Neonatal Intensive Care Unit Discharge Transitioning:

Nursing Practices, Perspectives, and Perceptions

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ABSTRACT

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By Arlene Lovejoy-Bluem

The American Academy of Pediatrics (AAP) delineated four criteria for management of perinatal care and discharge (DC) of high-risk neonates: 1) physiological stability, 2) tracking and surveillance of growth and development for each infant, 3) active parental involvement with the infant's care, and 4) follow-up care arranged with experienced primary care provider. Registered Nurses in California Neonatal Intensive Care Units (NICUs) were surveyed about NICU DC transitioning programs to 1) identify current common standards of care used in DC transitioning and 2) define the nature and extent of additional criteria and procedures used in DC transitioning. Useable surveys were obtained from 32 of the 79 facilities queried (41%): 17 (53%) Level II, 10 (31%) Level III, and 5 (16%) Level IV. All responding facilities were located in communities of 100,000 people or more. All but one of the facilities (97%) used all four AAP criteria for determining readiness for DC. Facilities differed in whether they also used weight, corrected gestational age, or both as criteria for DC. They differed in the definition of active parental involvement with care, the degree to which parents participated in DC planning, who arranged for post-DC primary care, and how outcomes of DC planning practices were evaluated. Profiles derived from these data can be used to expand procedures, guidelines, and policies for DC transitioning of the NICU graduate.

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Neonatal Intensive Care Unit Discharge Transitioning:

Nursing Practices, Perspectives, and Perceptions

Care and discharge (DC) planning in the Neonatal Intensive Care Unit (NICU) vary according to 1) leadership styles and competencies; 2) the knowledge base of nursing and medical staff; 3) the systems which support the work of physicians, nurses, and support staff; 4) the policies, regulations, and laws that dictate scope of practice for physicians, nurses, and support staff; and 5) the nature of the physical facility (Committee on Fetus and Newborn, American Academy of Pediatrics [CFN AAP], 2008; Newman & Parrott, 2013). Despite these factors, there is a core set of practices that characterize DC transitioning (American Academy of Pediatrics [AAP] & American Congress of Obstetricians and Gynecologists [ACOG], 2012). In general, DC planning can be characterized on a continuum according to the needs of the neonate.

The simplest level of DC planning involves healthy, full-term neonates who are typically discharged from low-risk inpatient hospitalizations accompanied by their mothers who were hospitalized for maternity services. These neonates are most often discharged one to three days after the day of their birth even when transferred to the NICU for 48 hours of antibiotic treatment of suspected sepsis. Transition of any newly born infant's healthcare to the ambulatory setting follows a common pattern (AAP & ACOG, 2012) and includes several screening procedures/tests conducted in the hospital nursery before DC: critical congenital heart defects (Jegatheesan, Song, Angell, Devarajan, & Govindaswami, 2013), metabolic disorders (Botkin, 2005), hearing (Beswick, Driscoll, & Kei, 2012), jaundice (Mah et al., 2010) and car seat challenge/testing (Davis, Condon, & Rhein, 2013). The birth hospital staff indicates on each screening order which primary care provider (PCP) will receive the screening results. The PCPs receive newly born patients via one of the following routes: 1) assignment via contractual link

from a third party payer; 2) stated maternal preference according to her past experience(s) with prior children or via a recommendation from the mother's social network; 3) a referral list of PCPs accepting Medicaid patients. Nursery nurses transmit notification to the PCP via telephone and via facsimile of the particulars of the birth and patient identifiers. This transition to ambulatory care is formalized when the PCP: 1) comes to the nursery to perform the history intake and the physical examination, 2) accepts the case by documentation on the medical record, and 3) notifies the mother of how to initiate the first visit to the PCP's office/clinic. This transitioning process traditionally meets the needs of all stakeholders and is reflected in published healthcare guidelines for normal newborn care that originate primarily from two professional medical organizations, the AAP and ACOG (2012).

The focus of this project, however, is on DC planning at the other end of the spectrum: DC planning for pre-term, injured, or ill newborns, which is far more variable and complex than that of healthy, full-term infants. Newborns who demonstrate signs/symptoms of physiological impairment in health at birth or in the hospital nursery shatter this common model of care transition into two phases: 1) transfer to a special care nursery or NICU and 2) later DC from the NICU to the ambulatory care setting (CFN AAP, 2008; McAllister, Cooley, Bourdeau & Kublthau, 2013; Smith, Hwang, Kukhovney, Young, & Pursley, 2013; Doran et al., 2012). The NICU meets the acute care needs of a small (in numbers and in physical body weights) pediatric population (Centers for Disease Control and Prevention [CDC], 2012). The NICU is highly specialized, involves many healthcare professions, directly and indirectly, and is, consequently, extremely expensive (Profit et al., 2010; Richardson et al., 2001). Third party payers and healthcare regulators for this population are primarily federal and state governments (e.g., Centers for Medicare and Medicaid Services [CMMS]; California Children's Services [CCS])

along with accreditors such as The Joint Commission (TJC). These regulatory agencies recognize the need for tailored quality metrics and benchmarks in the acute care populations yet often formally exclude the NICU population in the reporting of perinatal core measures (TJC, 2013). Moreover, although expensive, the funds expended in the care of high risk neonates are small compared to the healthcare resources utilized by geriatric consumers, whose expenses are also reimbursed via government funding in Medicare and Medicaid. Whereas, guidelines and toolkits on DC transitioning abound for the geriatric population (Halasyamani, et al., 2006; Jack & Bickmore, 2011; Legrain et al., 2011; Schall, Coleman, Rutherford, & Taylor, 2011), guidelines for DC planning are not centrally compiled and enforced for NICU graduates.

Several perinatal healthcare professional organizations have attempted to address clinical care guidelines for the NICU population (AAP & ACOG, 2012; DiBlasi, Myers, & Hess, 2010; Lund, Osborne, Kuller, Lane, Lott, & Raines, 2001; National Perinatal Association, 2012). However, clinical outcome metrics for infants *discharged* from the NICU are scarce in the literature. The scarcity has been attributed to known gaps and barriers to implementation by the healthcare stakeholders (i.e., healthcare professionals and third party payers), especially in the medical profession (Cochrane, Olson, Murray, Dupuis, Tooman, & Hayes, 2007; Cabana et al., 1999; Doran et al., 2012; Grimshaw et al., 2004; Magluta, de Sousa Mendes Gomes, & Wuillaume, 2011; Teasdale, Brady-Murphy, & McSorley, 2009). Most published studies on NICU DC outcomes focus on very low birthweight ([VLBW] less than 1500 grams) infants (Doran et al., 2012; Nowakowski et al., 2010), an even smaller subpopulation of the vulnerable infants cared for in NICUs. However, strategies for management or regionalization of high risk perinatal care have been delineated (Doran et al., 2012; Nowakowski et al., 2010) and quantified to support cost containment and return on investment in specialized NICU training and

equipment. In 2008, the AAP listed four revised criteria for "hospital discharge of the high-risk neonate": 1) physiological stability, 2) tracking and surveillance of growth and development for each infant, 3) active parental involvement with the infant's care, and 4) follow-up care arranged with experienced PCP (CFN AAP, 2008). However, the AAP did not quantify these criteria with outcome metrics. Thus, NICUs do not have a common written standard for conducting and evaluating DC planning, which makes it difficult to generate practice-based evidence on best practices. This project surveyed Advanced Practice Registered Nurses (APRNs) and neonatal RNs in California NICUs about DC transitioning programs to 1) identify current common standards of care used in DC transitioning and 2) define the nature and extent of additional criteria and procedures used in DC transitioning.

Literature Review

The electronic databases CINAHL Plus, Cochrane Library, Ovid Nursing Database, ProQuest Nursing & Allied Health Science, PsycINFO, and PubMed were searched using the key words *neonatal discharge*, *discharge planning*, *discharge processing*, *high-risk infant follow-up*, *medically fragile infants*, *NICU graduates*, and *special needs infants*. This strategy yielded information on DC/transfer of neonates and infants from the acute care setting to the ambulatory setting or sub-acute care setting. Reference lists in the most pertinent articles were cross-matched for maximum retrieval of relevant literature. Published research on DC from the NICU extends back to the 1980s with efforts to link individualized plans for home nursing care to successful early DC (Brooten et al., 1986; Brooten et al., 1988; Brooten, 1995; Raddish, & Merritt, 1998). The literature examines six broad areas of interest: parent stress, parent readiness, home environment, follow-up programs, outcomes management, and guidelines.

Parental stress. The literature on the parents' well-being during their child's transition from pediatric in-patient acute care to ambulatory follow-up care includes interrelated concepts of parental depression, anxiety, stress, distress, and emotional trauma. Psychosocial and behavioral research with parents of NICU infants has been documented extensively over the last decade, although with mothers more than fathers. Karatzia, Chouliara, Maxton, Freer, and Power (2007) provided a literature review of post-traumatic stress disorder (PTSD) in mothers of premature NICU patients, while Lefkowitz, Baxt, and Evans (2010) compared PTSD symptomatology to generic post-partum depression. In 2013, Rogers, Kidokoro, Wallendorf and Inder examined the at-risk characteristics of mothers of NICU patients for depression before DC, as did Raines (2013a). Miles and Brunssen (2003) established a stressor scale for use with mothers in the NICU before DC. Zarnardo, Freato, and Zacchello (2003) assessed for maternal anxiety at DC from the NICU. In 2010, Rowe and Jones studied maternal stress and coping after DC, while Feeley et al. (2011) scrutinized maternal PTSD six months after DC from the NICU. Ballantyne, Benzie, and Trute (2013) investigated depressive symptoms among immigrant and Canadian mothers. Melnyk, Crean, Feinstein, and Fairbanks (2008) researched maternal anxiety and depression after DC from the NICU. The challenge of assuring communication with mutual understanding with adolescent parents was analyzed by Boss, Donohue and Arnold (2010). Bakewell-Sachs and Gennaro (2004) reviewed parenting the post-NICU ex-premature infant, while Olshtain-Mann and Anslander (2008) discovered that parents are still at risk for psychological stress two months after NICU DC. Shaw et al (2014) found marked reduction in trauma symptoms, anxiety and depression with a multi-session program for mothers in the NICU based on cognitive behavior therapy and redefining the infant. Docherty, Lowry, and Miles (2007) demonstrated that the stressors of parenting ex-premature infants, combined with poverty

and the care of the medically fragile infants in the home, led to chronic depression and feelings of isolation.

Studies of paternal depression by Mackley, Locke, Spear, and Joseph (2010) and by Garten, Nazary, Metze and Buhrer (2012) provided support to the theory that parental distress and PTSD have common signs and symptoms regardless of gender as long as parental attachment and bonding are evident. Carter, Mulder, Frampton, and Darlow (2007) studied long-term *parental* distress nine months post-NICU DC. Boykova and Kenner (2012a; 2012b) and Zamanzah, Namnabati, Valizadeh, and Badiee (2013) provided a multi-cultural perspective on the transitioning of parents from the NICU to home.

Typical developmental goals of childbearing adults include societal and personal expectations of creating a healthy nuclear family, providing nutrition, and maintaining a toxic-free environment in utero and in the home. This literature, taken as a whole, suggests that these expectations of achieving the "normal and healthy" parenting role combined with the personal feelings of "failure" to achieve full gestation in the pregnancy, interact with the lived experiences in the NICU to provoke severe anxiety, distress and chronic post-traumatic stress in parents before, during, and following DC.

