms of CHD,[3] and the human eye cannot detect cyanosis until oxygen desaturation approaches 80%.[4] Failure or delay in diagnosing CCHD in the nursery may lead to significant organ damage, long-term complications, such as developmental delays and learning disabilities, and even death. Timely diagnosis in the immediate newborn period is especially important for CCHD infants born with ductal-dependent circulation.

Pulse oximetry has been suggested as a potential screening tool for CCHD. In 1995 research efforts were initiated by Hoke and colleagues at Johns Hopkins University to study the efficacy of neonatal pulse oximetry screening for CHD and CCHD in the nursery.[5,6] Large, population-based studies conducted in Sweden, Germany and England have provided evaluation of the sensitivity and specificity of pulse oximetry and have shown more complete identification of CCHD in nurseries utilizing this technology.[7,8,9,10]

Specificity, the ability of the test to correctly identify normal infants, has been consistently high—98-100%.[12] *Sensitivity,* the ability of the test to correctly identify infants with critical CHD, has been more variable, ranging from 25-98.5%. This variation in reported sensitivity values is partly due to the fact that studies have differed in screening protocols and recommendations, including cut-off values, age at screening, probe placement and oximetry technology.[13] By combining pulse oximetry after 24 hours of age with physical examination, and using a screening protocol that included the measurement of oxygen saturations of the right

hand and one foot, a Swedish team produced a specificity of 97.88% percent and a sensitivity of 82.76%.[7]

In 2009, the American Heart Association (AHA) and American Academy of Pediatrics (AAP) released a scientific statement on the potential use and value of pulse oximetry as a screening tool for CHD. The statement recognized the potential for improved detection of CCHD using pulse oximetry screening. However, universal screening was not recommended in 2009 because of the need for additional study regarding the implementation of screening.[13]

Screening for CCHD: Current Research

Implementing CCHD screening in a community hospital was recently studied at Holy Cross Hospital in Silver Spring, MD through a partnership with Children's National Medical Center in Washington, DC. Prior to beginning the study, education on CCHD screening was provided to all nurses and physicians on staff. Professionals conducting screening were instructed to obtain a preductal/postductal oxygen saturation measurement of each eligible participant by placing the pulse-oximetry probe on the right hand and foot. Screeners were instructed to report the time required to screen each infant, any barriers that they encountered and any reason(s) for missed or incomplete screenings.[14]

This research found that the implementation of CCHD screening is feasible and that no additional nursing staff is required to implement it. During the study period 6,841 infants were enrolled and identified as eligible for screening. Of these, 98.6% were successfully screened according to protocol. The average screening took less than 4 minutes per infant and barriers were reported in only 2.4% of enrolled newborns.[14]

Based on the results of earlier research and of this community-based study, as well as experience helping other nurseries implement screening, Children's National Medical Center created an evidence-based toolkit to guide hospitals in the implementation of a screening program.[15] The toolkit contains recommended steps for initiating a screening program, educational materials for families and providers and advocacy resources. To date, the toolkit has been requested by approximately 75 organizations. In addition, it was translated into Modern Standard Arabic and is currently being used to aid the Health Authority of Abu Dhabi, United Arab Emirates, in the implementation of screening in all 23 of their birthing facilities.[16]

Coming to a Nursery Near You

An increasing number of stakeholders, including healthcare providers, parent advocates and legislators, have begun to advocate for the support of universal CCHD screening. Many hospitals in the United States and in other countries began or completed implementation of CCHD screening in their nurseries even before formal endorsements or recommendations. In May 2011, Maryland became the first state to pass and enact CCHD screening legislation. Later that month New Jersey became the first to mandate that CCHD screening should be conducted for all neonates born in birthing facilities in the state. Other states that have passed, or are currently considering legislation to mandate screening include Indiana, Minnesota, Wisconsin and Connecticut.[17]

