Family-Centered Developmental Care Practices and Research

What Will the Next Century Bring?

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ABSTRACT

Family-centered developmental care is an essential element of neonatal intensive care. It is of particular importance when the infant is vulnerable and at greater risk for poor outcomes complicated by a family unit that is easily challenged by the unique needs of the infant. Yet, all infants and their families deserve this philosophy of caregiving. Family-centered developmental care must continue to be tested through research to determine which interventions work, what does not work, and which interventions need further refinement. This article provides a brief history of where we have been in neonatal caregiving, provides definitions for family-centered developmental caregiving and offers some “predictions” about where these practices need to be in the next century. Research questions and strategies are also addressed. As we continue to forge ahead integrating this philosophy into the caregiving arena, it is important to remember that there are many unanswered questions.

Key Words: family-centered developmental care, holistic caregiving, long-term developmental outcomes, macroenvironment, microenvironment, neonatal intensive care unit

Historical underpinnings of neonatal caregiving

Neonatal caregiving had an unlikely beginning with preterm newborns taken from families, classified as feeble and weaklings and displayed as oddities to the public. Yet, we learned from those beginnings how to save the lives of these infants. With the advent of miniaturization of technologies for neonates, high-risk infants could be monitored, ventilated, and transported in incubators to regionalized centers for specialized care. Neonatology was conceived as a specialty and is...
thrive with multiple subspecialties and many collaborating raters within the interdisciplinary team and only recently, families were considered partners in these caregiving teams.2–4 Neonatal scientists and practitioners working together led the way in helping us to better understand that saving lives was not enough. The quality of life for vulnerable high-risk preterm infants and their families after newborn intensive care needed to be considered and thus, early intervention was tested and found to make a difference.5,6 Later in 1986, Public Law # 99-457 Part H made these services more available to at-risk infants and families.7 This law placed the focus of care within the context of the family in the home environment and encouraged collaboration among health professionals. Early intervention was brought into the NICU because the law alleged that early intervention must begin at birth for at-risk infants. As we learned more about the interaction between attachment and development, the NICU opened its doors to families with 24-hour visiting, routine family meetings and finally, families participating in rounds and sharing in all areas of caregiving and decision-making.8,9 The partnership between healthcare providers and families remains tenuous in many NICUs. Yet, as we consistently invite families to be members of the caregiving team, they are visitors no more; they are our partners. In this philosophy of care, families are essential caregivers in the NICU who share in every aspect of care for their vulnerable high-risk infants.

Neonatal care has continued to evolve with an increasing focus on brain development, its plasticity and how we must consider the long-term neurodevelopmental effects in everything we do.10,11 Brain development in the NICU and during early infancy emerges at an unprecedented rate. Unique neuropathways are developing based on the interplay of the infant’s genetic makeup and the experiences she encounters.10,11 It is now accepted knowledge that infants are active participants in their own development and can interact and react to the environment around them.10,11 With this knowledge, the importance of providing an appropriately stimulating environment for infants is increasingly recognized.5,12 Family-centered developmental care fosters brain development that manifests itself in later learning and behavior.10–12 Follow-up care for these infants has also become an important aspect of neonatal caregiving, acknowledging that success is not just getting the infant and family out of the NICU.

What is family-centered developmental caregiving?

Family-centered developmental care is an essential element of newborn care. Provision of such care is not a new trend, however, our understanding of the short- and long-term implications are only just beginning to be revealed.13–16 Of late, this aspect of caregiving has received heightened attention, but it is important to remember that as recently as 2002 developmental care was listed as a useless therapy in a professional journal and many aspects of the caregiving philosophy are not routinely implemented in NICUs across the country or around the globe. Fundamental to these caregiving interventions is a heightened awareness of the short- and long-term effects of the macro- and microenvironments on both the infant and their family in the NICU.17–18