Parent readiness. In the context of the NICU and DC from it, the construct of readiness includes preparedness, confidence, empowerment, and satisfaction. Assessment and quantification of readiness for DC, including tool development, began with nursing scholars in the 2000s (Weiss et al., 2008; Weiss & Lokken, 2009; Weiss & Piacentine, 2006; Weiss et al., 2007; Weiss, Ryan, & Lokken, 2006; Weiss, Ryan, Lokken, & Nelson, 2004). Discussions of constructs of DC readiness and preparation are readily available (Bernstein, et al, 2002; Burnham, Feeley, & Sherrard, 2013; Smith, Dukhovney, Zupancic, Gates, & Pursley, 2012;

Smith, Hwang, Dukhovny, Young, & Pursley, 2013; Smith, Young, Pursley, McCormick, & Zupancic, 2009). "Parental confidence" appears strongly related to participation in baby care and skin-to-skin or Kangaroo Care (KC) in the NICU (Murdoch & Franck, 2011; Raines & Brustad, 2013). "Parental empowerment" appears to support parental confidence (Melnyk & Feinstein, 2009; Raines, 2013b). Parental perceptions of the NICU experiences and their aftermath have been examined in the context of DC planning (Bain, Findlay, & Grieg, 2003; Mancini & While, 2001); transition from acute care to home (Hutchinson, Spillett, & Cronin, 2012); caring for their infants in their homes (Murdoch & Franck, 2011); ethics in neonatal acute care (Pinch, Spielman, & Harrison, 1993); maternal feelings at DC (Rabelo, Chaves, Cardoso, & Sherlock, 2007; Raines, 2013b); adaptation to home life after DC (Bissell & Long, 2003); and the health status of infants post NICU DC (Schiariti, et al., 2008). Parent satisfaction was detailed and quantified with tools in Butt et al. (2009), Cescutti-Butler, and Galvin (2003), Chelelelin, Dunham, and Stewart (2013), Latour, Duivenvoorder, Hazelzet, and vanGoudoever (2012), McCormick, Escobar, Zheng, and Richardson (2008), Tsironi, Bovaretos, Tsoumakas, Giannakopoulou, and Matzio, (2012), and Weiss, Goldlust, and Vaucher (2010).

This varied literature provides a foundation for the conclusions that parents sense personal isolation in the NICU and want to participate in bedside discussions with professionals. Parents also express frustration and bewilderment at the skills needed to care for infants and at the potential impact of their low health literacy. Although they evaluate the competencies of bedside staff in caring for their infants (Cescutti-Butler & Galvin, 2003; Latour, Duivenvoorder, Hazelzet, & vanGoudoever, 2010), they will not spontaneously express questions or concerns without facilitated discussion with the NICU nursing or medical leadership (Brett, Staniszewska,

Newburn, Jones, & Taylor, 2011; DeRouck & Leys, 2009; Erickson, Ditomassi, & Adams, 2012; Gaal, Blatz, Dix, & Jennings, 2008; Weiss, Goldlust, & Vaucher, 2010).

Home environment. Planning for successful NICU DC must actively consider critical resources needed in the transition from the NICU to home. To identify the at-risk home environment, specifics such as utilities, food, hygiene (hands, diapers, and laundry), neighborhood safety and transportation must be evaluated (Bieda, Forsythe, Kirchick, & Maher, 2007; Engelke & Engelke, 1992; Forsythe, Maher, Kirchick, & Bieda, 2007). Miquel-Verges, Donohue, and Boss (2011) examined the added risk of low English proficiency of caregivers. Lower socioeconomic class and low health literacy were linked to costly unplanned healthcare utilization (Bardach et al., 2013; LeGrain et al., 2011). Escobar et al. (1999) studied the rehospitalizations of infants soon after newborn and NICU DC and again six years later (Escobar et al., 2005). The primary diagnosis for 30-day readmissions was jaundice in late preterm infants (LPIs) followed by urinary tract infections and respiratory infections (Escobar et al., 1999). These factors were especially true for NICU graduates who were born at less than 1000 grams (Escobar et al., 2005).

The DC of the medically fragile or technology-dependent NICU graduate has evolved due to adaptations in the home for these special needs children and their caregivers (Berry, Agrawal, Cohen, & Kuo, 2013; Hummel & Cronin, 2004; Parker, 1991; Robinson, Pirak, & Morrell, 2000). Technology in the home can include intravenous feeding, enteral feeding tubes, ventilators, gastrointestinal ostomy products, humidifiers, nebulizers, monitors/analyzers, compressors, oxygen tanks, suction equipment, tracheostomy supplies, oral and intravenous syringes, and dressing supplies. Most of these pediatric cases qualify for home nursing care, but the availability of adequate home nursing staff coverage is a day-to-day or shift-to-shift

arrangement (Committee on Child Health Financing, AAP, 2006). Hayes et al., (2011) addressed the growing opportunity to use electronic technology for monitoring in the home. These changes will require changes in DC planning, first to allow for "earlier" DC from the NICU and second to provide the training parents need to feel competent and confident in their ability to manage the infant's healthcare at home. Evaluation of the success of discharging infants who are technology-dependent will require carefully designed programs for generating both research and practice-based evidence.

Follow-up programs. The availability of pediatric ambulatory care programs (primarily centered on high-risk infant clinics merged to medical homes) is increasing for NICU graduates (Ballantyne, Stevens, Guttmann, Wilan, & Rosenbaum, 2012; Kuppala, Tabangin, Haberman, Steichen, & Yolton, 2012; Phillips-Pula & McGrath, 2012; Purdy & Melwak, 2012; Tang, Feldman, Huffman, Kagawa, & Gould, 2012; Vohr, Wright, Hack, Aylward, & Hirtz, 2004). The Medical Home Model originated with AAP in the late 1960s (National Center for Medical Home Implementation, 1967) and now exists across age spans with efficiencies/accountabilities addressed in the Patient Protection and Affordable Care Act of 2010 and Medicaid Waiver 1115 projects (McAllister et al., 2013; Newman & Parrott, 2013; Wade, et al., 2008). The CCS regulates and oversees all High Risk Infant Follow-up (HRIF) programs in California (Purdy & Melwak, 2012; CCS, 1999). Via this oversight, the California Perinatal Quality Care Collaborative (CPQCC) has championed quality improvement activities in NICUs and in HRIF clinics. Grimmer and Moss (2001) documented the development of a quality assessment tool for DC activities via community networks. These changes in policy and funding will lead to changes in DC planning because they support early recognition of the potential for extended care

models that allow parents to care for children in the home rather than the NICU, but provide a safety net in an ambulatory-care clinic tailored for the needs of the high-risk infant.

Outcomes management. A focus on outcomes in the NICU population is evident in Bardach et al. (2013); Goyal, Teeters, and Ammerman (2013); Kirkby, Greenspan, Kornhauser, and Schneiderman (2007); Melnyk et al. (2006); and Taylor (2012). The most current literature uses outcomes and metrics from adult programs primarily due to the common federal funding sources. The LPIs (born at $34^{0/7}$ to $36^{6/7}$ weeks gestation) constitute the majority of NICU admissions, although the durations of their hospitalizations are much shorter than those of the VLBW newborns (Amiel-Tison, Allen, Lebrun & Rogowski, 2002; Doran et al., 2012; Engle, Tomashek, Wallman, & CFN, 2007; Escobar, Clark, & Greene, 2006; Goyal, Fager, & Lorch, 2011; Hwang et al., 2013; Premji, Young, Rogers, & Reilly, 2012; Samra et al., 2013; Whyte, 2012). Three nursing interventions have proven most beneficial in DC transitioning: teaching (Aris et al., 2006; Schlittenhart, Smart, Miller & Severtson, 2011; Sneath, 2009), active listening as a therapeutic intervention with parents' stress/anxiety (Segre, Chuffo-Siewert, Brock, &O'Hara, 2013) and advocacy with active participation in continuity in care (Boss & Hobbs, 2013).

Oversight of the DC program and associated interventions within a NICU has been proposed for any of three disciplines: nursing, case management (Reynolds, 2013) and medical social work (Robison, Pirak & Morrell, 2000). Some authors (Brooten et al., 1988; Purdy & Melwak, 2012; Radtke, 2013; Weiss et al., 2007) advocate for the APRN in the leadership role, supported by NICU RNs (AAP, 2014; National Association of Neonatal Nurses [NANN], 2014). Although some evidence exists that NICU RNs did not have sufficient knowledge to anticipate home health care needs of their patients (Scherf & Reid, 2006), many authors advocate for the

RN in the leadership role and provide job titles: DC planner (CCS, 1999), nurse coordinator (Broedsgaard & Wagner, 2005), attending RN (Erickson, Ditomassi, & Adams, 2012), nurse advocate (Jack et al., 2009), and liaison nurse (Peters, Fleuren, & Wijkel, 1997). Still others endorsed the role for all RNs at the bedside (Brooten 1995; Brooten, et al., 1986; Grazel, R., Phalen, A., & Polomano, 2010; Lasby, Newton, & vonPlaten, 2004; Melnyk & Feinstein, 2009; Parker, 1991).

There is ample literature that outcomes management improves patient health and that systematic testing of interventions yields evidence-based guidelines for best practice. To implement this evidence, DC planning will need a dedicated coordinator with a clear line of responsibility and accountability to all of the disciplines involved in identifying when the neonate is ready for transition and what the infant's needs for post-DC care are.

Guidelines. Toolkits for NICU DC are available, such as the VON's Quality Improvement Kit: Improving Discharge Management (VON, 2009) and the Transitioning Newborns from NICU to Home: A Resource Toolkit (Agency for Healthcare Research and Quality [AHRQ], 2013b). These toolkits stem from collaborative research efforts in subpopulations of NICU graduates. These toolkits have stopped short of quantification of outcome metrics for the critical transition from acute care to ambulatory primary care; no practice guidelines are available on how to provide or evaluate specific quality mechanisms in pediatric transition of healthcare (Phillips-Pula & McGrath, 2012; Walston et al., 2011).

Data are collected on several aspects of care. Neonatal professional caregivers routinely send data from inter-facility transports, hospital admissions, and developmental outcomes to state and national collaboratives (e.g., CPQCC and VON), but the reports from these organizations are statistical analyses linked primarily to birthweights (Horbar et al, 2001; Horbar,

Soll, & Edwards, 2010). Actual DC transitioning data have not been systematically defined and reported.

Survey of NICU DC Transitioning Practices

The literature on DC transitioning provides methods for assessing: the nature and extent of parent stress and readiness; the adequacy of the home environment and follow-up care; the role of outcome management; and the usefulness of current guidelines. The next logical step is to examine what is being done in NICUs. Such practice-based evidence would define the *de facto* common standard. It would highlight what *can* be done and would serve as a needs assessment for what *should* be done. This project used the extant literature to develop a survey to quantify the common standard for Level II, III, and IV facilities and implemented the survey in the state of California.

Method

Institutional Review

This program evaluation project had two major components that minimized risk to participants: 1) information was recorded in a manner that respondents could not be identified, directly or indirectly; and 2) information was compiled and archived so that any disclosure of the responses could not reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation. Any concerns among the respondents were mitigated by careful disclosure of the purpose of the evaluation project, the procedures for securing the data, and the assurance that all data would be reported as aggregate, anonymous results. Data were compiled on a secure, encrypted server, stored on a flash drive maintained in a locked cabinet, and analyzed using password-protected files on a password-

protected computer. The project proposal was reviewed and approved by the university's institutional review board as *exempt* (Appendix A).

Target Population

California NICUs comprise a large and unique segment of acute care for newborns and infants within the complex systems of healthcare in the United States (Cardinal & Shum, 1993). Federal insurance programs (CMMS, 2012), CCS (1999), and the California Department of Health and Human Services (2013) regulate California NICUs. Mandated minimum nursing staff ratios (Aiken, et al., 2010; Auerbach, Buerhaus, & Staiger 2014) began in 2004. Under Title 22 of the California Code of Regulations (section 51013), CCS defines benefits according to a list of specific "medically eligible" conditions in the NICUs to provide selected therapy, care services, and case management. CCS reimbursements tend to slightly exceed those of Medicaid for these specified conditions. Therefore, most NICUs in California enroll in the CCS approved provider program in one of three levels of care (LOC): intermediate, community, or regional. These CCS LOC roughly equate to the AAP's designations in their 2012 policy statement on "Levels of Neonatal Care" II, III, and IV (CFN AAP, 2012) respectively. According to the California Department of Health Care Services (CDHCS), there are 22 regional NICUs, 83 community NICUs, and 15 intermediate NICUs in the program. Of the 13 centers providing extracorporeal membrane oxygenation (ECMO) therapy, 12 (92%) are regional NICUs.