In October 2010, the Health Resources and Services Administration's (HRSA) Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) recommended to Health and Human Services Secretary Kathleen Sebelius that screening for CCHD be added to the recommended uniform screening panel (RUSP).[18] To further develop this recommendation, the SACHDNC convened a group of experts in Washington, DC to discuss best-practice. The outcomes of this meeting, including recommendations for implementing programs, protocols for screening infants, suggested screening equipment and management of infants who fail the test, were pre-released by *Pediatrics* and appear in the November 2011 issue of the journal.[19]

On September 21, 2011 Secretary Sebelius endorsed the SACHDNC's recommendation that CCHD screening be added to the RUSP.[20] In addition, she called for extending research on issues related to implementation and surveillance of screening in varied populations. The AAP, AHA, American College of Cardiology and the March of Dimes have all endorsed CCHD screening.[19,21]

Implementing Your CCHD Screening Program

Through our experience in research and implementing screening as the standard of care, numerous lessons about best-practice have been learned. We hope they will assist you in establishing your own screening program.

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Planning Your Program

The value of involving an interdisciplinary team from the very beginning cannot be overstated. The team must include both leadership (physician and nursing) and bedside staff. Each member of the team will have significant contributions to make based on individual knowledge, expertise and experience. Because bedside staff have an intimate understanding of care-delivery and staffing models, they often have helpful ideas on integrating CCHD screening into their existing workflow. At one hospital we failed to involve bedside caregivers before suggesting screening protocols and were immediately met with stony resistance. Our protocols for screening were at odds with their existing workflow.

There is no one-size-fits-all method for introducing CCHD screening into care delivery and staffing models. Each nursery should determine how best to implement and pair screening with other tasks, as well as who should be responsible for performing screening procedures. In our experience most nurseries choose to pair CCHD screening with metabolic screening, hearing screening or daily weights. In addition, some nurseries have decided that registered nurses will perform screening, while others have delegated this task to certified nursing assistants or patient care technicians, as long as methods are within their scope of practice.

We have noted that advocates for screening, both nurses and physicians, are important factors in successfully starting a program. Preferably, these "champions" are already known on the unit as resource experts on screening policies and protocols. Use of advocates is especially important during the early stages of implementation and during the enculturation of screening into daily practices.

Equipment

Necessary equipment for screening should be considered early in planning and must include a pulse oximeter and infant probes. Current recommendations are that the equipment has been approved for use in newborns and is motion-tolerant.[19] Either disposable or reusable probes may be used. If reusable probes are used proper mechanisms for cleaning must be included in the screening protocol. It is wise to initiate the ordering process early, as it often takes weeks for an equipment order to be approved, move through purchasing, and be processed by the vendor. Prior to implementation of CCHD screening we often invite vendor representatives to provide information about their pulse oximetry equipment, ensuring that methods will be safe and readings accurate.

Education and Training of Care Providers

Education of professional staff is one of the most important factors in ensuring a successful program. Nursing staff need to learn about screening protocols, as well as safe

Figure 1: Performing Pulse Oximetry on the Neonate

Performing Pulse Oximetry (Pulse Ox) with the Infant Patient: Education for Providers

Pulse Ox – Dos

1. If you are using disposable pulse ox probes, use a new, clean probe for each infant. If you are using reusable pulse ox probes, clean the probe with the recommended disinfectant solution between each infant. Dirty probes can decrease the accuracy of your reading and can transmit infection. A disposable wrap should be used to secure the probe to the site.
2. The best sites for performing pulse ox on infants are around the palm and the foot. An infant pulse ox probe (not an adult pulse ox clip) should always be used for infants.
3. When placing the sensor on the infant's skin, there should not be gaps between the sensor and the infant's skin. The sides of the probe should be directly opposite of each other.
4. Nail polish dyes and substances with dark pigmentation (such as dried blood) can affect the pulse ox reading. Assure that the skin is clean and dry before placing the probe on the infant. Skin color and jaundice do not affect the pulse ox reading.
5. Movement, shivering and crying can affect the accuracy of the pulse ox reading. Ensure that the infant is calm and warm during the reading. Swaddle the infant and encourage family involvement to promote comfort while obtaining the reading. If possible, conduct screening while the infant is awake.
6. Pulse oximeters have different confidence indicators to ensure that the pulse ox reading is accurate. Determine the confidence indicators for the pulse oximetry equipment that you are using.
7. If an infant requires pulse ox monitoring for an extended amount of time, assess the site where the probe is placed at least every two hours. Monitor for signs of irritation and burning of the skin.

