JOGNN

PRINCIPLES & PRACTICE

The Nurse Champion Model for Advancing Newborn Screening of Critical Congenital Heart Disease

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Keywords
Nurse champion
newborn screening
critical congenital heart disease
pulse oximetry

ABSTRACT

Critical congenital heart disease (CCHD) is the leading cause of death in infants younger than age one year in the United States. Early detection and timely intervention can significantly reduce newborn morbidity and mortality. In Texas, nurse champions provided leadership to develop an educational program to screen newborns for CCHD using pulse oximetry. Results demonstrated the value of nurse champions in creating an effective educational program. Nurses are positioned to educate and advocate for universal CCHD newborn screening.

JOGNN, 43, 497-506; 2014. DOI: 10.1111/1552-6909.12474

Accepted April 2014

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The authors report no conflict of interest or relevant financial relationships.

Critical congenital heart disease (CCHD) is the leading cause of death in infants younger than age one year (Gilboa, Salemi, Nembhard, Fixler, & Correa, 2010), whereas the consequences of prematurity are the leading cause of neonatal deaths (Centers for Disease Control and Prevention [CDC], 2011).The term *CCHD* refers to a group of serious heart defects that are present at birth. Annually in the United States, 4,800 infants are born with CCHD, and nearly 280 newborns with unrecognized CCHD are discharged home after birth (Knapp, Metterville, Kemper, Prosser, & Perrin, 2010). Fifty percent of infants with missed CCHD diagnosis die at home or in the hospital emergency room (Chang, Gurvitz, & Rodriguez, 2008), and many of those who survive experience neurological problems and severe developmental delay (Chang et al., 2008; de-Wahl Granelli et al., 2008). Early detection and timely intervention of CCHD can significantly reduce morbidity and mortality among newborns.

Pulse oximetry screening is an effective process that can increase the early detection of seven primary CCHD defects: tricuspid atresia, hypoplastic left heart syndrome (HLHS), total anomalous pulmonary venous return (TAPVR), truncus arteriosus, Tetralogy of Fallot, transposition of the great arteries, and pulmonary atresia with intact septum (Table 1). Secondary targets are other complicated CCHDs that may present with hypoxemia or a differential of circulation to the right arm versus the lower extremities. These abnormalities result from problems with the formation of one or more parts of the heart during the early stages of embryonic development and affect the flow of blood to the lungs and/or body. In some CCHD defects, such as pulmonary atresia, blood flow to the lungs can become completely occluded if medical interventions are not initiated soon after birth. Most infants with CCHD require surgical intervention within the newborn period.

Pulse oximetry is a painless, noninvasive technique to measure the pre- and postductal oxygen saturations of newborns once they are at least age 24 hours. The values are evaluated using an algorithm to assess whether further evaluation is needed. Although pulse oximetry screening does not replace a thorough clinical assessment of the newborn, it can help identify hypoxia that is undetected by the human eye. Pulse oximetry in newborns has been investigated and supported as a simple, economical tool for identifying CCHD

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that is complementary to prenatal ultrasound and postnatal clinical evaluation (Hines, 2012; Mahle et al., 2009).

Compelling evidence of the value of CCHD newborn screening (NBS) prompted the secretary of the U.S. Department of Health and Human Services to approve adding CCHD NBS to the uniform newborn screening panel (Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, 2011).As of March 2014, 32 states have passed legislation mandating CCHD NBS, and others are in some phase of the process of adopting legislation (Association of State and Territorial Health Officials [ASTHO], 2014). As states begin to operationalize mandates and more states adopt legislation, nurses are in a position to play a leadership role in continuing the momentum to ensure all newborns are screened for CCHD. Legislation is only one step in the process. Education of health care providers, particularly nurses who are on the front line of newborn care, is another essential component.