The Section on Perinatal Pediatrics of the AAP identified nine "neonatology (medical) fellowship training" programs in California (9% of the 96 in the country), making California a leader in professional education for neonatal health care. The CCS regulations for NICUs require at least one full-time equivalent (FTE) clinical nurse specialist (CNS) with extensive neonatal nursing experience to oversee the DC planning and the delivery of optimal neonatal

nursing care in each regional NICU, at least 0.5 FTE neonatal CNS in each community NICU, and encourages a neonatal CNS presence in each intermediate NICU (CCS, 1999).

California is one of 39 states that recognize CNS as a protected title (National Association of Clinical Nurse Specialists, 2014), but California CNSs are not authorized to prescribe or furnish pharmaceuticals or devices. The California Board of Registered Nursing (BRN) issues a separate certification for CNS after completion of educational requirements (graduate degree in an authorized CNS program) and verification of a current California Registered Nurse license. Renewals of CNS state certification and RN licensure are required biennially in California. National professional certification as a CNS is recommended for practice, but is not mandatory in California. The California BRN in its 2012 survey of RNs in the state reported 657 RN FTEs / 100,000 population (compared to the national average of 854 / 100,000). Approximately, 3.1% of California RNs indicated their primary nursing role as neonatal care, a category distinct from mother/baby and normal nursery duties (Spetz, Keanne, Chu, & Blash, 2013).

California State legislation also includes one other important mandate pertaining to newborn health care in its perinatal centers and NICUs. Senate Bill 502 (California Legislative Information, 2011), the Hospital Infant Feeding Act, and Senate Bill 402 (California Legislative Information, 2013) cite the United States Healthy People 2020 goals for breastfeeding newborns and require all perinatal units in California to incorporate into formal policies and practices the most current evidence-based guidelines on early and exclusive breastfeeding. One impact of the legislation is that the majority of California NICUs have achieved or are seeking certification as *Baby Friendly* (www.babyfriendlyusa.org).

Recruitment

The target population was the 130 NICUs in the 2013 public list of member California hospitals in the CPQCC quality improvement organization (www.cpqcc.org/membership/member_hospitals). In California, state regulations (CDHCS, 2013) mandate that NICUs have the on-site services of an APRN in the CNS role in order to qualify 1) for recognition as a CCS facility eligible for extra funding/reimbursement for services and 2) as collaborative members for quality care improvement in the state network, CPQCC. Most neonatal CNSs and nurse practitioners (NPs) are intimately involved with DC planning in their respective NICUs, either as coordinator, care provider, or consultant to the NICU interdisciplinary team for optimal DC transitioning (CCS, 1999; Gaal, Blatz, Dix, & Jennings, 2008; Robison, Pirak, & Morrell, 2000). Thus, the CNS was targeted for a survey on DC transitioning practices. With the support of the California Association of Clinical Nurse Specialists (www.cacns.org) and local chapters of the NANN, contact information was obtained for 97 NICU facilities, 73% of the CPQCC members. Where a CNS was not currently on staff at the specific NICU, contact information for the neonatal NP was requested. Where an APRN was not currently available at the specific NICU, the nurse manager or DC coordinator contact information was requested.

A two-stage sampling process was used to obtain completed surveys (Figure 1). In Stage 1, an email invitation was sent to 97 facilities; 13 email addresses were not valid (13%). Within two weeks 20 surveys were returned (24%). In Stage 2, corrected email addresses were found for 9 of the 13 invalid addresses. Because the survey was anonymous, the identity of the 20 facilities that had returned surveys was not tracked. Thus, an email was sent to all 93 NICU facilities with contact information. The email expressed thanks to those who had completed the survey and

encouraged those who had not returned the survey to do so. Within two weeks an additional 14 surveys were returned (and 14 more invalid email addresses were identified). Review of the surveys indicated that 32 of 34 (94%) returned surveys provided useable data. Thus, the final return rate for completed surveys was 41% (32 of 79 facilities with valid addresses).

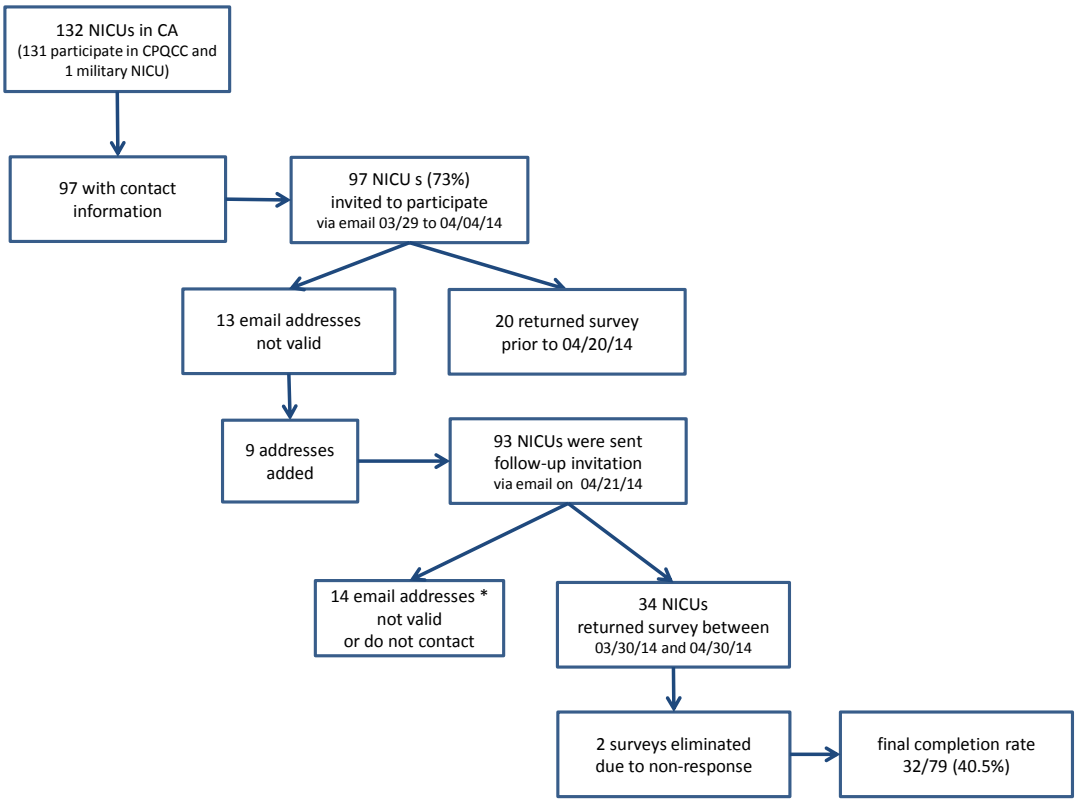

Figure 1. Flowchart of two-stage sampling procedure and outcomes of recruitment.

Survey Design

A careful review of the literature on methods for developing, standardizing, and evaluating DC planning procedures provided information on measuring DC phenomena: parental anxiety and depression (Ballantyne et al., 2013; Raines, 2013a, 2013b; Raines & Brustad, 2012; Rowe & Jones, 2010; Segre et al., 2013), parental satisfaction (Cho et al., 2012; Hospital Consumer Assessment of Healthcare Providers and Systems [HCAHPS] Survey, 2013;

Latour et al., 2012), parental lived experiences (Broedsgaard & Wagner, 2005; Burnham et al., 2013; Cheldelin, Dunham & Stewart, 2013; Howell & Graham, 2011), and nursing job satisfaction and lived experiences (Helder, Verweij, & van Staa, 2012). Other NICU outcome measures in the literature include: morbidities and mortality statistics (DeJesus et al., 2012; Latour et al., 2012; Lee et al., 2010; Mills, Sims, & Jacob, 2006), infection rates (Wirtschafter et al., 2011), lengths of stay and readmissions (Eichenwald et al., 2001; Lee, Bennett, Schulman & Gould, 2013; Perlmutter, Suico, Krass & Auld, 1998), and no shows and missed clinic appointments (Ballantyne et al., 2012). These reports were used along with model questionnaires used in studies of DC planning from adult and pediatric acute care settings (e.g., HCAHPS, 2013; Buchko, Gutshall, & Jordan, 2012; Howell & Graham, 2011) and recommendations from subject matter experts to develop a 41-item survey on NICU DC planning (Appendix B).

The survey evaluated current specific care practices for DC of NICU patients from acute care to ambulatory care. Because California regulations require an APRN in the NICU and they play a significant role in DC transitioning, the survey was designed for completion by the APRN. However, in looking for trends in NICU DC transitioning, it is the practices of the NICU as a whole and not the individual practitioner that are of interest. Thus, the demographic characteristics of the facility were collected rather than those of the respondent. The survey was divided into four segments. It begins by asking for facility descriptors such as bed capacity, current census, and specific specialty services provided, followed by questions which elicit the most common practices that occur at that NICU. The third section presents two hypothetical case studies. The first case is a relatively healthy formerly $29^{5/7}$ weeks gestation premature infant, who is now term and ready for DC home, while the second case involves a relatively

healthy LPI born at $34^{3/7}$ weeks gestation, who is now discharging at 21 days of chronological age. Questions elicit information on readiness assessment metrics (how they were developed, what they are, and how they are implemented), how DC preparation activities are measured, standard for ownership of the care transition, types of data shared among the neonatal caregivers and PCPs involved in care delivery, and how these factors are associated with infants' health outcomes. The final questions ask RNs to indicate which DC criteria/policies/procedures are critical to achieving positive health outcomes after DC.

Data Management

Email addresses were maintained on personal computers in password-protected accounts accessible only by the investigator. To preserve anonymity, the email addresses were maintained separately from the data and without a linking file. The survey did not collect contact information, such as name, nickname, IP address, email address, telephone or other personal identifying information. The survey data were stored on a commercial secure server (SurveyMonkey, Inc. Palo Alto, CA) in a password-protected account accessible only by the investigator and a faculty advisor. Survey data were downloaded to an SPSS database (SPSS v22, IBM/SPSS Inc. Chicago, IL) on personal computers in password-protected accounts accessible only by the investigator and a faculty advisor.

Analysis Procedures

Descriptive statistics (frequencies, percentages, means and standard deviations) were used to characterize the responding facilities and to summarize patterns of responses across all facilities and among sub-groups. Classification analyses (cross-tabulations and chi square tests) and comparisons of means (analysis of variance) were used to explore relationships among subgroups and variables.

Results

Characteristics of Facilities

The NICUs were divided into subgroups of specialty practices, which parallel the classification scheme from the AAP in their Policy Statement on Levels of Neonatal Care (CFN AAP, 2012). An index was created using Questions 1 to 6 (Appendix B) to enable facilities to be classified for analysis. Level II criteria (n = 17) were: providing critical care to neonatal patients without the services of an on-site pediatric general surgeon, pediatric neurosurgeon, or ECMO therapy for severe cardiopulmonary failure. Level III criteria (n = 10) were: providing critical care to neonatal patients with the services of an onsite pediatric general surgeon, with or without an on-site pediatric neurosurgeon, but no on-site ECMO therapy. Level IV criteria (n = 5) were: providing critical care to neonatal patients with the on-site services of a pediatric general surgeon, pediatric neurosurgeon and ECMO therapy. Thus, the sample included a representative mixture of CCS designated intermediate, community, and regional NICUs in California.