Family-centered caregiving acknowledges that the family is central to the care of the infant (child) and that if interventions are to have long-lasting effects the family must be a focus for implementation and evaluation.5,14,19,20 Family-centered care can be provided without providing developmentally supportive caregiving, however, in the truest sense of the definition the reverse is not true.20–22 Developmentally supportive caregiving strategies have a greater potential for long-lasting infant effects when the family is an integral aspect of implementation.8,9,19–22

Experiences shape who we are in so many ways, and as such, the family is integral to the provision of family-centered developmental care.10–12 Although the neonatal intensive care environment, with all of the technologies and health professionals, saves lives there are also long-lasting negative effects related to the noxious overstimulating environment. Developmentally supportive interventions in the NICU are strategies that support the infant to develop as “normally” as possible given the abnormal and noxious environment of the NICU. Implementation has begun to be tied to patient focused short- and long-term outcomes as well as quality care.21,22 Yet much remains unknown about how these interventions will effect long-term family dynamics and ultimately the child’s overall development.19–23 Now is an exciting time for neonatal nurses, other health professionals, and parents interested in promoting this philosophy of care. However, there is still much work to be done before all neonatal health professionals embrace the concepts of family-centered developmental care as fundamental to every caregiving practice in the NICU.

With the advent of family-centered developmental care, neonatal care has become less stereotypic, and more individualized to meet the needs of a particular infant based on individualized developmental assessments.24,25 These changes have primarily been spearheaded by Dr Heidelise Als and her team with the implementation of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP).25,26–28 Relying on the synactive theory and systematic NIDCAP observations of an
infant's behavior, an individualized plan for caregiving is developed.26 This program continues to guide practices and the integration of developmental care practice into routine caregiving in many NICUs in the United States and around the globe. Even those units that do not have trained NIDCAP trained professionals or an active program are influenced by its concepts and findings.

In addition, the Universe for Developmental Care is a new conceptual framework.27 It builds on the theoretical underpinnings of developmental care but extends it to include the Institute of Medicine's emphasis on patient focused care, safety, and quality improvement. In addition, core measures have been designed to provide objective parameters about the implementation process as well as to target where more emphasis is needed.28 This movement to bring these different concepts together will potentially shape practice, education, and research in the future of neonatal caregiving. There still remains is so much more that needs to be addressed. Outlined below are a few essential strategies for continuing to advance the practice and integration of family-centered developmental care into routine caregiving in the NICU:

- Increasing recognition by all health professionals that family-centered care is an essential aspect of individualized, developmentally supportive care, and is an essential foundation for all neonatal caregiving.
- Recognition that family-centered developmental care is interdisciplinary in nature and is an evolving change in the philosophy of care.
- Acceptance that an "elite group" of trained professionals will never move the masses forward toward understanding of family-centered developmental care as a standard of care. This change must come from within all neonatal healthcare professionals.
- Future research is strategically targeted to fill the gaps in the current evidence to support family-centered developmental care.
- Increasing evidence at high levels (best evidence) to support the use of family-centered developmental interventions and strategies is essential for full implementation. For example, research must be at the highest level and well-designed, randomized, controlled, clinical trials must be conducted to demonstrate the effectiveness of family-centered developmental care. However, it must also be noted that not all family-centered developmental strategies can be ethically studied in these frameworks (randomized control trials and other experimental designs) and other research frame-works must become acceptable to move the science forward.
- Cost analyses (using an economics model) of family-centered developmental care models and strategies are essential to understanding the full scope of implementation of family-centered developmental care.
- All stakeholders must be involved in implementation and evaluation of family-centered developmental care. This includes all disciplines, professional associations, and parent groups.

