

Developmental Observer

The Official Newsletter of the NIDCAP® Federation International

NIDCAP Federation International (NFI)

Founded in 2001, the NFI is an international, non-profit membership organization. The NFI encourages the implementation of developmental care and assures the quality of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) approach in all intensive, special care and newborn nurseries around the world. The NFI serves as the authoritative leader for research, development, and dissemination of NIDCAP, and for the certification of trainers, healthcare professionals, and nurseries in the NIDCAP approach.

“Learn to get in touch with the silence within yourself, and know that everything in life has purpose. There are no mistakes, no coincidences, all events are given to us to learn from.”

ELISABETH KUBLER-ROSS

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The Importance of Silence

Heidelise Als, PhD

“Eloquium est argentum; silentium est aurum.”
(Speech is silver, silence is gold.)

OLD ROMAN SAYING

“Don’t speak until you can improve on the silence.”

ATTRIBUTED TO HENRY SIMMONS, MD,
MPH, FACP, 1990



We all know the challenge of supporting nurseries to become calm and quiet places where an infant may hear the soft comforting murmur of the parents’ voice speaking or singing. The deleterious effects of high levels of “noise” in nurseries, toxic to all, infants, families and staff alike, are undisputed. It is all the more important, therefore, to meet the challenge we face in the nursery by first becoming steady and trustworthy sources of calm and quiet ourselves. Finding and maintaining the silence within so that we may assist others is a continuing process and often a real struggle. Our environment is polluted with sound, taxing and toxic to our well-being. What is it about humans that making noise is such a pervasive phenomenon? Our car doors beep when we open them and again when we close them; beeps remind us to take action with our seatbelts, washing machines and coffee maker alarms. Pedestrians walk about with ear buds that pipe music or podcasts, often loud enough for others to hear, directly into their ears and brains. Waiting rooms are pervasively equipped with television sets often set at high volume levels and non-adjustable. Airports, already oppressive with loudly rattling and clanking luggage carousels, provide travelers with continuous announcements and television newscasts set to increase in volume automatically when a plane arrives and passengers come through the gate into the waiting halls. We attempt to be heard in conversation by speaking at high volumes against this background din. Neighborhoods and whole towns complain about the noise pollution from commuter trains, truck and bus routes; some even must endure life beneath the flight paths of local airports. Communities insist on highway walls to gain at least a psychological protection.

Every so often when it becomes all too much, we attempt to regain our balance, “flee into nature,” leaving our electronic devices behind to refresh ourselves, or so we hope, in the quiet and silence of a forest, the mountains, a lake or the ocean. Nature’s sounds differ remarkably in their effects on us from the sounds we generate through our technological advances. We fail to recognize this disconnect and as a result our industries spend too little effort on designing and producing psychologically friendly, that is, quiet equipment. Too little aware of our deeply rooted biological vulnerability, we attempt to overcome our sub-cortical responses by cortical override. While our brains have developed impressive habituation mechanisms, this habituation comes at a high cost and this cost often takes us unawares.

At the beginning of every summer my family and I take our first hike of the season up Little Deer Leap in Central Vermont. It is a grade-3 hike, which takes about an hour and a half up. It is well worth the beautiful view of Pico Peak, the north face of Mount Killington, the Coolidge Range, and the Sherburne Pass. While we walk, after leaving the car at the trail head, the woods become ever quieter; our steps stir up leaves and an occasional rabbit or partridge. The wind's rustle in the trees is soothing and familiar. Yet, finally at the top, looking forward to the rest and view, I am always disappointed, remembering the reason for my annual, yet quite ineffectual, resistance to this particular climb. A strange distant rumbling permeates the quiet. My husband and the children respond to my discomfort by asking: "What rumbling?" to which I reply "Can't you hear the traffic way down on Route 4." Edging to the ledge drop, we see it down in the valley, the ant trail of cars up and down the highway. In vain, I attempt to tune out the sound. Everyone else seems to delight in nature's peacefulness.

"One Square Inch of Silence"

Hardly a place remains in the world that is truly silent, still, tranquil. This, almost spiritual quality, is necessary for silence of the mind, an inner peace and a clearing of our pressing thoughts and preoccupations. To "hear silence," brings openness, inner quietude, an attunement to nature's sounds, and to our inner selves.

There are fewer than a dozen quiet places left in the US, places where natural silence reigns over several square miles. Quiet is now measured in minutes, the number of minutes of the absence of noise encroachment. A silence of 15 minutes is extremely rare in the US and long gone in Europe, except in the northern most regions of Finland and Norway¹ (p 13). Our ever higher consumption of fossil fuels and the technologies they promote translates into more and more noise pollution. "Even far from paved roads in the Amazon rain forest the drone from distant outboard motors on dugout canoes and from the beep from a digital watch of the guide"¹ (p 13) intrudes on the sounds of nature.

In the US, the national government protected parks provide the hoped for places of escape from the noise and bustle of everyday lives. Gordon Hempton, one of the few acoustic ecologists, has mounted a national campaign to protect at least "One Square Inch of Silence" in the Hoh Valley in the Olympia

National Park in Washington State. He quotes William H. Stewart, Surgeon General (1965-1969) under L. B. Johnson, "Calling noise a nuisance is like calling smog an inconvenience"¹ (p 207).

Air-tourism is on the increase. Olympic National Park is the most likely area in the US to retain its natural quietude due to almost continuous rain or overcast skies, reducing air tourism. Yet even this pristine acoustic environment receives no special protection. Tours on demands such as those offered by Vashon Island Air advertise: "We fly past Mount Olympus and deep down into the Valley of the Hoh River, the only non-tropical rain forest in the World." And not a single person on the Park's staff is trained in acoustic ecology. Business and profits trump silence. How long will Hempton be successful in protecting his "One Square Inch of Silence?" By the time a single airplane's sound has travelled far enough to dissipate below audible levels, many square miles have been polluted. And anyone seeking solace will feel disappointed, "unbathed" by the cleansing power of quiet.

The Omnipresence of Anthropogenic Sound

Sound resulting from the influence humans have on the natural world is termed anthropogenic sound. This sound is for the most part noise, i.e. sound that is loud and/or unpleasant or that causes disturbance; it may have irregular fluctuations that accompany a signal but are not part of it and tend to obscure it; it may be confused, senseless and it is always undesired. Noise has become a modern plague found everywhere, at all times, and often at unsafe levels. It has become so prevalent that we take it for granted. It is so overlooked, and so systematically unmonitored that it is not included among the metrics that constitute more than 150 countries' rankings in the Environmental Performance Index (EPI)² (Fig. 7, p. 18) annually issued by the Yale University Center of Law and Policy to monitor the protection of human health and the protection of ecosystems from environmental harm. Nine issues with a total of twenty indicators are addressed: Health Impacts (Child Mortality); Air Quality; Water and Sanitation; Water Resources; Agriculture (Pesticide); Forests (Change in Forest Cover); Fisheries (Fish Stock); Biodiversity and Habitat Protection; and Climate and Energy. But noise pollution is not among them. Meanwhile our cities grow more toxic with noise, and we "drift towards a nation of shouters. The sound of our footsteps has all but disappeared"¹ (p. 322).