Table 1

Distribution of Community Size across NICU Facilities

	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 32)	
Urban & > 1 million	7	44%	4	40%	4	80%	15	48%
Urban & 250,000 to 1 million	6	37%	4	40%	1	20%	11	36%
Semi-urban 100,000 to 250,000	3	19%	2	20%	0	0%	5	16%
Missing	1	NA	0	NA	0	NA	1	NA
	17	100%	10	100%	5	100%	32	100%

The size of the communities served by the facilities is summarized in Table 1. Predictably, 80% to 100% of NICUs were located in large urban areas, because smaller semi-urban or rural areas find it difficult sustain the high costs of a neonatal critical care service

(Committee on Child Health Financing of the AAP, 2006; Melnyk & Feinstein, 2009; Perlmutter et al., 1998; Petrou & Khan, 2012; Richardson, 2001; Cardinal & Shum, 1993). Differences across levels of care (LOC) were not statistically significant, $\chi^2(4) = 2.63$, $p > .05$.

One-way analysis of variance (ANOVA) indicated that the number of licensed beds was significantly different across the three LOC, $F(2,29) = 7.07$, $p = .003$. Smaller facilities supported lower LOC: Level II $M = 25.29$ beds, $SD = 19.69$; Level III $M = 34.40$ beds, $SD = 12.77$; Level IV $M = 59.60$ beds, $SD = 20.53$. Percentage of beds filled in a typical daily census was not significantly different across LOC, $F(2,28) < 1.00$, $p > 05$: Level II $M = 58.13\%$, $SD = 17.77$; Level III $M = 67.60\%$, $SD = 17.35$; Level IV $M = 61.76\%$, $SD = 12.16$. This finding suggests that most facilities were not able to function at the full capacity of their licensed beds and further that the limits on capacity were unrelated to the level of services being provided.

The majority of respondents were NICU APRNs (Table 2). The nursing role of the respondents reflects the procedure used to gather contact information. Although Level II facilities were less likely to have an APRN available to complete the survey; differences across LOC were not statistically significant, $\chi^2(6) = 5.62$, $p > .05$.

Table 2

Respondent's Role in Facility

Respondent's Role	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 32)	
APRN (CNS or NP)	10	59%	9	90%	5	100%	24	75%
Nurse Mgr/Director or Asst Nurse M/D	4	23%	1	10%	0	0%	5	16%
Charge Nurse or Clinical Educator	2	12%	0	0%	0	0%	2	6%
DC Planner	1	6%	0	0%	0	0%	1	3%
	17	100%	10	100%	5	100%	32	100%

AAP DC Transitioning Criteria

The AAP's Committee on Fetus and Newborn published in 2008 their list of the four "common elements" based upon literature review of all randomized clinical trials for early DC from the NICU of high-risk patients (CFN AAP, 2008; Jeffries, 2014): physiological stability, coordinated tracking and monitoring of growth and development of the NICU graduate, demonstration of parental competency in infant care, and linkage with follow-up clinic care under a care provider with experience in the care of NICU graduates.

The prevalence of four practices that meet the first three AAP criteria is summarized in Table 3. All but one of the facilities engaged in all four of these practices. Nippling (bottle feeding) or breastfeeding for all intake was the distinguishing characteristic; all LOC reported adherence to this practice except for one Level IV NICU. This exception to the oral intake criterion most likely reflects the DC of those post-surgical infants with enteral tubes for nutritional intake. Home caregivers have shown over the years to be very competent in using this alternative feeding strategy, which includes security of the tube(s), skin care, and often tube replacement in the home. Therefore, if this AAP statement criterion of oral feeding were to be expanded to include enteral feeding, then all NICUs practice this measure of transition in care to the home setting (Berry et al., 2013; Hummel & Cronin, 2004; Parker, 1991; Robinson et al., 2000).

Average daily weight gain of 10 or more grams (regardless of specific body weights at DC), individual temperature maintenance by each infant without external heating entities (such as electronic warming devices), and competence demonstrated by the primary home caregiver (although measurable parameters of competence are not defined) were universally held as essential criteria for DC transitioning (Table 3).

Table 3

Adherence to AAP Recommendations for Discharge Transitioning Criteria

	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 32)	
Nipple all or breastfeed								
Yes	17	100%	10	100%	4	80%	31	97%
No	0	0%	0	0%	1	20%	1	3%
	17	100%	10	100%	5	100%	32	100%
Wt Gain 10 gms daily								
Yes	17	100%	10	100%	5	100%	32	100%
No	0	0%	0	0%	0	0%	0	0%
	17	100%	10	100%	5	100%	32	100%
Maintain Temperature								
Yes	17	100%	10	100%	5	100%	32	100%
No	0	0%	0	0%	0	0%	0	0%
	17	100%	10	100%	5	100%	32	100%
Competent Home Caregiver								
Yes	17	100%	10	100%	5	100%	32	100%
No	0	0%	0	0%	0	0%	0	0%
	17	100%	10	100%	5	100%	32	100%

In NICU practice over the years, care providers have also developed two "rule of thumb" criteria around infant readiness for DC: the criterion of a minimal body weight achievement and the criterion of a minimal adjusted gestational age (Brooten, et al., 1986; Brooten, 1995; Fink, 2011; Liu, Clemens, Shay, Davis, & Novack, 1997; Meerlo-Habing, Koster-Boes, Klip, & Brand, 2009; New, Flenady, & Davies, 2011; Picone, Paolillo, Franco, & DiLallo, 2011; Shepherd et al., 2013; Zecca et al., 2010). However, the data summary in Table 4 makes it clear that these practices are not universal in California NICUs, 35% to 80% of NICUs do not use weight as a criterion and the use of gestational age ranges from 34 to 36 weeks. Differences across LOC were not statistically significant for weight, $\chi^2(6) = 11.89$, $p > .05$ nor for gestational age, $\chi^2(4) = 3.40$, $p > .05$.

Table 4

Use of Additional Discharge Transitioning Criteria

	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 32)	
Minimum Wt for DC								
2200 to 2500 gms	0	0%	0	0%	1	20%	1	3%
2000 to 2200 gms	2	12%	0	0%	0	0%	2	6%
1800 to 2000 gms	9	53%	2	20%	1	20%	12	38%
Not a criterion	6	35%	8	80%	3	60%	17	53%
	17	100%	10	100%	5	100%	32	100%
Corrected GA for DC								
34 – 34 $^{6/7}$ weeks	7	47%	4	44%	0	0%	11	39%
35 – 35 $^{6/7}$ weeks	5	33%	3	33%	3	75%	11	39%
36 weeks	3	20%	2	22%	1	25%	6	21%
	15	100%	9	100%	4	100%	28	100%

Parental Involvement with Care

Although all facilities indicated that DC was not scheduled until the caregiver was competent, the parent's participation in the clinical care of neonates can be defined in a number of ways. Its use as a criterion in DC transitioning can begin at birth with kangaroo care (KC) and be followed by a checklist of competencies to attain during the NICU stay or it can be limited to a formal test prior to DC. The nature and extent of parental involvement was surveyed in detail; the frequency of practices related to parental involvement in care is summarized in Tables 5 - 7.

Active promotion of breast-feeding is not universal in California NICUs, although there appears to be an emerging trend in seeking Baby Friendly certification. Frequency of this practice was similar across LOC, $\chi^2(4)$ 1.35, $p > .05$ (Table 5).

Table 5

Breast Feeding in the NICU

	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 32)	
Baby Friendly Certified								
Yes	4	25%	4	40%	1	20%	9	29%
Application In	6	37%	2	20%	2	40%	10	32%
No	6	37%	4	40%	2	40%	12	39%
Missing	1	NA	0	NA	0	NA	1	NA
	17	100%	10	100%	5	100%	32	100%

Table 6

Kangaroo Care with Neonates

	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 32)	
KC in DR in 1st Hour								
Yes	16	94%	10	100%	5	100%	31	97%
No	1	6%	0	0%	0	0%	1	3%
	17	100%	10	100%	5	100%	32	100%
KC in Postpartum								
Yes	14	82%	8	80%	5	100%	27	84%
No	3	18%	2	20%	0	0%	5	16%
	17	100%	10	100%	5	100%	32	100%
KC in NICU Mom @ Bedside								
Yes	17	100%	10	100%	5	100%	32	100%
	17	100%	10	100%	5	100%	32	100%
KC in NICU Dad @ Bedside								
Yes	17	100%	10	100%	5	100%	32	100%
	17	100%	10	100%	5	100%	32	100%
KC NICU Stable ETT								
Yes	12	71%	8	80%	5	100%	25	78%
No	5	29%	2	20%	0	0%	7	22%
	17	100%	10	100%	5	100%	32	100%
KC NICU PICC Lines								
Yes	15	88%	10	100%	5	100%	30	94%
No	2	12%	0	0%	0	0%	2	6%
	17	100%	10	100%	5	100%	32	100%
MD Written Order to KC								
Yes	4	24%	0	0%	0	0%	4	13%
No	13	76%	10	100%	5	100%	28	87%
	17	100%	10	100%	5	100%	32	100%

All facilities practiced KC in some form (Table 6). All forms of KC were used in all Level IV facilities. While Level III and Level IV facilities practiced KC at the discretion of staff, 24% of Level II facilities required written medical orders for it (Table 6), $\chi^2(2)$ 4.03, $p > .05$. All but one facility had KC in the delivery room ($p > .05$), and 80% to 100% of facilities had KC post-partum ($p > .05$). All facilities allowed both mother and father to give KC at the bedside in the NICU. The majority of facilities at each LOC (> 71%) allowed KC with neonates who had enteral feeding tubes or central catheters ($p > .05$).

Family inclusion in managing the clinical care of a neonate remains restricted in all LOC. Practices during the "final stage" of training of NICU parents are summarized in Table 7. On-site sleep rooms (similar to rooms assigned to acute care practitioners for 24-hour on-call duties) are not commonly provided for parents of NICU patients. A minority of NICUs move the baby into a room with the parents for periods of simulated sole caregiving (with or without monitoring equipment).

Only 19% of Level II facilities allowed parents to sleep with the neonate in the NICU, while 80% or more of Level III and Level IV facilities did, a statistically significant difference across facilities $\chi^2(2) = 14.83$, $p = .001$ (Table 7). Similarly, only 50% of Level II facilities allowed parents to sleep with the neonate in a room outside of the NICU, while 80% or more of Level III and Level IV facilities did. However, these smaller differences across levels were not statistically significant, $\chi^2(2) = 4.92$, $p > .05$. Less than half of facilities (10% to 40%) allowed parents to sleep with the neonate in a room outside the NICU, $p > .05$; this finding was true regardless of whether neonate was on or off monitors. More than half of facilities (56% to 60%) allowed parents to provide caregiving at the NICU *bedside,* however, when the neonate remained on monitors; LOC were not significantly different in this practice, $p > .05$. None of the facilities

(0%) removed infants from monitoring equipment for parents to provide caregiving in the NICU as if in a home-like environment.