Bradshaw et al. (2012) conducted a study to determine if pulse oximetry screening for the detection of CCHD could be successfully implemented in a large community hospital and to evaluate feasibility of implementation. Although a nursing training component was discussed, involving a knowledge quiz and competency checklist, the focus of the study was on results of screening, barriers to screening, and amount of time required for screening (average 3.5 minutes). Hines (2012) explored collaborative development and testing of a nurse-driven algorithm for CCHD NBS, with results indicating "a protocol was easily implemented in a community hospital" (p. 151). The author described in-service education for all the nurses who cared for newborns, conducted by the researcher, and use of algorithm poster and other strategies to aid nurses' screenings. Records were reviewed after 3 months to assess completeness and accuracy of application of the algorithm as measures of educational impact and the collaborative process used for developing the screening protocol. Innovative programs to implement CCHD NBS are underway in an array of birthing facilities (Allen & Chubb, 2013; Kreiner, Schroeder, & Hopkins, 2013; Loyot & Palmer, 2013; Salazar, 2013; Simpson & Culp, 2013). Although these and other studies contribute to understanding the role of nurses

Table 1: Overview of Seven Critical Congenital Heart Disease (CCHD) Defects

Tricuspid atresia	A small or absent tricuspid valve that is usually associated with a small right ventricle and pulmonary stenosis.
Hypoplastic left heart syndrome (HLHS)	The underdevelopment of the left side of the heart, which can include the ventricle, aortic valve and ascending aorta.
Total anomalous pulmonary venous return (TAPVR)	A defect with multiple variations in which the veins carrying oxygen-rich blood do not connect to the left side of the heart.
Truncus arteriosus	One large artery arises from the heart (instead of a separate pulmonary artery and aorta)
Tetralogy of Fallot	A combination of four defects: ventricular septal defect, overriding aorta, pulmonary stenosis, and right ventricular hypertrophy.
Transposition of the great arteries	A defect in which the position of the two main arteries of the heart (pulmonary and aorta) are switched. This causes oxygen-poor blood from the right ventricle to be pumped through the aorta to the body and oxygen-rich blood to be pumped back to the lungs.
Pulmonary atresia with intact septum	A small or absent pulmonary valve with no ability to shunt through a VSD/ASD (intact septum). This affects the ability to pump blood to the lungs.

Note. Definitions adapted from Centers for Disease Control and Prevention (2013).

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and nursing education in CCHD NBS, further research is needed to elucidate best practices in educating nurses and other health care providers on CCHD NBS, and, as recommended by the American Heart Association and American Academy of Pediatrics (2012), across a broad range of newborn delivery systems.

CCHD NBS Pilot Education Project in Texas

In Texas, a law mandating CCHD NBS became effective September 1, 2013. In anticipation of this public health mandate, the Texas Department of State Health Services funded the Texas Pulse Oximetry Project (TxPOP), a joint education initiative of The University of Texas Health Science Center at San Antonio/Department of Pediatrics, Baylor College of Medicine/Department of Pediatrics, and Texas Department of State Health Services, to develop, implement, and evaluate an educational strategy for training health care providers on CCHD NBS using pulse oximetry, as well as a process for implementing an effective screening program at birthing facilities of various sizes and available resources. The project period was June 2012 to August 2013.

Project Planning

In June 2012, a core team was established, comprising neonatal and newborn nurses, physicians, educators, and public health professionals. The team hypothesized that education to increase understanding of CCHD and develop skills in CCHD NBS can improve reliability of screening and identification of newborns in need of follow-up care.

Needs assessments were conducted through face-to-face meetings with hospital personnel at 15 hospitals using a semistructured interview guide. Hospitals chosen represented a purposive, convenience sample, with access to varied resources and serving low-income populations, including hospitals on the Texas/Mexico border. Ultimately, six South Texas and seven Houston-area hospitals representing a rural, suburban, and metropolitan mix, participated in the pilot educational initiative. The two hospitals not included had characteristics similar to the other South Texas hospitals but chose not to participate as a management decision. The project team was satisfied with the number of hospitals in the sample.

Through the needs assessments at each of the 13 hospitals, a nurse was identified to champion CCHD NBS and TxPOP. Champions included staff nurses, charge nurses, nurse educators, and a neonatal nurse practitioner. They were recruited during discussions with newborn nursing teams and chosen based on factors unique to each setting. For example, some champions already had an existing leadership role whereas others desired to develop or enhance leadership. There were also pragmatic reasons such as who was available and had broadest exposure to nursing staff. All champions emerged voluntarily, and there was no coercion. As nurse champions, they served as leaders at each facility, training personnel, assisting with implementation of the screening at their sites, and helping with problem solving the barriers preventing CCHD NBS. They also helped ensure screening compliance and quality assurance within their hospitals by acting as resource nurses and facilitating reporting CCHD NBS results. South Texas nurse champions were provided a modest stipend for their efforts in quality assurance data collection and to acknowledge their role in the project. Houston-area nurse champions were rewarded through travel support and formal recognition at public meetings.