INTERDISCIPLINARY NATURE OF FAMILY-CENTERED DEVELOPMENTAL CAREGIVING

Moreover, direct caregivers of all disciplines, researchers, professional associations, and parent groups must work together to promote a change in practice that is "owned" by all and not turfed to any one discipline or group for implementation and evaluation. This is particularly true since collaborative caregiving is fundamental to the implementation of family-centered developmental care. Each discipline brings a rich history and perspective that is needed to embrace and deliver developmentally supportive care.2 We need a common language to move this goal forward and share in the vision of positive long-term developmental outcomes; the priority focus of providing family-centered developmental care.29 To continue to change this mindset, professionals from all disciplines must collaborate to support the full integration of developmental care into routine caregiving practices.2,29,30

Implementation strategies

Reducing and eventually decreasing short- and long-term outcomes requires a multimodal strategy. As we continue to move toward evidence-based “Best Practices” in the NICU, integration of family-centered developmental care practices into caregiving bundles must continue to be a priority. A care bundle is a systematic way to provide all elements of the care outlined in the bundle consistently and in concert to be successful. Research has shown that grouping essential caregiving tasks such as assessment techniques and treatment modalities with family-centered individualized developmental caregiving interventions into comprehensive “care bundles,” helps staff in the caregiving arena across disciplines remember to take all the necessary steps to provide optimal care to every patient, every time.31 A breakdown in the system (skipping a step or leaving an intervention out) has the potential to increase neonatal morbidity and mortality.
One might not believe that implementation of care bundles is congruent with the philosophy of family-centered developmental caregiving yet; we may not be able to choose what treatment modalities to deliver to provide best care. We can, however, choose to provide them in a way that is individualized and developmentally appropriate for a unique infant and family at this time. An essential aspect of bundle development is coming to consensus about how the interdisciplinary caregiving team provides individualized family-centered developmental care within comprehensive caregiving bundles for this type of patient or during this type of event is important to improving both short- and long-term outcomes. For example, neonatal caregivers are often faced with providing interventions that may be painful or have noxious side effects. The treatment modality may be necessary for provision of best medical care. Caregivers may not be able to decide to forgo the treatment but they can decide how to provide it in an individualized family-centered developmental way that is supportive of the infant and ultimately decreases both short- and long-term effects.

Providing care in this way acknowledges that care can be individualized while also making sure we follow a routine to be consistent in meeting the needs of all infants and families. Using this type of caregiving philosophy, we will provide care that is humane and acknowledges there are better ways to provide these assessment techniques and treatment modalities. Healthcare providers do have a choice about how interventions are delivered. Discussions can be difficult but they must occur and consensus must be obtained from all members of the interdisciplinary team for best caregiving outcomes to occur consistently. For example, preterm infants do need regular eye examinations to screen for development of retinopathy of prematurity and there are better ways to support the infant during these painful and noxious examinations.

One example of a bundle being tested for best practices and care delivery for the routine heel lance (currently under development by the Neonatal Node of the Joanna Briggs Evidence Based Practice Institute in Australia). For example, the heel lance bundle includes a parent or caregiver supporting the infant during the procedure, encouraging mothers when available to breastfeed during the procedure and promotion of comfort either with a pacifier or a pacifier dipped in sucrose. Identifying these areas in the bundle makes provision of family-centered developmental care an essential aspect of the bundle but still allows for some individualization based on the infant and the family. The bundled strategies together make a difference in the outcome not the implementation of just any one single assessment or treatment modality. Defining successful caregiving in this fashion encourages every member of the interdisciplinary caregiving team to work together and find new ways to consistently provide the right care for each patient in every situation.

Although many institutions have long followed these practices by implementing caregiving standards and policies to improve outcomes in and around childbirth and newborn care, the key is consistently using all the caregiving practices in concert as appropriate to meet the individualized needs of the infant and family. Care bundles need to be tested and must be in adherence with published best practices and national standards established by leading neonatal and newborn’s health groups, such as the National Association of Neonatal Nurses, the Association of Women’s Health, Obstetric, and Neonatal Nurses, the Vermont Oxford Network, and the National Institute for Health—Neonatal Network as well as the Center for Disease Control and the Agency for Healthcare Research and Quality. In addition, benchmarking with other like institutions can provide another avenue for assessing the quality of care delivery. Other frameworks and methods of quality improvement must also be considered such as plan, do, study, and act.