Table 7

Nature and Extent of Parental Caregiving in the NICU

	Level II – NICU (n = 16)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 31)	
Parent Sleep Room Within NICU								
Yes	3	19%	8	80%	5	100%	16	52%
No	13	81%	2	20%	0	0%	15	48%
	16	100%	10	100%	5	100%	31	100%
Parent Sleep Room Outside NICU								
Yes	8	50%	1	10%	1	20%	10	32%
No	8	50%	9	90%	4	80%	21	68%
	16	100%	10	100%	5	100%	31	100%
Baby is moved to Parent Room w/ Equip Remains On								
Yes	4	25%	4	40%	1	20%	9	29%
No	12	75%	6	60%	4	80%	22	71%
	16	100%	10	100%	5	100%	31	100%
Baby is moved to Parent Room w/ Equip Off Baby								
Yes	4	25%	1	10%	2	40%	7	23%
No	12	75%	9	90%	3	60%	24	77%
	16	100%	10	100%	5	100%	31	100%
Baby Remains in NICU on Monitors & Parent Provides Care at Bedside								
Yes	9	56%	6	60%	3	60%	18	58%
No	7	44%	4	40%	2	40%	13	42%
	16	100%	10	100%	5	100%	31	100%
Baby Remains in NICU off Monitors & Parent Provides Care at Bedside								
Yes	0	0%	0	0%	0	0%	0	0%
No	16	100%	10	100%	5	100%	31	100%
	16	100%	10	100%	5	100%	31	100%

Parental Participation in DC Planning

Family inclusion in DC planning of an individual NICU patient also remains restricted in all LOC. The frequency of implementation for each of the five practices examined on the survey was similar across LOC, $p > .05$ (Table 8). Parents were allowed to attend meetings of the interdisciplinary team for DC planning in only 20% to 24% of facilities (Table 8). Only one

facility allowed parent(s) to read or review the baby's chart and only one permitted parent(s) to chart in the baby's medical record. Use of virtual, electronic technology at the bedside for an outside family member to view the baby or to listen to an update on the baby has yet to rise to the prevalence of networking in social situations (6% use at Level II, 10% use at Level III, and no reported use at Level IV, $p > .05$). These four activities, major examples of family-centered care (FCC) practice, had extremely limited employment in the arena of infant critical care.

Journaling and checklisting a clinical pathway has a long history of use in the professional literature (Carly, 2012). These examples of evidence-based practice (EBP) had limited integration within the facilities (Table 8); only a third of facilities across all LOC employed it (35% at Level II, 30% at Level III, and 40% at Level IV, $p > .05$). Overall, the reporting facilities restricted active involvement of parents (and extended families) in care management and directly interfacing with protected information.

Table 8

Nature and Extent of Parental Participation in Discharge Planning

	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 32)	
Parent(s) Attend DC Mtgs								
Yes	4	24%	2	20%	1	20%	7	22%
No	13	76%	8	80%	4	80%	25	78%
	17	100%	10	100%	5	100%	32	99%
Parent(s) Read/Review Charting on Baby								
Yes	1	6%	0	0%	0	0%	1	3%
No	16	94%	10	100%	5	100%	31	97%
	17	100%	10	100%	5	100%	32	100%
Parent(s) Chart/Document in MR								
Yes	0	0%	1	10%	0	0%	1	3%
No	17	100%	9	90%	5	100%	31	97%
	17		10	100%	5	100%	32	100%
Use video on a cell phone or laptop to have family member view baby or listen to report								
Yes	1	6%	1	10%	0	0%	2	7%
No	16	94%	9	90%	5	100%	30	94%
	17	100%	10	100%	5	100%	32	101%
Parent(s) use journal or checklist								
Yes	6	35%	3	30%	2	40%	11	34%
No	11	65%	7	70%	3	60%	21	66%
	17	100%	10	100%	5	100%	32	100%

The CCS also mandates weekly interdisciplinary staff meetings for discussion of plans of care on each patient in the NICU. In most NICUs, this practice manifests as "DC rounds" where discussion focuses on pending or unresolved issues that must be addressed in order to achieve a successful transition out of the NICU in the next week or two. Therefore, often only the "recovering" NICU cases are detailed in these sessions. All facilities except one met at least once per week, $\chi^2(4) = 2.93$, $p > 0.05$ (Table 9); the facility not in compliance was a Level II facility that does not hold meetings. Although holding weekly interdisciplinary DC meetings is a nearly universal practice, only a few facilities (20% to 24%) include parents in the meeting (Table 8).

Table 9

Composition and Frequency of Interdisciplinary DC Meeting

	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Totals	
Interdisciplinary DC Meeting Frequency								
Daily	This option not selected by any respondent.							
Twice a week	1	6%	2	20%	0		3	9%
Once a week	15	88%	8	80%	5	100%	28	88%
Once every 2 weeks	This option not selected by any respondent.							
No DC meeting held	1	6%	0		0		1	3%
	17	100%	10	100%	5		32	100%
Med Director/Attending								
Yes	15	88%	9	90%	5	100%	29	91%
No	2	12%	1	10%	0		3	9%
	17	100%	10	100%	5		32	100%
DC Planner/Nurse Coordinator								
Yes	12	71%	10	100%	4	80%	26	81%
No	5	29%	0		1	20%	6	19%
	17	100%	10		5	100%	32	100%
APN: CNS or NP								
Yes	10	59%	8	80%	4	80%	22	69%
No	7	41%	2	20%	1	20%	10	31%
	17	100%	10	100%	5	100%	32	100%
Social Worker								
Yes	16	94%	10	100%	5	100%	31	97%
No	1	6%	0		0		1	3%
	17	100%	10		5		32	100%
OT/PT								
Yes	12	71%	8	80%	3	60%	23	72%
No	5	29%	2	20%	2	40%	9	28%
	17	100%	10	100%	5	100%	32	100%
MD or nurse from HRIF								
Yes	7	41%	6	60%	4	80%	17	53%
No	10	59%	4	40%	1	20%	15	47%
	17	100%	10	100%	5	100%	32	100%

By CCS mandate, the case discussion should include physicians, RNs, medical social workers, and other professionals as each case may warrant (occupational therapy, physical therapy, dietician, respiratory therapy, pharmacist, HRIF clinic, etc.). The data in Table 9

indicate that Level III and Level IV facilities are similar. It is common for them to have a physician (90% and 100% of Level III and IV facilities, respectively), medical social worker (100%), and DC Planner (100% and 80%, respectively) in attendance. It is less common to have an APRN (80%), OT/PT (80% and 60%, respectively), or HRIF representative (60% and 80%, respectively) in attendance. Although the same pattern holds true for Level II facilities, the percentage of facilities able to have fully staffed meetings is lower for each discipline (Table 9). Although this variation is meaningful and congruent with resources present at different LOC, the differences across LOC are not statistically significant for any discipline ($p > .05$).

Arrangement for Post-DC Primary Care

The final of the four AAP criteria for DC is assuring follow-up care. Transition of the new NICU graduate to primary care requires identifying a qualified PCP, scheduling follow-up care, and introducing parents to providers and their clinics. This process can be time-consuming and frustrating and is especially so in regions where providers with the required expertise are scarce. Assistance from hospital staff can meaningfully ease the transition for parents. The degree of assistance provided in making the first appointment varied by LOC (Table 10). Only one Level IV facility (20%) provided it. More than half (59%) of Level II facilities provided it, but 90% of Level III facilities provided it. These differences were not statistically significant, $\chi^2(4) = 7.66$, $p = .11$. Further assistance may be provided in the form of face-to-face meeting between PCP and parents in the NICU or in the primary care clinic, either physically or virtually. The only practice (of the five practices examined on the survey) that was frequently implemented was the practice of providing written instructions to the parent. Differences in frequency of the five practices across LOC were small and not statistically significant, $p > .05$ (Table 10). None of the facilities used videoconferencing technology to facilitate virtual meetings (Skype,

Facetime, GoToMeeting), despite the technologies' availability, affordability and security (Shaw & Ferranti, 2011; Yeo, Ho, Khong, & Lau, 2011).

Table 10

Procedures for Arranging Post-discharge Primary Care

	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 32)	
Who Schedules 1st Clinic Appt								
NICU Nurse/staff	5	29%	5	50%	0	0%	10	31%
Other hosp nurse/staff	5	29%	4	40%	1	20%	10	31%
Parent or primary caregiver	7	41%	1	10%	4	80%	12	38%
	17	99%	10	100%	5	100%	32	100%
Written handout to direct/ connect parent to clinic/PCP								
Yes	9	53%	7	70%	4	80%	20	63%
No	8	47%	3	30%	1	20%	12	38%
	17	100%	10	100%	5	100%	32	100%
PCP Meets Parent in NICU Before DC								
Yes	0	0%	1	10%	0	0%	1	3%
No	17	100%	9	90%	5	100%	31	97%
	17	100%	10	100%	5	100%	32	100%
Provide Tour of Primary Clinic to Introduce Staff								
Yes	0	0%	0	0%	1	20%	1	3%
No	17	100%	10	100%	4	80%	31	97%
	17	100%	10		5	100%	32	100%
Electronic Tech to visually connect parent to primary clinic staff								
Yes	0	0%	0	0%	0	0%	0	0%
No	17	100%	10	100%	5	100%	32	100%
	17	100%	10	100%	5	100%	32	100%
Primary Clinic handles Introductions for Parents								
Yes	9	53%	2	20%	1	20%	12	37%
No	8	47%	8	80%	4	80%	20	63%
	17	100%	10	100%	5	100%	32	100%

Providing the PCP with a complete DC summary also assists with the neonate's transition. Two practices were common, faxing the summary to the provider or allowing the provider to access the electronic record. They accounted for 65% to 80% of the facilities (Table

11). Differences across LOC were not statistically significant, $p > .05$. Allowing PCPs to have access to the electronic record should become more prevalent in NICUs as *meaningful use* incentives roll out under CMMS's program for critical access hospitals. It is noteworthy that in Level II facilities, the number of facilities that had parents carry a hard copy of the DC summary to the PCP matched the number that gave PCPs access electronically.

Table 11

Procedures for Providing Discharge Summary to Primary Care Provider

How DC Summary to PCP	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 32)	
Hardcopy given to parent to bring to 1st visit	4	24%	0	0%	0	0%	4	13%
Faxed copy before 1st visit	7	41%	5	50%	3	60%	15	47%
Emailed copy securely	1	6%	2	20%	0	0%	3	9%
Copy via USPS	1	6%	0	0%	1	20%	2	6%
Clinic staff comes to pick up copies	0	0%	1	10%	0	0%	1	3%
PCP is linked electronically to MR for NICU	4	24%	2	20%	1	20%	7	22%
	17	101%	10	100%	5	100%	32	100%

Evaluation of DC Transitioning Programs and their Outcomes

Although a few NICUs at each level reported that they did not have any formal evaluation program, the majority of facilities did, $\chi^2(2) < 1$, $p > .05$ (Table 12). The most common practice at Level IV facilities was to ask parents to return a written survey by postal mail, $\chi^2(2) = 1.56$, $p > .05$. The most common practice at Level II and III facilities was to make a follow-up phone call, $\chi^2(2) = 4.57$, $p > .05$ (Cochran & Blair, 2012). Despite the literature demonstrating its efficacy (Amato-Bowen, 1997; Brooten et al., 1986) very few facilities used post-DC home visits to evaluate DC programs or health outcomes $\chi^2(2) < 1$, $p > .05$.

Table 12

Methods of Evaluating Discharge Transitioning Programs

	Level II – NICU (n = 17)		Level III – NICU (n = 10)		Level IV – NICU (n = 5)		Total (N = 32)	
Eval DC Program Written Survey to Mail Back								
Yes	9	53%	7	70%	4	80%	20	63%
No	8	47%	3	30%	1	20%	12	37%
	17	100%	10	100%	5	100%	32	100%
Eval DC Program Phone Contact 3 Days Post DC								
Yes	12	71%	7	70%	1	20%	20	63%
No	5	29%	3	30%	4	80%	12	37%
	17	100%	10	100%	5	100%	32	100%
Eval DC Program Home Visit w/ Report to NICU								
Yes	2	12%	1	10%	0	0%	3	9%
No	15	88%	9	90%	5	100%	29	91%
	17	100%	10	100%	5	100%	32	100%
Eval DC Program – None								
Yes	2	12%	1	10%	1	20%	4	12%
No	15	88%	9	90%	4	80%	28	88%
	17	100%	10	100%	5	100%	32	100%

Respondents' comments. Respondents were asked to provide evaluative comments about the efficacy and effectiveness of their DC transitioning practices. Many respondents listed multiple factors in answers to three prompts; each was counted separately, so the total number of responses exceeds the sample size.