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 gretchen Lawhon, PhD, RN, CBC, FAAN
Associate Editor for Science Jeffrey R. Alberts, PhD



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Archeo-Acoustics

This has not always been so. Our world used to be much quieter. So quiet in fact that until recently anthropologists paid little attention to the acoustics of ancient environments, thus overlooking the implications and impact of such quiet daily living conditions. Emergence of the novel fields of “acoustic anthropology” and “archo-acoustics” reflects the increasing interest in this topic. Steven J. Waller, a biochemist and acoustic anthropologist by avocation, describes a natural occurring acoustic phenomenon appreciated by many early civilizations, which had been intentionally reproduced, to break the silence of earlier times, namely echoes. Echo myths are found in many cultures, often attributed to supernatural entities,³ such as the Native American tales of spirits who speak through portals in rock walls. These ancient myths show that echoes were widely worshipped as divine gods, were considered to be the “earliest of all existence” and were systematically sought out.

When not found naturally, they were created. Ancient builders designed subterranean soundscapes as stirring as any modern movie special effect. When priests at the temple complex of Chavín de Huántar in Central Peru sounded their conch-shell trumpets 2,500 years ago, tones magnified and echoed by stone surfaces seemed to come from everywhere, yet nowhere, supernatural and otherworldly. But there was nothing mysterious about their production. According to archaeologists at Stanford University, the temple’s builders created galleries, ducts, and ventilation shafts to channel sound, displaying not only expert architectural skill but also acoustical engineering prowess.^{4,5}

The findings add to a growing body of research suggesting that controlled natural sound was more important to our ancestors than archaeologists once realized. Today we live in a less thoughtfully controlled sound-saturated society, full of iPods, thunderous special effects in movies, and thousand-watt boom car stereos. These modern acoustic environments result in sonic cacophony while our ancient ancestors may have sculpted their soundscapes in an attempt to reach the divine.

Until very recently, archaeology has been strictly visual.⁶ The acoustic studies at Chavín de Huántar and elsewhere show the value of broadening the field of archeology into acoustic archeology and helping us understand the roots of our manufactured sound world.

The Dangers of Modern Anthropogenic Noise

In stark contrast to the purposeful spiritual, even mystically intended sound phenomena, our modern day technology-generated pervasive sounds not only have little to do with the spiritual but are destructive. Here a few examples.

“Where have all the songbirds gone?” is a popular lamentation of today’s bird watchers. The Audubon Watchlist in 2000 listed 25 species of US songbirds in decline; by 2007, 59 species were on the endangered list and an additional 119 species were listed as near endangered. Climate change is a big issue and noise pollution goes hand in hand with climate change. Increase in fossil fuel production underlies both. Our landscapes are losing their voice. Bird song-ranges are shrinking. Birds have been found to adapt their songs so as to be heard above the din



Photography by Christopher Hopkins Ais Duffly

Being and becoming occurs in being held, being in the moment. Are we prepared?

of rural and urban noise pollution. And whole song repertoires already have been lost. Human activity has caused an, in evolutionary terms, sudden rise in, especially, low-pitched noise levels.^{7,8} These frequencies are detrimental to birds through direct stress, masking of predator or associated danger calls, and by general interference with acoustic signals, which serve mate selection, offspring protection, and territory defense. Significantly reduced reproductive success has been documented in noisy territories.^{9,13}

Similarly toxic noise effects have been documented in oceans where they affect large mammals such as dolphins and whales. Oil industry’s seismic explorations and drilling, the low rumble of the ever growing number of commercial ships and, likely most harmful, military sonar, have been implicated in the increasingly high number of dolphin and whale strandings and deaths. Despite these concerns all efforts to modify or eliminate, especially military sonar emissions, have been overruled by presidential decision claiming paramount security interests of the US.^{14,16}

The word “noise” stems from Latin *nausea*, meaning disgust, annoyance discomfort, and literally seasickness. The later Old Provençal *nauza* refers to quarrel. For humans noxious sounds and smells are impossible to ignore, processed by sense receptors which have evolved specifically to protect us from toxins. While we have passed odor laws, we are slow to acknowledge the need for noise pollution laws.

William Stebbins¹⁷ points out that in the course of evolution mammals capitalized on the sense of hearing more than any other vertebrate or invertebrate group. The range of human hearing far surpasses the requirements to hear spoken language or even to appreciate music. Human hearing graphed by frequency range and decibel level shows that human speech encompasses the center of the range. Sounds produced by musical instruments and appreciated by the human ear extend well beyond the human vocal range. Yet even beyond the sound range of our musical instruments there are many sounds, namely natural sounds that the human ear is capable of perceiving. Human hearing is exquisitely sensitive.

Moreover, the human hearing mechanism is always turned

on.¹⁸ After humans have habituated to a sound, and even in sleep, the human body nevertheless responds to noise. The elicited nervous system, hormonal and vascular changes, the fight or flight response, has far reaching consequences. Noise, even at levels that are not harmful to hearing is perceived subconsciously as a danger signal, alerting epinephrine, nor-epinephrine and cortisol level secretions.¹⁹ And loud enough noise leads to hearing loss: The World Health Organization (WHO) based on the work of Berglund and Lindvall²⁰ among other research, recommends that unprotected exposure to sound levels greater than 100 dB, (jackhammers, snowmobiles), should be limited in duration (4 h) and frequency (four times/yr). The threshold for pain is usually given as 140 dB (boom-cars). Adults should avoid exposure to *impulse noise* (gunfire and other intense brief bursts e.g. from firecrackers, cap pistols, and other toys) above 140 dB with a limit of 120 dB for children. Exposure may result in sudden and permanent hearing loss. Levels greater than 165 dB, even for a few milliseconds, are likely to cause acute cochlear damage. As stated by the League for the Hard of Hearing: “Ears do not get used to loud noise - they get deaf.”

Even when not leading to hearing loss, noise pollution interferes with spoken communication. By affecting language comprehension it may lead to a number of disabilities and behavioral changes such as problems with concentration, fatigue, uncertainty, lack of self-confidence, irritation, misunderstandings, decreased working capacity, disturbed interpersonal relationships, stress reactions and increased aggression. Some of these effects may lead to increase in the frequency of accidents, disruption in the classroom, and impaired academic performance.²⁰⁻²² Particularly vulnerable groups include children, the elderly, and those not familiar with the spoken language.²³

Despite the evidence of the medical, social, and economic effects of noise, including those incontrovertibly resulting from sleep disturbance, noise pollution is increasing in our cities. It impairs the ability to enjoy one's property and leisure time and increases the frequency of antisocial behavior.

Noise makers and the businesses that support them are as reluctant as smokers to give up their bad habits. It is clear from the statistics on reduction of smoking, that laws can change undesirable behavior; laws could also change noise reduction in ways that would benefit society as a whole.