Training and Empowering Nurse Champions

All of the TxPOP nurse champions participated in a train-the-trainer meeting facilitated by lead nurse educators from the TxPOP core team to prepare for their roles in their respective hospitals and were subsequently integrated into the TxPOP core team. Key learning objectives for the train-the-trainer seminar were to ensure nurse champions were able to (a) discuss the rationale for newborn CCHD screening, (b) identify the steps for screening and follow-up on a newborn using an algorithm for CCHD screening, and (c) effectively explain CCHD screening results to families.

Following the recommendations of Kemper et al., (2011), endorsed by the American Academy of Pediatrics (Mahle et al. 2012), the nurse champions were educated to conduct screening on newborns greater than 24 hours old. By waiting at least 24 hours, the effects of the closing of the newborn's ductus arteriosus on oxygen saturation may be detected. To conduct pulse oximetry in newborns, sensors or "probes," are wrapped around the newborn's right hand (preductal) and either foot (postductal) (Figure 1). Further, nurse champions were educated on using the algorithm, endorsed by the AAP (Mahle et al., 2012), to evaluate oxygen saturations and determine whether further

Figure 1. Postductal Placement of Probe for Pulse Oximetry.

evaluation is needed. In fact, with input from nurse champions, a modified algorithm was developed, including color-coding, to aid understanding (Figure 2).

A meeting manual with preliminary versions of education materials for the hospital trainings was prepared. At the meeting, nurse champions reviewed and edited draft educational materials and the curriculum. Based on nurse champion feedback, a one-hour, nursing curriculum was developed, including the aforementioned key objectives, targeting nurses in the newborn nursery setting. The curriculum was subsequently accredited for one hour of Category I continuing nursing education credit. A 10-item, multiple choice and true-false knowledge pretest and posttest was administered to the nurse champions and refined for use in the hospital-based nursing trainings. The tests included two algorithm questions that required decision-making about follow-up based on oxygen saturation readings.

With input from nurses, physicians, public health educators, and families, including Spanish speaking family members and health care providers, educational materials were produced and piloted. Significant collaborative efforts were involved in the design of all materials and translation, with vetting among the core team, nurse champions and their hospital-based colleagues, and representatives of families with attention to cultural and literacy issues. Over the course of project implementation, refinements to materials and production of additional materials ultimately resulted in a tool kit including items such as PowerPoint presentations for nurses and physicians; wall poster with algorithm to display in newborn nurseries for reference by nurses implementing screening; wall poster for display in prenatal classes to educate families; laminated algorithm cards to post beside pulse oximeters; brochures, in English and Spanish, for families about CCHD NBS and positive screen results; sample physician orders; sample nursery policy; sample screening log; and a 4-minute testimonial video, "Taryn's Story." The materials in the tool kit are adaptable and available at no cost from the Texas Pediatric Society website (Texas Pediatric Society, 2014).

The materials developed for providers and families adhere to recommendations of a national work group of experts and stakeholders convened to discuss CCHD NBS (Martin et al., 2013). Chief among recommendations is providing guidance to parents about the limitations of pulse oximetry for detection of CCHD and signs and symptoms of congenital heart disease. The TxPOP algorithm laminate cards have the following statement highlighted, "Remind parents that CCHD newborn screening may not find all types of problems in a baby's heart." The general information CCHD NBS brochure for families explicitly states, "If your baby has any of these problems: tires out when feeding; breathing fast or not breathing well; seems hard to wake, bring your baby back to the hospital right away. If your baby looks gray or blue color in/about the face, call 911 first for help . . . ."

Staff Nurse Training

At least two nurse trainings were scheduled for each participating hospital. All nurses caring for newborns at each facility were invited and encouraged to attend the trainings, as they would ultimately be implementing the screening. Training dates were initiated on average one month prior to the initial 6-month screening period. Additional trainings were offered if requested by the nurse champions. At the initial training, each newborn nursery unit was provided a poster with the TxPOP algorithm to use as reference and visual reminder to conduct screenings. Small laminated cards with the color-coded algorithm were also provided for placement beside the pulse oximeters used by nurses for screening. Bilingual parent brochures were also provided.