Pulse Ox – Don'ts

1. Never use an adult pulse ox clip when obtaining a pulse ox reading for an infant. Using an adult clip on an infant will give you an inaccurate reading.
2. Blood flow is needed to obtain an accurate pulse ox reading. Never attempt to obtain a pulse ox reading on the same extremity that you have an automatic blood pressure cuff.
3. Bright or infrared light, including bilirubin lamps and surgical lights, can affect the accuracy of the reading. Ensure that the infant is not placed in bright or infrared light while pulse ox is being performed. You may cover the pulse ox probe with a blanket to ensure that extraneous light does not affect the accuracy of your reading.
4. Do not use tape to apply the pulse ox probe to the infant's skin.

Pulse Ox - Caution!

5. The pulse is needed to determine the oximetry reading. Pulse ox is not accurate if the patient is coding or is having a cardiac arrhythmia. Remember: No pulse, no oximetry!
6. Pulse ox readings are not instantaneous. The oximetry reading that is displayed on the monitor is an average of readings over the past few seconds.

and correct methods for performing pulse oximetry on a newborn. Physicians, nurse practitioners and others involved in screening, such as residents and nursing students, should be educated as well. After the screening protocol has been initially implemented, it is helpful to periodically refresh the caregivers about the protocol and provide updates on the unit's progress. We've found that badge cards and posters are helpful as a quick reference for protocol questions.

Education of Parents and Guardians

Efforts to educate parents and guardians about CCHD screening with pulse oximetry should include vigilance for the signs and symptoms of CHD: cyanosis, poor feeding, weight loss, tachypnea and diaphoresis. They should be advised to contact their pediatrician if these arise.

Parents must also be informed that the protocol, no matter how expertly followed, does not detect all forms of CHD.[19]

Overview of CCHD Screening Protocol: Implications for Nursing Care

Pulse oximetry should be performed after the newborn is 24 hours of age. If early discharge is planned, screening should occur as close to discharge as possible. Pulse oximetry should be conducted in a quiet area with parent(s) present to soothe and comfort their infant while he or she is awake, calm and quiet. Because deep sleep, crying and cold affect oxygen saturations the infant should be warm and in the quiet alert state when the procedure is performed.[19,22]

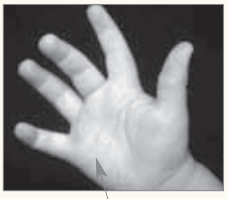
The pulse oximetry probe should be securely placed on the outer aspect (pre-ductal) of the right hand or wrist and one foot (post-ductal) (Figure 1). The light emitter portion of the probe should be on the top of the hand or foot and the photodetector should be directly opposite (Figure 2). Simultaneous saturation measurements are not required. Pulse oximetry measurements can be done sequentially as long as there isn't a long gap between measurements. Prior to recording oxygen saturations, all readings should be checked for accuracy by using confidence indicators specific to the pulse oximetry equipment being used.[19,22]

Oxygen saturations should be documented according to the protocol established by the hospital. The protocol that was recommended by the national work group is described below.[19,22] If the infant's oxygen saturation is ≥95% in either extremity, with

Figure 2: Education on Pulse Oximetry Probe Placement

Pulse Ox Probe Placement Education

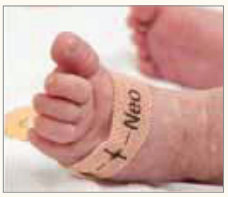
1. Select an application site on the outside, fleshy area of the infant's hand or foot.