The Urgent Importance of Chosen Silence

As a direct response to the continuous auditory assault, many are choosing to offset the toxic effects with chosen silence, be it through yoga, retreats, meditation or other silent practices. Historically, chosen silence has been linked to religious practice such as the vows of silence taken by Christian monastic orders and also known as *Mauna* [the Silent One] in Hinduism, Jainism, and Buddhism. Examples from antiquity are Pythagoras of Samos (circa 570 – circa 495 BC), the Ionian philosopher and mathematician, who imposed a strict rule of silence on his disciples; in ancient Roman religion, the Vestals or Vestal Virgins (circa 720 – circa 380 BC), priestesses of Vesta, goddess of the hearth, also were bound to severe silence for long years. Prophets have gone into the wilderness for long periods of silence and

meditation. Christian religious orders such as the Benedictines, Cistercians, Trappists, Carthusians, and Carmelites incorporate silence to this day as one of the essential rules of their communities. Other examples are Days of Silence such as Good Friday in the Catholic tradition or the Sabbath in Judaism, intended to promote better understanding of and dedication to a higher being, to achieve enlightenment. Often such religious or spiritual accounts accept “ineffability” i.e. the effects of such silence cannot be readily expressed in words. True mystics and hermits of both Western and Eastern traditions typically have little to say about their experience of silence. For instance, the biographer Vicky Mackenzie²⁴ reports that Jetsunma Tenzin Palmo, a British Buddhist nun, who spent three years high in the Himalayas in radical silence, publically said only: “Well, it was not boring.”

Since the 18th century there are more secular sources of silence stories. The Romantic Movement writers like William Wordsworth and Henry Thoreau, while theist in their understanding yet militantly non-religious, emphasized the value of nature and silence. Onward from the mid-nineteenth century many accounts speak of lone adventurers, explorers of remote areas, mountain climbers, solo sailors, hikers, even swimmers, solitary by choice, they seek silence and remove themselves from their social day to day environments. They also largely tend to be mute about their inner emotions as if it defeats the very nature of their experience. In “A Book of Silence” Sara Maitland²⁵ reports an extraordinary example referring to the Sunday Times sponsored, first “Golden Globe” race in 1968, of sailing single handedly nonstop around the globe (pp. 43-45). Two experienced solo-yachtsmen, Robin Knox Johnson and Bernard Moitessier independently from one another and the Times “Golden Globe” race had already decided and prepared to navigate the globe. The race therefore was framed such that it was impossible not to enter, by default making both participants. Moitessier announced that the very idea of such a “Race” made him nauseous. He had made a “pact with the gods” in reparation for what he considered an earlier “dishonest” book that he had written. Participation in the “Race” would sully the whole enterprise. Nine yachtsmen were entered in the race. Only one finished, Robin Knox Johnson. For all others it was not the sailing itself that proved the hurdle, no one was killed by the waves or the wind, but it was the emotional response to it. Their will was altered by the silence and isolation. For instance, Moitessier chose to round the Cape of Good Hope a second time, headed back across the Indian Ocean from whence he had just come; on into the Pacific, finally landing in Tahiti. In his diary he wrote: “I really felt sick at the thought of getting back to Europe...; does it make sense to head back for a place knowing that you will have to leave your peace behind?... I feel a great strength in me. I am free, free as never before. Joined to all nonetheless, yet alone with my destiny.”²⁶ (p. 164),²⁵ (pp. 56-57). This experience of strength and freedom is what Maitland²⁵ considers a common effect of such chosen silence.

Maitland describes a recognizable sequence of emotional experiences of being in silence, based on her review of many accounts by others and on her own six-week period of planned silence living alone in a small cottage on the Isle of Skye, the most northerly island of the Inner Hebrides of Scotland. She recounts,



Every so often when it becomes all too much, we attempt to regain our balance, “flee into nature”, leaving our electronic devices behind to refresh ourselves...in the quiet and silence of a forest, the mountains, a lake or the ocean.

that the first result is an extraordinary *intensification of physical sensation*, smells, taste, listening and hearing sounds such as the wind, the song of a bird, the experience of seeing color, the sensations of temperature, cold, wet, warm etc. Sensations become direct and total. As Maitland puts it: “It felt entirely NOW and physical”²⁵ (p. 49). This then leads to an intensification of emotions, with crying, laughter, excitement, and anxiety quite disproportionate to the occasion, yet normal appearing at the time. Next is the experience of disinhibition. Those living in planned silence may abandon their daily routines of personal hygiene and customary dress codes as “banal vanities.” The public self becomes stripped away “leaving the true self naked” as arctic explorer and geologist Augustine Courtauld stated, having lived for five months in complete solitude in a tent on top of the Greenland ice-cap²⁷ in²⁵ (p. 54). A third experience Maitland²⁵ describes is that of hearing voices, often perceived as helpful and joyous rather than worrisome or pathological, and apparently serving communication of one’s stressed self to one’s more optimistic self. Additionally, natural sounds may become imbued with language-encoded meaning. The wind or ocean waves seem to be speaking or singing. Pinker²⁸ describes the “language instinct,” as the instinct to make sense of what one does not understand, a translation into language of non-language phenomena. Our brain is an efficient interpreter of sound. As John Cage,²⁹ composer and music theorist, has said: “There is no such thing as ‘real’ silence. There is always some sound, even if it is only the sound that our body makes, our breathing, our heart beat.” Finally, Maitland speaks of the feeling of being given an incredible gift which she terms “givenness”²⁵ (p. 62). It engenders an indescribable joy, a bliss, intense happiness that moves into a feeling of “oneness” and an extraordinary sense

of connectedness, a connectedness to the universe, to absolutely everything²⁵ (p.63), a feeling of communion and complete peace and certainty of being, without “pride or fear or surprise ... where each thing is simple... free to the right, free to the left, free everywhere”²⁶ (p. 164),²⁵ in (p. 65). This gift of connectedness is both integrative and connecting the self to something larger, the world, the other. Feelings of a loss of boundary between the self and the other, the self and the cosmos, even a sense of boundary confusion may occur at this stage. It may become harder to keep track of time, and track of danger. A certain exhilarating daring, almost a state of rapture may ensue, where everything appears feasible and delightful. Maitland interprets it as a shaking off of the rules, boundaries and safety codes of daily life, of the culturally instilled protection from and fear of risk taking. Such liberation seems freeing, induces joy and even giddiness, as a child might experience when taking a daring step. It engenders a “thrilling peril”; “a state of bliss that is simultaneously fiercely joyful” for which Maitland²⁵ (p. 74) uses the French term “jouissance,” a joy that bypasses the moderating and mitigating influences of reason, an “over the top,” unmitigated joy, as children experience quite naturally and that Wordsworth bemoans because of its fleeting nature in his “Ode: Intimations of Immortality from Recollections of Early Childhood.”³⁰ Prolonged silence appears to help us regain this state of “exhilarating consciousness of being at risk, in peril”²⁵ (p. 78), this sublime daring, even if only for limited periods. The ineffability of experience ties in with the feeling of bliss.

The lasting benefits of planned silence experiences connect us back to ourselves and those around us, “without pride or fear or surprise” to use Moitessier’s words. These are the personal attributes that our work as developmental professionals demands and expects of us. This is why the vulnerable infants and their families trust in us and our care. It is our professional responsibility to make room for such silence and its effects in ourselves, so that we can be ourselves fully.