Trainings were typically implemented in a meeting classroom near the newborn nursery unit or actually in the unit. At the beginning of the class, the TxPOP pretest was implemented and each nurse received a meeting packet with TxPOP tool kit materials. Two TxPOP nurse educators were designated to coteach the trainings with nurse

champions. The Houston-based TxPOP nurse educator conducted trainings with nurse champions in Houston area, and a nurse educator in San Antonio worked with nurse champions to implement South Texas trainings. The educators presented the PowerPoint for nurses, followed by hands-on demonstration of screening and discussion of algorithm scenarios. A posttest was implemented at the end of the one-hour session. As an incentive, one continuing nursing education (CNE) credit was awarded to each nurse for completion of the education and evaluation of program, reported through an online system. Nurses unable to attend the CNE-accredited training were provided informal, one-on-one training by nurse champions.

Texas Pulse Oximetry Project educational materials for health care providers and families are adaptable and available at no cost from the Texas Pediatric Society website.

Results

Between December 1, 2012 and February 28, 2013, a total of 215 nurses at the 13 participating hospitals participated in the one-hour, CNE-approved nursing trainings, the only formal method for teaching CCHD NBS in these hospitals. This represented 55% of the total nurses that could have direct patient care with newborns in the participating hospitals, such as in newborn

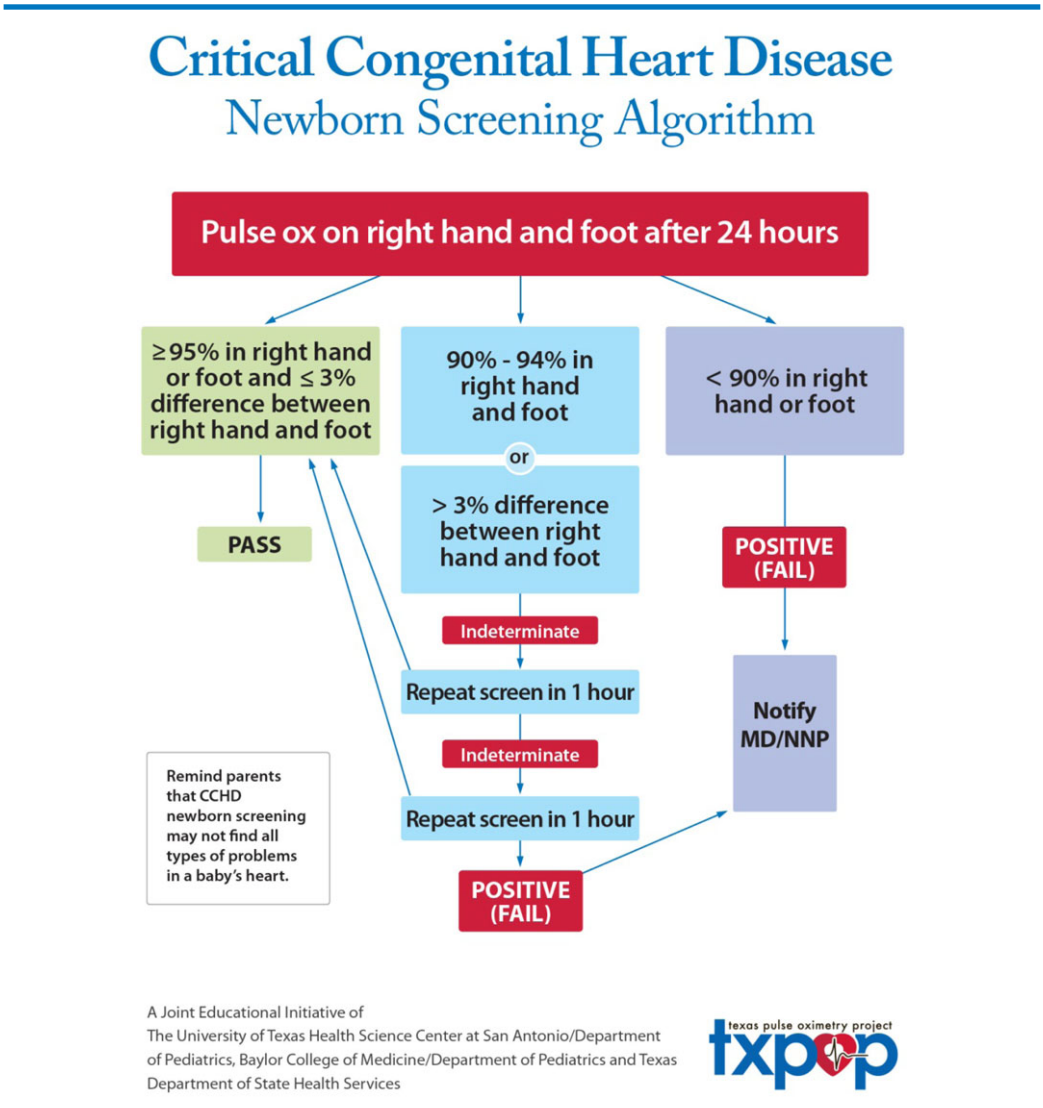

Figure 2. Texas Pulse Oximetry Project Algorithm.

Table 2: Texas Pulse Oximetry Project – Knowledge Pre/Posttest Results

	Number of nurses/ hospitals	Pretest Ave.	Posttest Ave.	Two algorithm questions on pre–test	Two algorithm questions on post–test	CCHD question on pre–test	CCHD question on post–test
South Texas	113/6	73%	91%	44% correct	84% correct	58% correct	91% correct
Houston Area	102/7	69%	94%	30% correct	84% correct	64% correct	98% correct

Note. CCHD = Critical congenital heart disease.

nurseries and mother/baby units. Comparison of pre- and posttest results demonstrated improvement in nurses' knowledge of CCHD NBS post-training (Table 2). Pretest scores prior to nursing education showed insufficient knowledge of CCHD and the screening algorithm, even in hospitals with an established screening program. In hospitals where screenings were already being implemented, nurses' pre- and posttest scores still showed a relative lack of knowledge on the subject, especially algorithm questions prior to training. The CCHD Screening Knowledge Test is provided as an online supplement to this article. In all trainings, algorithm questions (two questions out of 10) were missed the most frequently, especially on the pretest. These questions required application of an algorithm that was new and somewhat complicated to interpret which challenged the nurses. The low pretest scores in facilities that were already performing CCHD screening suggest that a yearly competency and review should be performed in facilities to maintain nursing knowledge of the subject matter. An anecdotal report from one of the South Texas hospitals also indicted that there are potential challenges in settings with a high use of agency nurses.