Research strategies
Neonatology is a relatively young area of medicine and as such, there is still much to learn about all aspects of neonatal care. Most of what we know about family-centered developmental care interventions is still tentative and more evidence is needed to support the outcomes of these practices. Both procedural and substantive research questions need to be answered. Interdisciplinary teams need to collaborate to conduct the research and answer these questions. The research to-date is not as powerful as it could be; the designs are weak with small sample sizes making replication, or generalization of the results difficult. More ways to measure and test developmental interventions need to be designed. Even so, the plausibility of family-centered developmental care intervention appears logical and credible. As such, we have provided a short list of the research that is desperately needed to support this trajectory. This list is not intended to be exhaustive but it is provided as a means for reflection about where research appears to be most needed.

POTENTIAL RESEARCH QUESTIONS
• What caregiver delivery models will facilitate healthcare professionals to move beyond a disease and procedural-based orientation to caregiving, facilitating movement to incorporate a
broader more holistic view that encompasses family-centered developmental care?

- Would NICUs more readily implement some form of family-centered developmental care if specialized training were made available, readily accessible, and affordable?
- How can psychometrically sound family-centered developmental care research be initiated and completed across diverse caregiving settings?
- How can we best test different approaches to the delivery of family-centered developmental care such as NIDCAP and/or Universe of Developmental Care?
- What is the ideal NICU to support both short-term outcomes and long-term development? Especially, since both the micro- and macroenvironment must be considered.
- What is the best way to support developmentally appropriate positioning in the NICU? What are the most developmentally appropriate positions and for which infants and at what time? How can families be an important aspect of supporting best positioning for infants in the NICU?
- How can acuity tools be redesigned to account for the time required to provide family-centered developmental caregiving? How do we deliver family-centered developmental care that is cost effective and timesaving?
- How do staff knowledge, attitudes, and beliefs about family-centered developmental caregiving affect the implementation of these practices and how can these attitudes be changed?
- What methods can be used to improve communication around caregiving in the NICU? This might include communication about caregiving that sometimes gets lost in the current system as well as communication between disciplines as well as communication with families.
- How do we affect organizational changes that will promote or facilitate the integration of family-centered developmental care?

CONCLUSIONS

Individualized, family-centered developmental care is growing in importance as an essential healthcare foundation for caregiving of infants and families. Where must it go in the future? Listed below are some predictions we have made for family-centered developmental care in the next century.35 We believe that only with continued changes in attitudes and beliefs about this philosophy can these predictions become real and as such the list of predictions is important for understanding where this philosophy is headed. The predictions also provide a clear understanding of the essential elements and continuing to reflect on where we want to go will keep us all on track.

1. Family-centered developmental care will be embraced as fundamental to healthcare with newborns, infants, and families.
2. Family-centered developmental care will not only become a part of standard orientation and continued competency evaluation for health professionals in the NICU; it will become the driving force for all aspects of neonatal care.
3. Families will be full partners in caregiving in the NICU.
4. Family-centered developmental care will be the basis for collaborative caregiving and an expectation throughout both the perinatal and neonatal period.
5. Family-centered developmental care will be a model for interdisciplinary education and healthcare management.
6. Evidence will mount to support positive healthy outcomes for newborns, infants, and families when developmental care is the overarching philosophy of care.
7. Interdisciplinary research studies will increase to examine all aspects of developmental care.

In summary, family-centered caregiving must be embraced as a philosophy underpinning neonatal care that is deemed essential care. As such family-centered developmental care is an essential aspect of providing excellent, clinically sound care to every infant and family who enters the healthcare arena. The developmental care movement will only continue to move forward if there is support from all levels of professional education and practice. We believe that this philosophy is now “standard care” with a foundation, which includes professional knowledge that any professional who has contact with newborns and infants needs to provide holistic, individualized, infant, and family-centered care.36 Share the vision with others; if the vision is not shared and the “policy” sits in a manual, family-centered developmental care will not continue to gain momentum and our predictions will not be realized. Every neonatal caregiver must work together to make this our guiding philosophy of care; the babies and families will thank us for our efforts!

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