Silence for years or months or even six weeks, as Maitland chose, is unrealistic for most of us. Yet the awareness of, and planned cultivation of the many moments of silence that offer themselves daily are feasible for all of us. The moment we pause in greeting a familiar bird, in watching a flower, observing a person, the pause of listening and tuning in, if only quite simply into our own breathing as meditation teaches us, this is well available to us all. And all of us have the power to cultivate actively an increased awareness of the intrusive, frequently gratuitous technology-based noise that we create ourselves. In doing so we can help to reduce and eliminate it; we have the power to educate, train and practice increased awareness of our often idle chatter, and our anxious over-talking to camouflage our fear of losing our public self, and “being naked”, our true selves. The practice of silence will give us the strength and the joy to hold the moment, and hold the other in the moment and in silence. Being and becoming occurs in being held, being in the moment. Are we prepared?

Acknowledgement: Krista Tippet’s interview with Gordon Hempton inspired me to write this column. The interview, entitled ‘The Last Quiet Places - Silence and the Presence of Everything’, was aired as part of her National Public Radio (NPR) Program Series ‘On Being’.



Treating Babies and Families Affected by Neonatal Abstinence Syndrome in the Newborn ICU

A New Challenge for Family-Focused Developmental Care

In the last several years, the number of babies identified as needing medical assistance to wean from narcotics, to which they were exposed in utero, has increased dramatically in many parts of the United States and in several other countries. This group of babies includes both infants whose mothers are enrolled in treatment programs in which they are provided methadone or buprenorphine, in the context of appropriate psychosocial therapy and supports, as well as infants of women struggling with an addiction to prescribed narcotics, illegally obtained narcotics, or “street drugs” such as heroin. In the last several months, a number of NICUs in our region have admitted more babies experiencing neonatal abstinence syndrome (NAS) with a census as high as a quarter of the NICU population. This relatively new group of babies has created challenges for all providers, but especially bedside nurses; on the positive side, many of the strategies and approaches found to be helpful in NIDCAP care of preterm infants are also extremely helpful in caring for these babies and their families.

Medical Issues

Mothers who are working to overcome their disease of addiction are often most effectively treated with medications such as methadone and buprenorphine, which combat their cravings and increase their chances of successful return to a productive life. They are typically counselled in their treatment programs that trying to “come off” these medications is medically dangerous to their infants, and increases their chance of relapse during this vulnerable periods.¹ Thus, despite the fact that between one half and two thirds of their babies will require medical intervention to wean off of their physiologic dependence on such drugs, these mothers are making the correct choice for the health of both themselves and their infants. After delivery, infants are observed for five days, a necessary period to determine whether the infant will show symptoms of withdrawal. Once these symptoms begin, structured symptom observation tools² are employed to try to quantify the degree of the baby’s symptoms, and make appropriate decisions about the amount and type of medication needed to diminish the infant’s symptoms. The same tools are then used to guide the gradual reduction of medication until the baby is symptom-free without medication.

Developmental Issues

Hospitals vary in their facilities available for the care of these babies and families. In some hospitals, babies are cared for in

typical newborn nurseries, which tend to be busy, active, noisy, and limited in parent participation space. NICUs with adequate support for parent participation, and a calm atmosphere, represent a step up in terms of meeting the needs of the infant and family. NICUs with single family room facilities allow families to stay with their infants in a supportive environment, and provide the comfort measures that have been shown to diminish symptoms and shorten the weaning process. Many of the strategies that are comforting for babies weaning off narcotics are very similar to those that support premature infants. Individualizing support based on the cues of each baby is critical. Clearly, nurseries whose staff are trained and supported in providing NIDCAP based care have many resources to support these babies. Infants often benefit from swaddling, sucking opportunities, skin-to-skin holding, gentle vestibular stimulation, limited environmental sound and light, and other strategies- which, of course, will change over time as the baby matures and need to be individualized in response to the cues of the infant. Additionally, awareness of the nutritional needs and feeding challenges experienced by some of these infants is critical to providing maximally supportive care.³

Family Support Issues

The long-term outcome of babies treated for NAS is clearly heavily dependent on the ability of their mothers to remain in treatment, to manage their disease of addiction, and to feel comfortable, confident and competent in the care of their infants. The last part of this statement applies to all families, but is particularly relevant in babies born prematurely or with other developmental challenges. Professionals supporting families impacted by addiction may find that their challenges are somewhat different than typically seen in parents without these issues, so that even if they have extensive experience in the NICU, they may need to educate themselves about the most effective ways to understand and support these families. There is limited published research on this issue, though a paper by Cleveland and Bonugli⁴ based on a small qualitative study, highlighted issues that were very consistent with the experiences of this author and other colleagues. They note that mothers with a history of substance abuse are disproportionately impacted by histories of trauma, abuse, mental illness, and other severe life stresses. They report often overwhelming feelings of guilt and shame, and are acutely sensitive to feeling judged and misunderstood by professionals.

While some of them find support in their extended families, others report rejection and judgment by family members as well. When nursing staff and other professionals reach out to these mothers and explicitly support their efforts, successes, and caring for their babies, these efforts are often deeply appreciated and potentially healing. Fortunately, the NIDCAP approach to care for all families in the NICU offers powerful strategies for supporting such communication. In the author's nursery, ongoing efforts are in place to support breastfeeding and skin to skin care, family involvement in understanding and contributing to the scoring of NAS scales, and daily communication with the medical team. Single patient rooms, with 24-hour parent participation, provide maximum opportunity for parents to be the primary caregivers for their infants, although for some families, this is a process that takes time and excellent communication skills to encourage their assuming what may seem like an intimidating role. The offer of a neurodevelopmental assessment prior to discharge, using the Brazelton Neonatal Behavioral Assessment Scale (BNAS)⁵ or the Assessment for Preterm Infants' Behavior (APIB),⁶ with parent observation and participation, has facilitated many parents to see their infant's strengths and competencies after many days of focusing on their signs of discomfort during withdrawal.

Staff Support Issues

For NICU nurses, as well as for the developmental and medical professionals in the unit, reflection and education are equally important as this new role evolves. In the author's unit, several efforts are underway to meet these needs. A series of reflective sessions led by the unit psychologist both address the emotions that the nurses experience when they care for babies with NAS and their families, and provide information about the disease of addiction, especially as it impacts women, and about current approaches to treatment. Meetings facilitated by the unit social worker and psychologist are underway with community providers of treatment services, so that the care provided by these programs and by the NICU are as coordinated, consistent, and mutually supportive as possible. As the NICU team learns more about drug treatment, and the staff of the treatment programs learn more about the process of treating NAS, the hope is that outcomes for infants and families will continue to improve.

Finally, it should be stated that much remains to be learned about the best ways to care for babies and families wrestling with this difficult and challenging problem. Multidisciplinary approaches, and collaboration between the world of substance abuse treatment and the world of newborn care and follow-up, is needed. Research in this area is challenging for many reasons⁷ and demands resources and commitment to ensure that infants, mothers, and other family members experience the best possible outcomes.

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The 26th Annual NIDCAP Trainers Meeting

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St. Joseph's Hospital NIDCAP Training Center, Phoenix, Arizona



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Annual NFI Membership Meeting

October 17, 2015

1:30PM – 3:30PM (MST)

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St. Joseph's Hospital NIDCAP Training Center, Phoenix, Arizona

NIDCAP Care in the Moment



Photograph by Melissa Barnes

A mother's hands support her daughter during care.



Debra Paul, OTR

Home At Last

*Have you seen the beauty of the rose
while walking in the snow?*

*Have you smelled its fragrance in the air
before it started to grow?*

*Have you felt the softness of the snow
even though it wasn't there?*

*Have you closed your eyes and opened your heart
to believe what your mind wouldn't dare?*

I have.