CCHD NBS was implemented and data collected on screening results for 6 months following the education, between February and July 2013. Screenings were done using Food and Drug Administration (FDA)-approved pulse oximeters for newborns that are motion sensitive and either single-use disposable or reusable probes. Data indicated a high compliance and competency in implementing CCHD screening in the newborn population. Of 11,322 (96%) newborns screened after 24 hours, there were 11 positive screens and a false positive screening rate for CCHD of 0.088, lower than the 0.14% false positive rate published (Thangaratinam et al., 2012). Of the 11 positive screens, there was one confirmed case of a secondary target of CCHD NBS. Most of the other newborns with positive screens had other non-CCHD diagnoses, suggesting that CCHD screening still led to identification of conditions even when they were not primary or secondary targets of the screening program.

Implementation in the different hospitals was fairly uniform in that the one-hour, CNE-accredited training was implemented, nurses began CCHD NBS, and the nurse champions monitored screening, collecting, and reporting aggregate data on screening results on a monthly basis to the project data analyst. In addition, nurse champions provided one-on-one education to nurses in the unit as needed. Individual variations between units included where to document the screening and results, either through an electronic medical record (EMR), a logbook, or paper charts. The mode of documentation was discussed, and each unit developed a standard based on the needs and resources of the facility. Although the timing of CCHD screening was recommended between age 24 hours and discharge, most units timed CCHD screening to be performed with 24-hour laboratory tests as they felt the practice of associating CCHD NBS and bloodspot screening would decrease missed screens.

All facilities received the same instructions on frequently asked questions from parents and informational brochures for parents. Feedback from family members was not obtained after initial development of brochures. Nurse educators for the project remained available to assist nurse champions during the 6-month period of screening and data collection. In smaller units, one nurse champion was sufficient to act as a resource while monitoring CCHD screening compliance. However, in larger units with more nursing staff and a higher birth rate, nurse champions reported designating up to two other nurses to help monitor compliance and act as additional resource nurses (such as a designated nurse on night shift).