Respondents (N = 28) reported that the following practices prevented readmissions within 30 days:

- Teaching and involving parents (n = 13)
- Requiring infant physiologic maturity per AAP DC criteria (n = 12)
- Assessing parent's competence in care (n = 7)
- Administering Snynagis (n = 5)
- Planning for follow-up healthcare and assessment (n = 5)

- Team decision on infant and parent readiness for discharge (*n* = 3)

Respondents (*N* = 29) reported that they achieved best outcomes when they adhered to the following practices:

- Parental involvement and education early in the hospitalization ("hands on early and often") (*n* = 17)
- Early planning for and assessment of follow-up with PCP (*n* = 13)
- Reinforcement of learning by bedside RNs ("teach, teach, teach") (*n* = 6)
- Emphasizing breastfeeding and skin-to-skin contact (*n* = 6)
- Assessing parent's readiness, competence, confidence (including rooming in when needed) (*n* = 5)
- Assessing infant maturity (*n* = 4)
- Regular meetings with interdisciplinary teams (*n* = 3)

Respondents (*N* = 27) reported that they could improve health outcomes and better prevent readmissions if they could:

- Access better DC teaching materials and have more time for DC education with hands-on demonstration of skills (*n* = 8)
- Include families more deeply in the process of care, bonding, and advocacy (*n* = 5)
- Provide "rooming in" services (*n* = 4)
- Establish follow-up contact to see how the families are doing (*n* = 3)
- Coordinate services better (*n* = 2)
- Assess infant maturity better (*n* = 2)
- Increase breastfeeding; provide more lactation support (*n* = 2)
- Identify parental distress earlier (*n* = 1)

Respondents seemed acutely aware of current practice limitations within each NICU and across the community of NICUs. Their ideas for enhancing health outcomes were congruent with the literature and were already in place in many facilities, suggesting that the ideas would be acceptable and feasible, if properly resourced.

A noteworthy absence from the list of factors contributing to success was formal evaluation of services and outcomes. It is not clear what metrics RNs would use to quantify the impact of changing services on health outcomes or to hold themselves and others accountable. Defining acceptable metrics and standardizing their use should assist NICUs in evaluating performance and justifying practice change.

Summary

The prevalence of key DC practices is summarized in Table 13. It is clear from this table that unlike the practices of assessing physiological stability and development, the practices of assessing parental competence and providing for follow-up care were not universally implemented. Thus, Table 13 highlights 1) the need for specific definitions of practices that support the AAP (2008) DC criteria, 2) areas where guidelines for standardizing practice would be helpful, and 3) potential targets for quality improvement and EBP implementation projects.

Table 13

Prevalence of Key Discharge Criteria

Criterion Category	Criterion	Level II (n = 17)	Level III (n = 10)	Level IV (n = 5)
Physiological Stability	Nippling, Breastfeeding, or Stable ETT	100%	100%	100%
	Maintain Temperature	100%	100%	100%
Growth and Development	Weight Gain (10 gm daily)	100%	100%	100%
	Minimum Weight (1800 to 2500 gm)	65%	20%	40%
	Minimum Corrected Gestational Age (34 to 36 weeks)	100%	100%	100%
Competent Caregiver	Kangaroo Care at Bedside for Mother and Father	100%	100%	100%
	Kangaroo Care at Bedside with ETT	71%	80%	100%
	Kangaroo Care at Bedside with PICC	88%	100%	100%
	Neonate Moved to Parent's Room with Monitors	25%	40%	20%
	Neonate Moved to Parent's Room without Monitors	25%	10%	40%
	Parents Access Neonate's Medical-Nursing Chart	6%	0%	0%
	Parents attend DC Meetings	24%	20%	20%
	Parent participates by Facetime/Skype	6%	10%	0%
Link to Follow-up Care	Staff Schedule 1st PCP appointment	58%	90%	20%
	Parents Meet with PCP in NICU	0%	10%	0%

Discussion

The focus of this project was on DC planning for pre-term, injured, or ill newborns in the transition from acute to ambulatory care. This project surveyed California NICUs about DC transitioning programs to 1) identify current common standards of care used in DC transitioning and 2) define the nature and extent of additional criteria and procedures used in DC transitioning. The sample, while small, was representative of the target population and had sufficient statistical

power for large effect sizes. There were clear patterns of common practice, as well as meaningful differences in practice. Differences appeared to be the result of differences in resources and mission appropriate to the LOC provided by the facility. As a whole, the results provide a clear picture of how EBP for DC transitioning is implemented in California NICUs. Thus, they can serve as a starting point for creating service benchmarks and setting aspirational goals.

Characteristics of Facilities

The NICUs were easily divided into three LOC using a standardized practice definition of services current at the time of the data collection. As expected given the organization of California NICUs, the majority of respondents were Level II facilities, but there were sufficient Level III and IV facilities to adequately represent the LOC. The majority of facilities were located in large urban areas, but smaller semi-urban centers were adequately represented as well. Given their mission as regional definitive care facilities, it is not surprising that Level IV facilities were more than twice as big as Level II facilities and almost twice as likely to have an APRN available to complete the survey. This group of characteristics is a clear indication of the representative nature of the sample and lends credibility to the results.

AAP DC Transitioning Criteria

The AAP guidelines for DC of the high-risk infant (CFN AAP, 2008) are implemented across all NICU LOC in California. This finding is highlighted, because it suggests not only that guidelines *have been* adopted, but also that in this multi-disciplinary field, guidelines are a sufficient condition for standardization. Thus, the process of expanding and disseminating additional evidence-based guidelines should be well accepted.

The single exception to implementation of the AAP feeding criteria, when taken in context, does not reflect a failure to comply, but rather the specific context of definitive care.

Unlike Level II and III facilities, Level IV facilities may discharge the infant to another NICU or discharge an infant who depends on technology aids in the home. These data suggest that current guidelines should be expanded to recognize that some discharged NICU graduates are enterally or intravenously fed in the home setting. Further they should recognize that, with advances in technology, ventilator dependent graduates are managed in the sub-acute setting or in the home by trained family members and skilled caregivers. As more professional disciplines perform and report on clinical research there is a substantial potential for the development and deployment of additional evidence-based guidelines. As the AAP begins to endorse position papers from professional nursing organizations (AAP, 2014; NANN, 2014), they will also recognize and work with other disciplines to draft guidelines that more accurately reflect the complexities of some NICU graduates and the commonalities of many NICU subpopulations.

Expansion of the guidelines should address simpler criteria, as well. Future guidelines should address the criteria of minimum weight and age that are used by many, but not all, facilities. Evidence on the efficacy of these criteria should be compiled and standards for their application disseminated.

Parental Involvement with Care

When respondents were asked to list factors that account for good health outcomes in discharged neonates, issues of parent education, assisting with infant care from the beginning of the NICU stay, breast feeding, rooming in, and formal assessment of parent confidence/ competence were common themes, yet these practices were not universal. Nor were they consistently implemented at specific LOC. Rather they appeared to be implemented on the basis of the preference of staff or the resources available.

Although all NICUs indicated that a competent home caregiver was a DC criterion. It is clear from the differences among facilities within and across LOC that the procedures used to develop and assess competency varied substantially. Thus, the need for a clear definition of what constitutes the particulars of parental involvement and engagement exists. Although literature exists on the benefits of parental engagement both for the parent's emotional health and for the infant's care, meta-analyses of the scientific literature and the practice-based evidence should be completed to establish minimum levels of and types of behaviors that enhance health outcomes. These meta-analyses should be synthesized with data derived from discussions with subject matter experts across practice settings, across research settings, across disciplines, and with parent partners and community support entities. The Institute for Patient- and Family-Centered Care (IPFCC) and Baby-Friendly USA (BFUSA) can provide expertise and knowledge upon which nursing research can examine feasibility and efficiency in assessment tools, interventions, and shared responsibilities.

Existing nursing practice at the bedside in acute care neonatal settings must recognize currently evolving scopes of nursing practice. Data showing that practices are successfully implemented in some facilities across LOC can be used to demonstrate their acceptability and feasibility. Outdated nursing practices in NICUs must not disregard the independent functions inherent in current nursing practice acts. For example, in some cases a physician must write an order to permit kangaroo care or breastfeeding in the NICU. Professional literature and practice have established the benefits of KC for facilitating maternal bonding and early discharge (deLeon-Mendoza & Mokhachane, 2011; Flacking, Ewald & Wallin, 2011). Evidence also indicates that unless an infant is medically ordered as nil per os (NPO) or has documented glactosemia, breastmilk should be his/her best nutritional source (Section on Breastfeeding AAP,

2012). The Ten Steps to Successful Breastfeeding (BFUSA), especially the fourth (within one hour of birth) and eighth (on demand feedings) are achievable in all neonatal settings in acute care facilities when healthcare professionals craft their practice policies and philosophies to do so without impediments. Nurses as the bedside teachers and role models to new parents must maximize their influence in interdisciplinary practice and advocate for parental participation in baby care early and often in the NICU at every LOC.

Physical layouts of NICUs can impede or augment FCC practices. The NICU staff oversight of parents as they perform patient care in the NICU or in a parent sleep room must be based on need for assistance or assessment, not paternalism. NICU RNs must value and initiate the directives of FCC and advocate for realistic simulations of home environments for parents in the NICU. Burnham , Feeley and Sherrard (2013) documented the need for *removal of all electrical monitoring equipment* in the NICU when an infant has been determined to be ready to DC home, unless the infant will need the technology in the home (e.g., enteral feeding, ventilation). These simulations assist staff in determining parent readiness, assist parents in building confidence/competence, and assist infants with increases in opportunities for bonding.

Parental Participation in DC Planning

In open-ended comments, respondents emphasized the importance of parent education and engagement in DC planning that begins early in the NICU stay, yet implementation of these practices was extremely limited at all LOC. Existing medical and nursing practice at the bedside in acute care neonatal settings must recognize currently evolving electronic medical record technology and policy along with scientific evidence on the positive outcomes associated with parental engagement. Antiquated practices such as requiring parents to sign consents for release of patient information from the medical record even when the recipient is the parents should be

discarded along with informal policy from the administration that the nurse must manage the bedside medical record or the computer screen so a parent cannot readily walk up and begin to read/review the charting. Paternalistic rationales that parents cannot fully comprehend the medical terminology in the record should be replaced by practices focusing on early and continuing education for parents at the bedside and in consultations/rounds for maximizing comprehension.

Paternalism and avoidance of active processes for FCC in NICUs continue as prevalent patterns of communication. Institutional verbiage promoting FCC is not evident in practice or in the NICU communication policies. More activism under nursing leadership, from the bedside and from advanced practice, is needed to make FCC a reality in critical neonatal care. Failing to hold interdisciplinary DC planning meetings or failing to have all the personnel needed at them, and, in particular, excluding parents from the meetings is no longer tenable given the evidence of its positive impact and the availability of affordable communication technologies. Technology should be leveraged to support everyone's engagement in processes of care and DC planning. Videoconferencing (Adobe Connect, FaceTime, GoToMeeting, Skype, WebEx) and other similar technologies must become first line strategies to communicate with staff, families, and primary care providers (Blake, 2008; Hampton, 2012; Holt, Flint, & Bowers, 2011; Lindberg, Axelsson, & Ohrling, 2009).