*I could see our little babies before they ever came to be.
And every time I closed my eyes my prayers were not for me.
They were for the little ones that I did not yet know.
Each prayer was for a miracle; our blossoms in the snow.*

—LISA PELZER VETTER

This poem was penned many years ago by my sister Lisa, a freelance writer, and captures how I felt from the first moment my husband and I found out that we were pregnant. When we discovered that we were having not one, but two babies, my hopes and prayers doubled.

Parents prepare for parenthood in many ways – from decorating a nursery to deciding on baby names. When a healthy, fullterm baby is born and sent home with his or her parents after a short stay in the hospital, the mother can experience an emotional roller coaster of postpartum hormones, sleep deprivation, recuperation from childbirth itself, and taking care of a newborn; generally speaking, the adjustments that go along with having a beautiful new family member may take place gradually. Baby and parents have time to grow together. But what about the parent(s) of a baby who requires special care in the NICU and beyond? What about those parents?

Parents like me...and some of you. What about us?

Although I had been an occupational therapist for several years before our babies were born, the moment I laid eyes upon them and they were swiftly taken from my arms to the NICU, my professional cap came off and the mom cap was put on. So I feel as if I'm writing this article from both sides of the fence – as a professional and as a mother.

As parents of babies with special medical needs will tell us, there seems to be no time to learn things gradually. They have to learn...fast. They have to adjust...quickly. They need to know...now. They need to become an advocate. Their baby's advocate.



Jessa and her family. Kent and Kip are in the background and the girls are (left to right-Jillian, Jessa and Stella).

And then...finally, it is time to bring their baby, who spent time in the intensive care nursery, home. Time to celebrate, right? No more alarms, no more tubes, no more interruptions. Parents have looked forward to this day every single minute their baby has been in the NICU. They breathe a sigh of relief.

“We did it! We get to leave the clinical walls of the hospital behind and go home!” Gulp.

Reality sets in. Relief turns to apprehension. Specialists in the NICU are available to intervene in an infant's complex situation at a moments notice, but now with discharge looming, parents begin to wonder: “What do I do if...? Am I fully prepared for this?”

The Journey

Kip Dickson is the mother of Jessa, now 15 years old, was delivered late preterm and experienced several health related crises for several months after she was born. Jessa was diagnosed with a genetic deletion. Kip shares one of her reflections when Jessa was just five days old.

“She was sound asleep; naked except for a diaper, lying on her daddy's chest. As they both lay with peaceful breaths, her words came through me and the poem we wrote together set the stage for “Jessa lessons” to come. I was to slowly discover what an inspirational teacher she is. I am still in awe of how an incredibly wise and innocent soul could so deeply touch the lives of all who would welcome her in and truly listen.”

— Kip Dickson (Reproduced with permission)

A family realizes very quickly that the voice of advocacy does not stop once they leave the intensive care setting. In fact, this transitional phase is one of the most important that the family will go through. The need to be proactive is essential.

Maria Hopfgarten is the lucky mom of Jacob and Sarah, and wife of Joakim. Jacob is a 9-year-old strong little fighter who has a mitochondrial disorder. He has experienced multiple hospitalizations throughout his life and his family has remained steadfast in advocating for him during what has certainly been very stressful times when they were not sure if he would live. Despite Jacob's medical challenges, he is a happy loved boy who enjoys life to the fullest despite his challenges! His parents are both from Sweden and they have lived in the United States for the past 14 years. Maria loves to make a difference in the lives of others, and is inspired by Jacob every single day. His parents may have given him life, but Maria says that he teaches them about life.



Maria, Joakim, Jacob and his older sister Sarah

"I think with communication, comes partnerships. Over the years, we have built very strong relationships with Jacob's key doctors. We know who will support us in making the right decisions for our son, and we always involve them in any major decisions. We have a vested interest in our son together."

— Maria Hopfgarten

These two families understand the value of parental advocacy and have proven it time and again during their children's lives. It is our responsibility as healthcare professionals to help support and build upon all of our parents' skills so they can become effective advocates for their child – in the hospital and beyond – just as Kip and Maria did and continue to do every single day.

So, how can we help make this happen? How do we promote a proactive, nurturing environment that will set the stage for the family to thrive in the hospital, and after discharge to home?

Cultivating two-way communication is critical. There needs to be an open channel for both the family and the healthcare providers. Professionals and families are equal partners in the child's care and outcome. This means that both parents and caregivers need to pause and allow time for listening (really listening!), reflection, questions, and input. As caregivers, we must take the lead by encouraging families to engage in honest, robust dialogues. Soliciting input and insights from parents is one of the primary responsibilities of caregivers, not only while a child is

hospitalized, but especially with the transition to home.

Awareness that parents may be in crisis mode when their child is very sick, is crucial according to Maria, who speaks from first hand experience. Providers must take the lead in promoting an open line of communication and assure parents that their voice is being heard, because we truly do need their voice. Positive reinforcement is required often for parents to keep speaking up and out, and as parents begin to settle into the art of advocating for their infant, health care professionals should reinforce the value of their insights that might not have otherwise surfaced. We learn that the parent's voice is just as important as ours.

Their Stories

Kip and Maria agreed to share a few more of their insights to give us a bird's-eye view on the importance of building trustworthy relationships with care providers. They help us understand the significance of the parental voice when caring for a child with special healthcare needs. And as they will attest, a journey that starts in the NICU does not end there - especially when dealing with on-going chronic health issues.

KIP: "When she arrived, almost three weeks early and weighing 4 pounds, 2 ounces, my husband Kent and I were in shock. As health problems were discovered, urethral reflux at 3 days old, and an atrial septal defect at 5 weeks (later repaired at 4 ½ months with open heart surgery), we were eventually sent to the geneticist to begin the long and excruciatingly painful search for what was "wrong" with our daughter. As anyone who has traveled into the land of genetics knows, you do not return from the trip the same. The practice of reducing a child to numbers, measurements, and irregularities is about as agonizing and disrespectful a procedure as I have ever been a part of. They strip little ones of their dignity, but Jessa wouldn't let them touch her spirit. Eight months later, the diagnosis of genetic deletion/4p- was finally stamped on her chart. The geneticist's job was completed. They had closed the case of "why Jessa won't grow."

"I used to feel a desperate need to explain to people why Jessa was so little. I would receive looks of shock and disbelief when I would honestly answer the question of "how old is your baby"? Sometimes I even used to tell them all about her genetic deletion and how it made eating and growing so difficult for her. Most people actually weren't that interested, and the usual response was sort of an uncomfortable "oh I see," as they took a couple of steps backward. I realized that they don't "see," they could never really understand, and certainly they are thankful that they don't." (Reproduced with permission)

As NIDCAP Professionals, we play an important role in how we influence our colleagues and caregivers to, as Kips states, "understand." It is our duty to be tuned in to the infant and family's voice, and once the family leaves the hospital, the family's voice becomes more important than ever. They are the ones who have critical information to share with the medical team. Their input is essential to a child's ongoing care and treatment plan. Parents' insights, data and constant monitoring of their child's condition become the medical team's best resource, and one of

the most important things we can do for families is to help them believe in the value of their own voice.