Formative and Summative Evaluation

In May 2013, a midcourse meeting with nurse champions was convened to conduct a formative evaluation of the project. Meeting participants included the 13 nurse champions and other members of the TxPOP core team. Participants met in small work groups to discuss the strengths, opportunities, needs, and hopes for TxPOP and CCHD NBS, using an approach based on appreciative inquiry (Cooperrider & Whitney, 2005). Representatives from the small groups reported responses to the whole group as part of a general informal discussion. Feedback from the groups indicated that TxPOP education and implementation of screening in participating hospitals was going smoothly overall. There was strong leadership and collegiality, particularly among nurse champions and educators. The TxPOP tool kit was also perceived as a valuable resource.

Other findings were that TxPOP has fostered understanding about the whys of doing CCHD NBS among nurses who now have a greater appreciation of the value of pulse oximetry in the evaluation of an apparently healthy newborn. Newborn nurses have a new role in saving babies' lives, which has enhanced self-esteem. There is a greater sense of collaboration and coordination of care among newborn nursery nurses, neonatal nurse practitioners, NICU nurses, and physicians. The effect of the intervention on families was not a focus of this project except as it relates to screening results. Nurse champions also generated a list of recommendations and concerns for the Texas Department of State Health Services to consider going forward in implementing the CCHD NBS mandate (Table 3).

Table 3: Nurse Champion Recommendations to Texas Department of State Health Services

Use the nurse champion model to implement critical congenital heart disease (CCHD) newborn screening (NBS).
Make CCHD NBS a yearly competency for training nurses in newborn nursery.
Assign more than one nurse on the newborn nursery unit in all shifts as resource.
Investigate hospital resources for purchasing disposable and/or reusable probes and discuss probe preferences with nursing personnel. Lack of standardization and cost of probes can be problematic.
Delegate responsibility for tracking reusable probes to avoid misplacing or inadvertently discarding this equipment. Be aware of the warranty/replacement policy on reusable probes.
Consider working with the state health department and other policy-making organizations to find ways to reduce costs of probes.
Be aware of HIPAA protections in tracking information on CCHD NBS and outcomes.

At the end of the project, an online survey was implemented to obtain feedback from the nurse champions on their overall experience with TxPOP and CCHD NBS. All 13 nurse champions responded to the survey that included 14 items on a Likert-type scale. Items assessed perceptions of individual professional development, the hospital system for recording CCHD newborn screening results, and TxPOP team performance. Results of the survey indicated that 100% of respondents either *agreed* or *strongly agreed* with 12 of the 14 items, indicating they increased their knowledge of CCHD, improved their screening skills and communication skills.

In addition, only one of the 13 respondents disagreed that she improved her knowledge and skills, which could be due to having already been trained and experienced with CCHD NBS.

The final item on the survey was opened ended for comments. Seven nurses commented and, with one exception, all of the comments were favorable with statements such as:

> Thanks for asking my hospital to participate in the project. It has been a boost to department morale and has given us a sense of accomplishment, as well as an added sense of responsibility to our babies and our community.

The one critical comment came bundled with a positive note:

> This project was one of the smoothest projects I have been involved in planning, implementing, and evaluating. The education and support were invaluable. We did have some issues with supplies being backordered and unavailable for extended periods that caused a few babies to not be tested.

Use of nurse champions to facilitate education and implementation of newborn screening for critical congenital heart disease is a model that can be emulated by birthing facilities.

The results of the survey indicated the level of engagement of nurse champions with the project and their role in CCHD NBS in their respective hospitals. Clearly, there was a genuine sense of ownership and demonstrated leadership.

Discussion and Practical Implications

TxPOP nurse champions were effective in promoting implementation of CCHD NBS within their hospitals. Nurse champions' efforts clearly facilitated buy-in, participation, and education of nurses implementing CCHD NBS, as evidenced by the compliance with screening and the fact that only 55% of nurses participated in the one-hour CCHD NBS training. Although a direct correlation between CCHD NBS training, formal and informal, and the low false positive screening rate cannot be inferred, it is an interesting finding that warrants further study. The identification of a nurse champion to promote CCHD NBS for the project was subsequently recommended by Bradshaw et al. (2012).