Arrangement for Post-DC Primary Care

The results suggest that limited assistance is provided to parents to obtain follow-up ambulatory care for the NICU graduate. It is conceivable that the hand-off of the patient to the PCP of record will occur without difficulty or barrier; however, the efficiency and continuity of the hand-off should be evaluated, so that proactive practices, which facilitate the hand-off can be

implemented. It is not clear how useful written directions, teaching handouts, and medical record documents are in meeting the individualized needs of the patients; these processes should also be included in quality assurance assessments (Brett et al., 2011; Buchko et al., 2012; DeRouck & Leys, 2009). Standards of care exist for in-patient nursing care, but results of this survey suggest that there is no common standard for transitioning care to the PCP or ambulatory clinic. Quality assurance processes could verify not only that the PCP received a DC summary, but also that it was understood and used in the development of a plan of care. Ample evidence exists that when continuity of care is the shared goal of all providers, the process of DC transitioning is more efficient and efficacious (CMS, 2012; Meleth, Dahlgren, Sankaran, & Sankaran, 1995; Navar-Boggan, Halsey, Escobar, Golden & Klein, 2012; Ohler & Pham, 2013; Tang et al., 2012; vanWalraven, 2002).

Evaluation of DC Transitioning Programs and their Outcomes

Mail-back parental surveys are commonplace. However, for them to be effective in changing practice at the national level, they need to be standardized across facilities and states. Furthermore, modern information technologies should be leveraged to assure that all parents are able to provide evaluations in a timely fashion (electronic means of submission, patient portals to the NICU, video-interviewing, etc.). Telephone follow-up contact within the first few days after DC, a proven evaluation and intervention mechanism from adult and geriatric acute care transition (AHRQ, 2013a; Cochran & Blair, 2012; Johnson, Laderman, & Coleman, 2013; Lasby, 2004; Markley et al., 2013; Voss et al., 2011), along with home nursing visits (Brooten et al., 1986; Goyal et al., 2013), should be properly resourced and used to generate practice-based evidence on successful interventions at all LOC. Neonatal collaboratives must consider adopting these measures for data collection on a large scale. Consumer advisory groups, which have

become integral to the clinical and operational practices in hospitals, need to include NICU representation for a means to advocate for the neonate and their families.

Implications

Although special-needs neonates makeup only 10% of births, NICU care accounts for 75% of expenditures for acute care of the newborn (Behrman & Butler, 2007; Kofke-Egger, Ehrlich, & Udow-Phillips, 2010; Kornhauser & Schneiderman, 2010; Muraskas & Parsi, 2008). Educating parents and involving them in care is time-intensive for medical, nursing, and ancillary staff. Creating the physical infrastructure to support *rooming in* requires physical and fiscal resources, as well as substantial training of medical, nursing, and ancillary staff in the principles and culture of FCC. Coordination of care that includes staff arranging PCP visits to the NICU, virtual visits to the clinic, and initial appointments for follow-up care requires specialized services by trained personnel and incorporation of communication technologies into DC transitions. Creating and staffing evaluation centers that follow the NICU graduate with phone calls and home visits have large start-up costs. However, given that the cost of NICU care ranges from $3000 to $5,000 per day, significant cost avoidance can be achieved by these changes in practice. Managed care organizations have been able to reduce length of stay by 8% to 12%, reduce readmissions after NICU discharge by 30%, and achieve 95% satisfaction of family members (Behrman & Butler, 2007; Kofke-Egger, Ehrlich, & Udow-Phillips, 2010; Kornhauser & Schneiderman, 2010; Muraskas & Parsi, 2008). These savings can pay the cost of recommended changes in training, practice, and infrastructure.

Special interest groups in professional nursing organizations can provide the leadership necessary to investigate practice-based evidence across the United States to present optimal best practice modalities in DC transitioning of the NICU graduate with his/her parents or home

caregivers. This project clearly demonstrates that better data collection and uniform information infrastructure are needed to create evidence-based guidelines that standardize practice and create opportunities to advance practice by systematically assessing the success of interventions. Critical care as provided in the NICU exemplifies the extent of complexity in American health care (Stiles, Tayloe & Wegner, 2014).

Variations in transitioning practices, which are not congruent with best evidence, must be recognized. Where practice variations include barriers or impediments to safe, efficacious, and cost effective hand-off to primary care, practice must be standardized. Implementing FCC principles of parental participation in bedside care must be 24/7 with supporting resources in each NICU (Griffin & Abraham, 2006; Wataker, Meberg, & Nestass, 2012). The use of communication technologies in DC planning and transitioning has lagged behind the search for sophisticated care technologies (Ellsbury, 2010). The integration of mobile and social media technologies is essential to improve basic practices for care team interdependence and for full parental partnership with the professional health care team. Evaluation for quality improvement in DC transitioning must be present with standardized metrics in every NICU in order to determine outcomes and their validities.

Critical elements of transition from the NICU to home have been recognized in the literature for over two decades (Bruder & Cole, 1991). Quality care collaboratives (e. g., CPQCC, VON, etc.) are a proven method for addressing practices for better nutrition and infection reduction; they should expand their initiatives to include DC planning and its impact on the health of parents and infants. Nursing which has long proven to be the driver of DC transitioning can champion the benefits of sharing best practices by publishing evidence-based

findings and by continuing to promote the primacy of meaningful and reliable care coordination in “going home” (McAllister, Presler, & Cooley, 2007).

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Appendix A: IRB Letter of Approval

BRANDMAN University Chapman University System

BRANDMAN UNIVERSITY INSTITUTIONAL REVIEW BOARD

IRB Application Acton – Approval

IRB# 01151401

Date: 12-19-13

Name of Investigator/Researcher: Arlene Lovejoy-Bluem

Faculty or Student ID Number: B00384181

Title of Research Project:

Neonatal Intensive Care Unit Discharge Transitioning: Nursing Practices, Perspectives, and Perceptions

Project Type: ☑ New ☐ Continuation ☐ Resubmission

Funded: ☑ No ☐ Yes _____

Funding Agency; type of funding; grant number

Project Duration: (cannot exceed 1 year) February 2014 to January 2015

Principal Researcher's Address: PO Box 10788

Burbank CA 91510

Email Address: love1101@mail.brandman.edu Telephone Number: 818-504-9325

Faculty Advisor/Sponsor/Chair Name: Mary Z. Mays

Category of Review:

☑ Exempt Review ☐ Expedited Review ☐ Standard Review

I have completed the NIH Certification and included a copy with this proposal

NIH Certificate currently on file in the office of the IRB Chair or Department Office

Signature of Principal Investigator _____ Date 12/19/13

Signature of Faculty Advisory/Sponsor/Dissertation Chair _____ Date 12/19/13

APPROVED
By M Z Mays at 5:32 pm, Dec 19, 2013

BRANDMAN UNIVERSITY INSTITUTIONAL REVIEW BOARD
IRB APPLICATION ACTION – APPROVAL

IRB ACTION/APPROVAL

Name of Investigator/Researcher: Arlene Lovejoy-Bluem

Returned without review. Insufficient detail to adequately assess risks, protections and benefits.

Approved/Certified as Exempt form IRB Review.

Approved as submitted.

Approved, contingent on minor revisions (see attached)

Requires significant modifications of the protocol before approval. Research must resubmit with modifications (see attached)

Researcher must contact IRB member and discuss revisions to research proposal and protocol.

IRB Comments:

Determination by BUIRB on 02/06/2104 that IRB application #01151401is considered to be less than minimal risk to participants. Therefore, this application is approved as submitted under the category of Exempt Review.

IRB Contact

Name: Alan Enomoto

Telephone: (925) 930-2020 Email: enomoto@brandman.edu

IRB Certification: Alan Enomoto Digitally signed by Alan Enomoto DN: cn=Alan Enomoto, o=Brandman University, ou=School of Education, email=enomoto@brandman.edu, c=US Date: 2014.02.07 10:02:54 -08'00' Date: 02/06/2014

Appendix B: NICU Discharge Practice Survey

NICU Discharge Practice Survey

Abbreviations

AAP	=	American Academy of Pediatrics
CCS	=	California Children's Services
CCS-CPQCC	=	CCS-California Perinatal Quality Care Collaborative
CDC	=	Centers for Disease Control and Prevention
CNS	=	Clinical Nurse Specialist
DTaP	=	Diphtheria, Tetanus, acellular Pertussis
ECMO	=	Extracorporeal Membrane Oxygenation
HBV	=	Hepatitis B Vaccine
Hib	=	Haemophilus Influenzae Type b Vaccine
HRIF	=	High Risk Follow-up Clinic
IPV	=	Inactivated Polio Vaccine
MD	=	Medical Doctor/Physician
NICU	=	Neonatal Intensive Care Unit
NP	=	Nurse Practitioner
DO	=	Osteopathic Doctor/Physician
PCV	=	Pneumococcal Vaccine
PICC	=	Percutaneous/peripheral intravenous central catheter
ROP	=	Retinopathy of Prematurity
RSV	=	Respiratory Syncytial Virus
WIC	=	Women, Infants and Children Food and Nutrition Program

NICU DEMOGRAPHICS AND POLICIES:

1) Your NICU is located in what type of geographical area?

- ❒ In a large urban area immediately surrounded by other medium and large urban cities (the metropolitan population surrounding your NICU greater than one million)
- ❒ In a medium-sized urban area immediately surrounded by other medium and small urban cites (the immediate population surrounding your NICU is 250,000 to one million)
- ❒ In a small semi-urban area immediately surrounded by rural areas and scattered small towns (the immediate population surrounding your NICU is 100,000 to 250,000)

- ❒ In a small town immediately surrounded by rural areas and a few scattered smaller towns (the immediate population surrounding your NICU is under 100,000)

2) Your NICU has a total bed licensure (acute and intermediate): __ __ beds

3) Last week your NICU's average daily census in those licensed beds was: __ __ patients

4) Does your NICU currently provide general surgical services by an in-house pediatric surgeon?

❒ Yes ❒ We transport out for these services

5) Does your NICU currently provide pediatric neurosurgical services by an in-house pediatric neurosurgeon?

❒ Yes ❒ We transport out for these services

6) Does your NICU, currently provide ECMO for severe cardiopulmonary failure?

❒ Yes ❒ We transport out for these services

7) How often do you have appropriate staffing ratios in your NICU?

- ❒ Always
- ❒ Almost always
- ❒ Most of the time
- ❒ Only occasionally
- ❒ Never

8) During night shift, your neonatology (MD, DO, or NP) coverage is:

- ❒ Always available in-house (based in an on-site on-call room)
- ❒ Available via telephone, pager, or in-house depending on patient acuity
- ❒ Available via telephone or pager regardless of patient acuity
- ❒ Not available

9) What is your current role on the NICU healthcare team?

- ❒ NICU Nurse Manager/Director or Assistant Nurse Manager/Director
- ❒ NICU Advanced Practice Nurse (CNS or NP)
- ❒ Charge Nurse or Clinical NICU Educator
- ❒ Staff NICU Nurse
- ❒ Other: _____

10) Is your hospital/medical center Baby-Friendly Certified?

- ❒ Yes
- ❒ Baby Friendly USA currently has our application under consideration
- ❒ No

11) Skin-to-skin (Kangaroo Care) is practiced in our hospital/medical center (Select all that apply.)

- ❒ In the delivery room right after the baby is born and within the first hour of life
- ❒ In the post-partum ward with assistance from a nurse or family member
- ❒ At the NICU bedside, the mother may provide skin-to-skin care
- ❒ At the NICU bedside, the father may provide skin-to-skin care
- ❒ Stable NICU patients with endotracheal tubes may participate in skin-to-skin care
- ❒ Stable NICU patients with PICC lines may participate in skin-to-skin care
- ❒ A written medical order is required for skin-to-skin care to occur

12) Written NICU policies and procedures are available to our NICU staff via: (Select all that apply.)

- ❒ In hardcopy binder(s) on the unit
- ❒ Electronically via our intranet in the hospital/medical center only
- ❒ Electronically via our intranet from any computer via user name and password functions
- ❒ Our NICU policies and procedures are not currently available to our NICU staff

13) Our NICU policies and procedures are indexed for ease of use by staff in the following ways: (Select all that apply.)