We have all heard of the “360 degree review.” Essentially, we improve our view by soliciting feedback from all the people around us – including parents. The optimal care model is to stimulate and nurture a healing environment where the child is wrapped in the concept of the 360 degree view. Identifying key stakeholders and actively engaging them in the care model yields an environment where everyone thrives.

At the end of the day, everybody in the equation is responsible for the quality of care and attention to detail that only a family can bring.

Q & A

Question: We know how important it is as health care professionals to support and build upon parental skills to help family members become effective advocates for their infant in the NICU and beyond. What is your advice for professionals and for parents to make this happen?

KIP: “Learn to trust yourself and your gut instincts. It can take a while to get your footing and speak with authority, but with time you begin to get more comfortable and better able to advocate for your child. If you believe you’re not being listened to or respected, ask for a second opinion. Sensitivity is crucial for health care professionals when delivering difficult information to parents, and while most providers do this well, many do not. The experience my husband and I had with Jessa’s geneticist was truly devastating. What you say to families can stay with them forever.”

MARIA: “Parents know their children best. They will know, before healthcare providers do, if something is not right. It might be a subtle change, or it might be an intuition that something is wrong. By communicating that to your healthcare team, it could very well make a huge difference in the care the child is receiving.”

Question: As a parent of a child with special health care needs, how did you build on your communication skills along the way to feel more comfortable and competent in your role as your child’s advocate?

KIP: “Parenting in the neonatal intensive care unit can be a very lonely and alien experience for families, and early on, it can be hard to know what questions to ask. Throughout our journey it has been invaluable to have support from other parents who have been down this path. I was so fortunate to have three extraordinary mom friends who guided me through the early years, and continue to do so 15 years later. All of our kids have different issues, but the underlying themes are the same. Having people who truly do understand the journey has saved me many times. And now that I consider myself an “experienced” special needs mom, I love nothing more than talking to new parents who are going through similar experiences. Having support systems is key.”

MARIA: “I have often thought that I am lucky that I had a long career as a people manager before having Jacob. Communication was key in my work to be a good manager and leader. I realized quickly that this was probably the most important skill in

working with Jacob’s health care team as well. I researched Jacob’s conditions and diagnoses so I could have an educated discussion with his healthcare providers. If I didn’t agree with his doctors, I always respected their input but made a case for what I believed was the right treatment or next steps. I once had a doctor say “we are humans too.” I try to remember that, and always meet them in the middle. There were times when I had to take a stronger stand with Jacob’s team, when I did not agree with his medical team. I will spend time preparing my arguments and also involve people who I know will support my decisions. It can be exhausting to advocate for your child, but I know if I don’t do it, who will?”

Kip and Maria are clearly engaged parents - all the more reason for us, as caregivers, to have our radar tuned in to capture these important insights. It is critical to nurture relationships and help make the journey home from the hospital a smooth one. Although we are professionals, the mantra of “caregiver knows best” is not an optimal mindset. Success is best served through a working partnership between all parties involved.

Maria adds, “In the intensive care setting, time is often at play. If the parent’s voice can be heard, important information can be shared up front, possibly even saving a child’s life. We know right away if something is “off” with Jacob. We might notice a change in heart rate or in his breathing that doesn’t alarm any of the medical team members because it is within his range, but we know that something is bothering him because it is not within our child’s normal range. We feel we bring information to the table every time we have an interaction with Jacob’s medical team, and we feel we are able to give him the best care possible because of our knowledge and perspective.”

“Parents bring everything to the table. If a provider has a sense of humility and treats us as the real expert in our child’s life and we work together as partners, we will continually grow and teach each other.”

– Kip Dickson

*Have you seen the beauty of the rose
while walking in the snow?*

*Have you smelled its fragrance in the air
before it started to grow?*

Each one of these mother’s stories is the rose in the snow. Throughout Kip and Maria’s journey, they have blossomed and grown to become strong advocates for their children and for the community of parents that share similar experiences.

Heartfelt thanks and gratitude are expressed to Maria and Kip for sharing each of their stories. Maria Hopfgarten serves on several Quality and Parent Advisory Committees at Children’s Hospital Colorado. She lives in Broomfield, Colorado with her husband Joakim, Jacob and his older sister Sarah. Kip Dickson is a Montessori teacher who works and lives in Boulder, Colorado with her husband Kent, Jessa, and her two older twin sisters, Jillian and Stella.

Developmental Continuum of Neonatal Sucking Performance Based on the NOMAS® (Neonatal Oral-Motor Assessment Scale)

Marjorie Meyer Palmer, M.A., CCC-SLP

Preliminary Clinical Observations

Introduction

As medical technology advances and preterm infants are able to survive in ever increasing numbers with smaller birth weights, younger gestational ages, and more medically complex diagnoses, oral feeding for these infants has become a universal concern. Despite the plethora of information available on neonatal sucking and the coordination of suck/swallow/breathe in the healthy term infant, oral feeding in the preterm infant continues to be poorly understood and the normal course of maturation of efficient feeding remains controversial. It has been reported that respiration and suck are gestational age-dependent reflexes modulated in the brain stem and increasingly gestational age with maturation correlates with a lower frequency of apnea and the development of sucking rhythm.¹⁻⁶ It has also been reported that experience with oral feeding results in a more rapid maturation of sucking.^{7,8} Other studies have reported opposing views that early oral stimulation may not result in earlier weaning from nasogastric tube feeding;^{9,10} and that stimulation of non-nutritive sucking in preterm infants accelerates oral feeding success.¹¹ Finally it has been reported that the process of maturation is considered to be the most responsible factor for coordination of sucking ability in the infant.^{5,6,12,13} Despite this controversy (i.e., development of sucking in the preterm infant), it is generally agreed that the sucking profiles of the preterm infant are significantly different from those of the healthy term infant.¹⁴ The well coordinated feeding pattern of the healthy term infant is characterized by a 1/1/1 coordination of suck, swallow, and breathe.¹⁵ When infants are unable to coordinate suck/swallow/breathe they may forfeit available energy necessary for feeding and be unable to continue sucking which may result in failure to thrive. Usually this incoordination is because of an inability to maintain adequate ventilation while sucking and swallowing.¹⁵ In 1979, Crook defined this type of incoordination of suck/swallow/breathe as characteristic of a disorganized suck.¹⁶

Other infants may demonstrate a dysfunctional suck¹⁷ that may be a possible early indicator of neurological damage.¹⁵ A dysfunctional suck is characterized by abnormal movements of the tongue and jaw observed during early reflexive nutritive sucking that are not seen in the typically developing preterm or healthy term infant.^{17,18} These movements include excessively wide jaw excursions that interrupt the intra-oral seal on the nipple, a flattened tongue configuration with an absent tongue groove, and jaw excursions that are too short to allow for an adequate degree of suction.¹⁷ Dysfunctional NOMAS® scores were associated with decreased transcerebellar diameter and lower Dubowitz scores.¹⁹