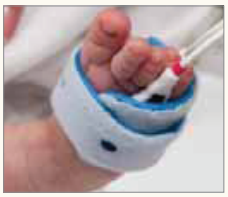


RH Application Site

Foot Application Site

2. Place the photodetector portion of the probe on the fleshy portion of the outside of the infant's hand or foot.
3. Place the light emitter portion of the probe on the top of the hand or foot. Place the photodetector directly opposite of light emitter, on the bottom of the hand or foot.
4. Remember: The photodetector and emitter must be directly opposite each other in order to obtain an accurate reading.
5. Secure the probe to the infant's hand or foot using the adhesive or foam tape recommended by the vendor. It is not recommended to use tape to secure probe placement.
6. Some vendors use visual images such as a star or bar to specify which side of the probe should be placed on top of the hand or foot. You may choose to use a helpful statement such as, "Raise the bar" to help you to remember proper probe placement.





a ≤3% difference between the two (defined as the highest oxygen saturation minus the lowest oxygen saturation), he or she will pass the screening test. No additional evaluation will be required unless signs or symptoms of CHD are present (Figure 3). If the newborn passes the screening and does not require additional cardiac evaluation, the physician or nurse practitioner caring for the infant does not need to be notified.

However, if oxygen saturation is <90% in the hand or foot, the infant automatically fails the screening test. These results should be documented according to protocol and the infant should be immediately referred to the physician or nurse practitioner for additional evaluation.[19,22]

If the oxygen saturations are ≤95% in both the hand and foot or there is a ≥3% difference between the two on three measures (each separated by one hour) the newborn should be referred for additional evaluation. These results should be documented according to protocol and the infant's medical provider should be notified. The physician or nurse practitioner managing the infant should rule out infectious and pulmonary pathology as the cause of the low oxygen saturations. If the origin of hypoxemia is not clear, an echocardiogram and a cardiology consultation should be obtained before discharge to rule out congenital heart disease.[19,22]

Conclusions

CCHD screening is the newest member to the RUSP and is endorsed by most major associations. As such, we will continue to see an increasing number of our nurseries initiating screening programs for their infants. We applaud nurses for their special efforts to improve the outcomes for infants affected by CCHD. They have raised the bar for nursing care with the special service they provide.

For more information about pulse oximetry screening, or about how to begin a program in your nursery, visit www.childrensnational.org/pulseox.

About the Authors

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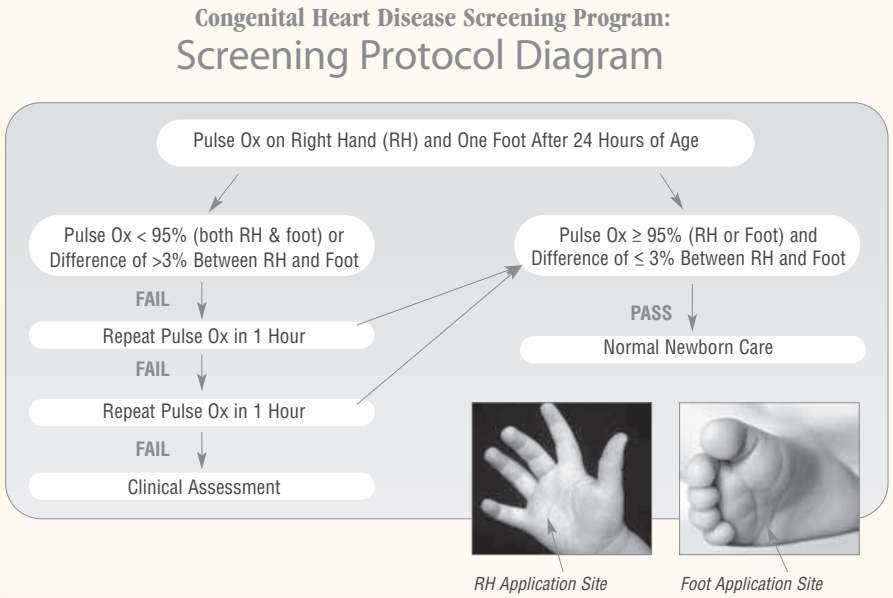
Figure 3: CHDSP Screening Protocol



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