- ❒ Key words in an index at the end of the manual
- ❒ Table of Contents alphabetized by key terminology
- ❒ Use of "Find" function on the intranet
- ❒ Currently there is no indexing for ease of use by staff

14) Our NICU nursing staff are trained in our policies and procedures in the following ways: (Select all that apply.)

- ❒ Assigned reading in new employee orientation of selected policies and procedures
- ❒ Via preceptored clinical experiences (shown how to perform procedures and when)
- ❒ Interactive online modules on specific neonatal procedures
- ❒ Staff nurses have the responsibility to review and revise policies and procedures as part of their clinical ladder or as part of their expected duties in the NICU.
- ❒ Our formal NICU policies and procedures are not part of any particular training process for nursing staff

Discharge Practice:

15) How often does the neonatal interdisciplinary team hold discharge planning rounds/meeting in your NICU?

- ❒ Daily
- ❒ Twice a week
- ❒ Once a week
- ❒ Once every two weeks
- ❒ Our NICU does not hold regularly scheduled discharge planning rounds/meetings

16) Which of the following neonatal team members almost always attend your NICU discharge planning rounds/meeting? (Check all that apply.)

- ❒ NICU medical director or attending
- ❒ NICU discharge planner/nurse coordinator
- ❒ NICU advanced practice nurse (CNS and/or NP)
- ❒ NICU social worker
- ❒ NICU occupational/physical therapist
- ❒ High-risk follow-up physician and/or nurse
- ❒ Our NICU does not hold regularly scheduled discharge planning rounds/meeting.

17) Does your medical center currently provide on-site ambulatory high-risk follow-up services for NICU graduates?

❒ Yes ❒ We refer to another center for these services (off our site)

18) Which of the following criteria must be met before discharging a "typical" ex-prematurely born infant from your NICU? (Select all that apply.)

- ❒ Eating well (nippling all feedings, breastfeeding all feedings)
- ❒ Gaining appropriate weight (average daily gain of 10 grams or more)
- ❒ Maintaining temperature without electronic thermal equipment
- ❒ Home caregiver has shown competency in the baby's care

19) What is the earliest corrected (adjusted) gestational age that your NICU will consider discharging a growing ex-preemie who has no problem with apneas or desaturations?
__ __ weeks and __ days

20) At what minimal weight does your NICU consider discharging a growing ex-preemie who is eating well and has no other issues needing in-patient treatment?

- ❒ 2200 to 2500 grams
- ❒ 2000 to 2200 grams
- ❒ 1800 to 2000 grams
- ❒ Minimal weight is not a criterion for discharge

21) How many days after the last dose of oral caffeine will your NICU discharge an ex-preemie who has no further apneas or desaturations after that last dose?

- ❒ 5 days or more
- ❒ 3 to 4 days
- ❒ 1 to 2 days
- ❒ We send babies home on oral caffeine administered by the primary caregiver

22) When a NICU baby has been treated for apnea of prematurity, how long must s/he be free of (self-resolved) apneic episodes or desaturations before discharge home?

- ❒ More than 95 hours
- ❒ 72 to 95 hours
- ❒ 48 to 71 hours
- ❒ 24 to 47 hours

23) Are babies who are diagnosed with *apnea of prematurity* sent home on apnea monitors and/or pulse oximetry?

- ❒ Always
- ❒ Almost always
- ❒ Most of the time
- ❒ Only occasionally
- ❒ Never

24) In your NICU, parent(s) can participate in the discharge planning process in which of the following ways? (Select all that apply.)

- ❒ Attend discharge planning rounds/meetings
- ❒ Chart/Document in the baby's medical record
- ❒ Read/review the day's charting on his/her baby
- ❒ Use video (Facetime, Skype, etc.) on a cellular phone or laptop to have a family member view the baby and/or listen to a verbal report from staff
- ❒ Using a journal or checklist (provided by your NICU) to record the progress toward discharge of his/her baby

25) Who schedules the first ambulatory pediatric clinic appointment for a new NICU graduate?

- ❒ The NICU nurse/staff
- ❒ Other hospital nurse/staff
- ❒ The parent or primary home caregiver

26) How soon after discharge does your NICU recommend and plan for the first ambulatory pediatric appointment to occur?

__ day(s) after NICU discharge

27) How does your NICU connect/link the parent to the primary care practitioner for the baby? (Select all that apply.)

- ❒ Provide a handout of written instructions/directions to the primary care clinic
- ❒ The primary care practitioner meets the parent face-to-face in the NICU before discharge
- ❒ Provide a tour of the primary care clinic to introduce ambulatory staff to the parent
- ❒ Use electronic technology at the bedside in the NICU to introduce the parent to ambulatory staff visually (e.g., Facetime, Skype, Web conference, website, Twitter, etc.)
- ❒ None of the above; the clinic will handle introductions.

28) What is your NICU's practice on parental instruction in sleep position and sudden infant death syndrome (SIDS)? (Select all that apply.)

- ❒ Verbal instruction is provided by our NICU staff for all discharging cases
- ❒ Verbal instruction is provided by our NICU staff for selected cases only.
- ❒ Written handout on "Back to Sleep"/SIDS prevention
- ❒ No instruction in SIDS is provided in the NICU

29) What is your NICU's practice on parental instruction in cardiopulmonary resuscitation (CPR)?

- ❒ CPR instruction is provided by our NICU staff for all discharging cases
- ❒ CPR instruction is provided by our NICU staff for selected cases only.
- ❒ Parents are referred to community classes in infant CPR
- ❒ No instruction in CPR is provided or recommended

30) Regarding instruction to parent(s) on administration (drawing up and dosing) of medication to the baby in the home, which of the following is/are practiced in your NICU? (Select all that apply.)

- ❒ Instruction is provided only when take-home medications are ordered.
- ❒ Instruction is provided in the NICU or at the out-patient pharmacy by the hospital's pharmacy staff.
- ❒ Instruction is provided by the NICU nurses at the bedside.
- ❒ Instruction is provided with written handouts on each specific medication ordered
- ❒ Instruction includes how to determine dosing of over-the-counter antipyretics (e.g., acetaminophen) whether or not this medication is ordered by the NICU physician/NP.

31) Which of the following services does your NICU use to evaluate the quality of discharge for each patient and primary home caregiver? (Select all that apply.)

- ❒ Written survey to mail back to the NICU
- ❒ Telephone contact within 3 days after discharge
- ❒ Home visit by nursing staff that includes a report to our NICU
- ❒ None of the above

32) How does your NICU provide a parent or primary home caregiver with an extended period of time (e.g., 6 to 10 hours or more) to provide all baby care before discharge? (Select all that apply.)

- ❒ A parent "sleep" room is provided outside the NICU
- ❒ A parent "sleep" room is provided within the NICU
- ❒ The baby is moved into the parent room with the parent and monitoring equipment remains on the baby
- ❒ The baby is moved into the parent room with the parent but monitoring equipment is off the baby
- ❒ The baby remains in the NICU on monitoring equipment and the parent provides care at the bedside in the NICU.
- ❒ The baby remains in the NICU but is removed from monitoring equipment for this extended period of time. The parent provides care at the bedside in the NICU.

33) How does the primary pediatrician (for the discharged baby) obtain a copy of the discharge summary (from the NICU)?

- ❒ A copy is given to the parent/caregiver to give to the pediatrician at the first clinic visit
- ❒ A copy is faxed to the primary pediatrician before the first clinic visit
- ❒ A copy is emailed via secure email to the primary pediatrician
- ❒ A copy is mailed via USPS to the primary pediatrician as soon as possible
- ❒ A staff person from the clinic comes to the NICU to pick up the discharge summaries
- ❒ The primary pediatrician(s) is/are linked electronically to our hospital's electronic medical record

Hypothetical Case, Baby A is an ex-29 $^{5/7}$ weeker who had a difficult NICU course, is now 64 days old chronologically, and read y to discharge home):

34) If Baby A has not been successful in taking all feedings by mouth at 39 $^{5/7}$ weeks adjusted gestational age, what will your NICU do in order to discharge her home?

- ❒ Instruct the parent or primary home caregiver in gavage feedings
- ❒ Consider placing a gastrostomy tube before discharge
- ❒ Delay discharge until Baby A achieves full oral intake no matter how many days it may take to achieve full oral intake
- ❒ Transfer Baby A to a higher level of neonatal care for evaluation of alternate feeding methods

35) What other referrals would you make for Baby A as part of your discharge planning *before* discharging him/her home? (Select all that apply.)

- ❒ Regional Center
- ❒ WIC
- ❒ Occupational Therapy Clinic
- ❒ Supplemental Security Income
- ❒ CalWorks
- ❒ California Children's Services benefits
- ❒ All referrals are made by the High-Risk Infant Follow-up Clinic or the primary pediatrician

36) Which of the following "shots" (vaccines/antibodies) has Baby A received in your NICU? (Select all that apply.)

- ❒ HBV at 30 days of chronological age
- ❒ IPV, DTaP, PCV, HiB, and second HBV at sixty days of chronological age
- ❒ Rotavirus on the day of discharge
- ❒ Synagis™ if the discharge occurs in December.
- ❒ Our NICU does not administer vaccines; the baby will receive these first "shots" in the pediatrician's clinic

Hypothetical Case, Baby B is an ex-34 $^{3/7}$ weeker who had an uneventful NICU course, is now 21 days old chronologically, and ready to discharge home:

37) What screenings will be done (or have already been done in the NICU before Baby B's discharges home? (Select all that apply.)

- ❒ Metabolic
- ❒ Hearing
- ❒ Critical congenital heart disease
- ❒ Carseat challenge
- ❒ None of the above

38) Before Baby B is discharged from your NICU, how will s/he receive the first HBV vaccine?

- ❒ Day before or day of discharge from our NICU
- ❒ 21 days of age is too early to administer HBV#1
- ❒ At his/her first pediatrician/clinic visit
- ❒ After 30 days of age in the pediatric clinic
- ❒ Unknown

39) Which of your NICU's discharge practices do you think are responsible for preventing re-hospitalization of babies within 30 days of NICU discharge?

40) Based on your experience in the NICU what discharge practices do you think are responsible for the best outcomes for discharged babies from the NICU?

41) Which discharge practices do you think should be added to your NICU's practices to improve good health outcomes for the baby or to reduce re-hospitalization of babies within 30 days?

Appendix C: Abbreviations

Abbreviations	
AAP	American Academy of Pediatrics
ACOG	American Congress of Obstetricians and Gynecologists
AHRQ	Agency for Healthcare Research & Quality
APRN	Advanced Practice Registered Nurse
BFUSA	Baby Friendly USA
BRN	Board of Registered Nursing
CCS	California Children's Services
CDC	Centers for Disease Control and Prevention
CDHCS	California Department of Health Care Services
CFN	Committee on Fetus and Newborn
CMMS	Centers for Medicare and Medicaid Services
CNS	Clinical Nurse Specialist
CPQCC	California Perinatal Quality Care Collaborative
DC	Discharge
EBP	Evidence-Based Practice
ECMO	Extracorporeal Membrane Oxygenation
FCC	Family-Centered Care
FTE	Full Time Equivalent
HRIF	High Risk Infant Follow-up
IPFCC	Institute for Patient- and Family-Centered Care

Abbreviations (continued)

IRB	Institutional Review Board
KC	Kangaroo Care
LOC	Level of Care
LPI	Late Preterm Infant
NANN	National Association of Neonatal Nurses
NICU	Neonatal Intensive Care Unit
NP	Nurse Practitioner
PCP	Pediatric Care Provider
PTSD	Post-Traumatic Stress Disorder
RN	Registered Nurse
SIG	Special Interest Group
TJC	The Joint Commission
VLBW	Very Low Birth Weight (less than 1500 grams)
VON	Vermont Oxford Network