The NOMAS®

Based upon the concepts described above, the NOMAS® (Neonatal Oral-Motor Assessment Scale) was developed in 1983 and revised in 1990 (page 14) as a clinical evaluation of neonatal sucking patterns. This bedside observation tool enables the examiner to differentiate the normal, disorganized, and dysfunctional suck. The NOMAS® identifies 28 characteristics of jaw and tongue movements that are observed during a two-minute nutritive sucking sample. Since 1994 professionals have been required to become reliable in the administration and scoring of this assessment in order to accurately use it to diagnosis the neonatal suck pattern in the preterm and term infant up to 44 weeks post conceptional age (PCA). Both the normal and disorganized categories on the NOMAS® have demonstrated acceptable psychometric properties²⁰ and preliminary data suggests that the NOMAS® is a “reliable assessment tool that provides an objective, standardized, and observational measure” of infants’ feeding maturation.²¹ In addition, Macmullen and Dulski found that the NOMAS® evaluation of sucking ability correlated with gestational age, weight, and behavioral state in normal healthy newborns.²² DaCosta et al. reported that this observational tool is most commonly used to assess the nutritive sucking skills of infants,²³ and it has been examined more consistently and showed more consistent results in psychometric properties than other feeding assessments.²⁰ The performance of the infant on the NOMAS® may also be useful in the prediction of later developmental outcome.^{21,24}

Efficient feeding is secondary to coordination of the pharyngeal swallow with respiration and the episodes of deglutition apnea are reported to decrease with maturity.²⁵ This is representative of the maturation of the preterm infant and it has been hypothesized that “feeding is a neurodevelopmental process of maturation.”²⁵ Based upon this hypothesis, only infants with a disorganized suck pattern are described here in order to track the maturation of sucking development.

Early Development of Sucking

Grybowski first identified the immature suck pattern of the preterm infant as consisting of short sucking bursts of 3-5 sucks per burst followed by a pause of equal duration during which swallowing and breathing occurred.¹³ When an infant is not able to self-regulate in this manner, episodes of deglutition apnea resulted and these deglutition apnea events were reduced as the infant matured.²⁵

By comparison the healthy full term infant will usually have the neurological maturation and respiratory support necessary to demonstrate a mature/continuous burst suck pattern. This pattern consists of sucking bursts of 10-30 sucks per burst, with swallowing and breathing occurring during the sucking burst,

followed by a brief pause.¹³ The average ratio of suck/swallow/respiration has been reported to be 1:1:1.^{12,15} An infant born at term must suck, swallow, and breathe in a coordinated manner during successful oral feeding. When an infant is born prematurely these skills may not yet be fully mature or coordinated.²⁶ In addition to the lack of neurodevelopmental maturation, infants with respiratory problems, such as bronchopulmonary dysplasia, have an even more difficult time with the coordination of suck/swallow/respiration and demonstrate low sucking pressures, short sucking bursts, infrequent swallows, and prolonged episodes of deglutition apnea.²⁷

Infants who are born prematurely may also be unable to regulate their cardio-respiratory system during oral feeding resulting in increased heart rate and decreased oxygenation. Attention to cardio-respiratory regulation and the relationship between feeding performance and cardio-respiratory stability in the preterm infant may provide information as to an infant's readiness to feed.⁷ Adequate coordination of suck/swallow/breathe appears to be crucial for an infant to feed without episodes of desaturation, apnea, bradycardia, and/or aspiration. An alternation of the suction and expression components of suck are not sufficient, therefore, for an infant to feed safely by mouth⁹ and the coordination of respiration needs to be in place for successful oral feeding to occur. It has been reported that swallowing first occurs at 13 weeks and sucking at 18 weeks in utero while the suck/swallow coordination is present at 32-34 weeks gestational age. The suck/swallow/breathe coordination necessary for a continuous burst pattern, however, usually does not occur until closer to term, at about 37 weeks post conceptional age.¹²

Evaluation of Sucking: Administration and Scoring of the NOMAS®

The evaluation of the infant suck pattern was based on clinical observations as described on the NOMAS® (Appendix A). This assessment consists of three diagnostic categories: normal, disorganized, and dysfunctional sucking that are based on 28 characteristics of jaw and tongue movement during the first two minutes of nutritive sucking on a bottle. The NOMAS® is also used with breast feeding infants but the evaluation requires more than two minutes. Since these clinical observations were done only with bottle feeders a discussion of breast fed infants is not appropriate here.

A normal suck refers to either the self-regulated immature suck of the preterm infant, or the continuous burst pattern of the healthy term infant, both of which have been previously described, and a disorganized suck that refers to "a lack of rhythm of the total sucking activity" (suck, swallow, and breathe),¹⁶ while a dysfunctional suck is identified by "abnormal movements of the tongue and jaw".¹⁷

The administration and scoring of the NOMAS® is taught during a three-day course. Participants are required to observe infants at bedside in the neonatal intensive care or special care nursery during the first two minutes of a routine bottle feeding in order to accurately diagnose their suck pattern. A two-minute sample was selected to observe the best performance of the infant, since younger infants are not often able to sustain the suck well. Participants are required to

pass an inter-rater reliability standard, in order to use the NOMAS® as an assessment tool after completing the course.

Method

Clinical observations of sucking patterns in infants from 31 to 44 weeks PCA were undertaken. The purpose was to determine whether or not there is a correlation between developmental maturation and sucking ability, based upon the NOMAS®. Only those infants who were diagnosed with a disorganized suck on the NOMAS® were observed. Infants with a normal suck (i.e., no difficulty with the coordination of suck/swallow/breathe) or those infants with a dysfunctional suck (abnormal movement of the jaw and tongue during sucking²⁸) were excluded. The subjects included one hundred and twenty (120) infants from the intensive care and special care nurseries. Gestational and post conceptional ages for the infants were recorded. Infants ranged in age from 31 to 44 weeks PCA. The first two minutes of nutritive sucking on a bottle at bedside were recorded on videotape during a routine nursery feeding of each subject. Infants were evaluated on the NOMAS® while being fed by staff nurses in either a Level II or Level III intensive care or special care nursery. Nursing and physician agreement with respect to the infant's readiness to begin nipple feeding, was required. The nipple used for the feeding had been pre-selected by nursing staff for each infant prior to the bedside observation. All subjects were videotaped once at bedside during a three-day NOMAS® Certification Course conducted in nurseries located in the United States, Canada, Asia, and Europe. A two-minute videotape of the mouth during nutritive sucking was taken using a Panasonic Palmcorder, PV-D407, after signed parental consent was obtained. In some cases the parent was available to feed the infant during the observation. The videotape was part of the course and as such was not considered to be a study at the time of the videotaping. All infants observed were medically stable and had a physician's order to proceed with bottle feeding. Because these infants were only observed as part of the 3-day NOMAS® Certification Course observers were not privy to detailed medical information.

The number of infants in each group included:

31-31 6/7 weeks PCA	= 2
32-32 6/7 weeks PCA	= 3
33-33 6/7 weeks PCA	= 6
34-34 6/7 weeks PCA	= 11
35-35 6/7 weeks PCA	= 18
36-36 6/7 weeks PCA	= 30
37-37 6/7 weeks PCA	= 11
38-38 6/7 weeks PCA	= 11
39-39 6/7 weeks PCA	= 10
40-40 6/7 weeks PCA	= 6
41+ weeks PCA	= 12

Each videotape was reviewed and the number of sucks that occurred during the two-minute sample was counted. Isolated sucks (i.e., one or two sucks occurring alone) were subtracted in order to obtain the total number of sucks contained within sucking bursts during the two minutes. Based upon the average

number of sucks and the range of sucks per two-minute nutritive sucking sample, a developmental correlation was outlined. Since all infants were videotaped during a NOMAS® Certification Course, a minimum of at least four examiners evaluated each infant at bedside and inter-rater reliability for the diagnosis of the disorganized suck was established. Three of these examiners were course participants and one examiner was the NOMAS® course instructor. Scoring of the suck pattern was done after the two-minute observation was completed followed by a discussion of the results.