Use of nurse champions to facilitate education and implementation of CCHD NBS is a model that should be emulated by birthing facilities. Thompson, Estabrooks, and Degner (2006) described the origins and primary attributes of champions identified in the literature. Schon (1963) initially developed the concept of champion in military innovation. The concept has since been studied extensively in management, health care, and other industries. Champions are advocates of new ideas or projects for which they feel personal ownership. The champion's role is internal to the organization and the champion who emerges is well connected to people and resources of the organization (Thompson, Estabrooks, & Degner, 2006). The close connection of nurse champions with their colleagues in implementing a change is essential. Research indicates perceiving the benefit of a practice and intrapersonal networks are the most important sources for persuading most nurses of the value of a new practice (Leeman, Baernholdt, & Sandelowski, 2007). TxPOP nurse champions helped to convey the benefits of CCHD NBS, the most significant being saving newborn lives, and were at the nexus of the informal communications network for establishing the CCHD NBS program in their respective institutions. The enhanced sense of collaboration and coordination of care reported by nurse champions among newborn nursery nurses, neonatal nurse practitioners, NICU nurses, and physicians is an unanticipated finding. Such collegiality can be used to improve practices such as developing a mother/baby–newborn nursery communication feedback loop on outcomes of babies identified with positive screens.

The TxPOP team recognizes needs and opportunities for advancing CCHD NBS after completion of this pilot project. There is a need to preserve the expertise, resources, and data collection practices within participating project hospitals; a need to institutionalize CCHD NBS into hospital policies, procedures, and quality assurance practices; and, in a broader sense, the need to advocate for implementation of universal CCHD NBS.

State laws for CCHD NBS vary, and not all states have legislation mandating CCHD NBS. To continue the momentum in promoting universal CCHD NBS, there are a number of meaningful ways nurses can serve as advocates. Nurses can (a) determine their state's position on CCHD NBS by linking to the ASTHO (2014) legislative tracking map and by reading the ASTHO (2013) policy brief. In addition, nurses can locate their March of Dimes chapters online to find out what their legislative liaisons are doing to promote CCHD NBS and how they can help advocate (March of Dimes, 2014); (b) become champions for CCHD NBS by learning more about CCHD and CCHD NBS through resources of the Centers for Disease Control and Prevention (CDC; 2013) and Children's National Medical Center (2014); (c) offer to serve as CCHD NBS champions in their own birthing facilities and provide education using resources such as those developed by TxPOP; (d) work with their local Association of Women's Health, Obstetric and Neonatal Nurses chapters to organize and provide CCHD NBS education to the membership; and (e) conduct educational research in their birthing facilities on the impact of education on CCHD NBS and share results.

Together, the neonatal nursing community can work to share information and find solutions to effective implementation of CCHD NBS such as lack of standardization of probes and barriers to tracking outcomes. Neonatal nurses are well positioned to educate colleagues and families about

life-saving CCHD NBS and to provide leadership to ensure that ultimately all newborns receive CCHD NBS and appropriate and timely follow-up care.

Acknowledgement

Other members of the Texas Pulse Oximetry Project Team include the following: Baylor College of Medicine/Texas Children's Hospital-Houston: Charleta Guillory, MD, FAAP; Myrthala Guzman, CAP-OM; Yvette R. Johnson, MD, MPH; Tiffany McKee-Garrett, MD; Valerie C. Moore, MD, MBA, FAAP; Alice Obuobi, MD; Elena Ocampo, MD.

The following Baylor College of Medicine/Texas Children's Hospital and South Texas nurse champions provided leadership for TxPOP and CCHD NBS in their birthing facilities, collected and reported data, edited and piloted educational materials, provided education, and contributed to program design, implementation and evaluation.

Amy Bomer, RN; Susan Browning, RNC; Kellie Chiari-Gibb, RNC; Patricia I. Crossland, RNC; Nikita Davis, MHA, BSN, RN; Virginia Goldsmith, RNC, BSN, MSEdu; Brenda Kelly, RN; Brenda Kratofil, RN; Helen Manibusan, RNC; Monique Pretty, RN, BSN, MSN; Other Team Members: Liza Creel, MPH, TxPOP Project Data Analyst; Debra Freedendburg, MD, PhD, Medical Director, Newborn Screening & Genetics, Texas Department of State Health.

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Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web-site:

Figure 3. CCHD Screening Knowledge Test