Findings

The percentage of sucks contained within nutritive sucking bursts increased with maturation (Table 1, page 15). This is in agreement with the findings of Gewolb, Bu'Lock, Grybowski and others.^{5,12,13,29-31} The range of sucks contained within sucking bursts during the two-minute sample also increased with maturation (Table 2, page 15). Infants at 31 weeks demonstrated from zero to eight total sucks in a two-minute nutritive suck sample; infants at 32 weeks had 10-49 sucks; and infants at 33 weeks had 23-59 sucks. Infants at 34 weeks demonstrated a range of 14-79 sucks in the two minutes. By 35 weeks PCA infants demonstrated as many as 127 sucks during the two minute nutritive sucking sample. At 36-36 6/7 weeks of age the maximum number of sucks in the first two minutes of nutritive sucking from a bottle was 123 and at 37-37 6/7 weeks was 145. The average number of sucks in the two-minute nutritive suck sample nearly doubled from 34 to 35 weeks PCA and more than doubled by 37 weeks PCA (Table 3 page 15). The average number of sucks contained within sucking bursts, the range of sucks and the maximum number of sucks in a two-minute sample of nutritive sucking increased with maturation and can be seen as a developmental continuum of sucking.

Discussion

In many nurseries both in the United States and in other countries oral feeding is usually not introduced to premature infants who are younger than approximately 34 weeks PCA. This explains the small sample size of infants available for review at 31 and 32 weeks PCA. When isolated sucks are observed, or when the infant stops sucking to breathe during the first two minutes of a nutritive suck sample, it was found not only to be a clinical symptom of a disorganized suck, but one more typically found in younger premature infants. Although the average nutritive suck is described as having one suck per second, some younger or sicker term infants may have a faster suck rate or sucks that are not accompanied by swallows and may demonstrate more than 120 sucks during a two-minute sample; while other full term infants may have a 3:1 suck/swallow ratio and also demonstrate more sucks than one per second. Additional research is needed in order to evaluate the impact of illness, medical diagnosis and respiratory difficulty on neonatal sucking and the NOMAS® results during the first two minutes of the nutritive suck. Based upon the literature it seems reasonable to suspect that the younger, sicker infants will have more difficulty with the coordination of suck/swallow/breathe, than the older healthier ones. This clinical observation of reflexive neonatal

sucking over time with increasing PCA, based on the NOMAS®, does show improved coordination of suck/swallow/breathe with maturation and correlates with other studies.^{3,5,6,9,12,13,15,16,22}

These findings are worth noting from a developmental perspective because they support the infant's readiness to feed at 35 weeks PCA and later, but not earlier, and correlate well with much of the literature.

Conclusion

This clinical observation demonstrates trends in sucking activity and changes in sucking performance with maturation both of which are identifiable by the NOMAS®. Evaluation of infant sucking, based upon the NOMAS®, agrees with previous reports that the development of nutritive sucking in the preterm infant is dependent upon maturation and neurodevelopment, rather than on learned behavior.^{5,6} As the infants matured they demonstrated a larger number of total sucks in a two-minute nutritive sample, a better ability to sustain the suck for two minutes, and a greater percentage of sucks contained within sucking bursts as indicated by the scores on the NOMAS®. These findings correlate with other studies that have documented the changes in nutritive suck patterns that occur in preterm infants over time.^{30,31}

The NOMAS® is an important feeding observational assessment as it evaluates the early nutritive suck of the preterm and term infant in the intensive care/special care nursery. It allows for clinical observation at the bedside and has established inter-rater reliability among examiners both at bedside and on videotape. In addition, the administration and scoring of the NOMAS® requires only two minutes and may be used as an effective screening tool for those infants who have just begun to feed orally. At this time it is unclear just how much can be predicted by the early evaluation of neonatal sucking, although a significant association has been reported between neonatal sucking patterns at 40 weeks post-menstrual age and developmental outcome at both 12 and 18 months corrected gestational age.³² It has been suggested that a standardized instrument for neonatal sucking evaluation may offer a cost-effective early screening strategy for preterm infants who are at greatest risk for developmental delay.³³ Since the NOMAS® is widely used in clinical and research environments and can be administered in just two minutes, it has been suggested that it serve as such an evaluation.^{20,21,23,24,34,35}

Further studies are needed, however, in the areas of feeding progress and improvement in sucking skills of preterm and term infants in intensive care and in the area of developmental follow-up as it correlates with neonatal sucking performance on the NOMAS®. Of particular interest are the infants who demonstrate clinical signs of stress during nutritive sucking on the NOMAS® since those infants may be more likely to develop a sensory-based feeding aversion later. Another area of interest is the sensory aspect of neonatal sucking and the infants who demonstrate deviations in their sensory response to nipple feeding. Sensory deviations such as perseveration, habituation, and poor adaptability are identified by the NOMAS® during the two-minute evaluation. It would be interesting to explore the possibility of the prediction of later sensory integration disorders,

NOMAS[®]

Neonatal Oral-Motor Assessment Scale (NOMAS)
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Jaw <u>Normal</u> <input type="checkbox"/> consistent degree of jaw depression <input type="checkbox"/> rhythmical excursions <input type="checkbox"/> spontaneous jaw excursions occur upon tactile presentation of the nipple up to 30 minutes prior to a feed <input type="checkbox"/> jaw movement occurs at the rate of approximately one per second (1/2 the rate of NNS) <input type="checkbox"/> sufficient closure on the nipple during the expression phase to express fluid from the nipple	<u>Disorganization</u> <input type="checkbox"/> inconsistent degree of jaw depression <input type="checkbox"/> arrhythmical jaw movements <input type="checkbox"/> Difficulty initiating movements: <input type="checkbox"/> inability to latch on <input type="checkbox"/> small, tremor-like start-up movements noted <input type="checkbox"/> does not respond to initial cue of nipple until jiggled <input type="checkbox"/> persistence of immature suck pattern beyond appropriate age <input type="checkbox"/> under 40 weeks PC (transitional suck)	<u>Dysfunction</u> <input type="checkbox"/> excessively wide excursions that interrupt the intra-oral seal on the nipple <input type="checkbox"/> minimal excursions; clenching <input type="checkbox"/> asymmetry; lateral jaw deviation <input type="checkbox"/> absence of movement (% of time) <input type="checkbox"/> lack of rate change between NNS and NS (NNS = 2/sec; NS = 1/sec)
Tongue <u>Normal</u> <input type="checkbox"/> cupped tongue configuration (tongue groove) maintained during sucking <input type="checkbox"/> extension-elevation-retraction movements occur in anterior-posterior direction <input type="checkbox"/> rhythmical movements <input type="checkbox"/> movements occur at the rate of one per second <input type="checkbox"/> liquid is sucked efficiently into the oro-pharynx for swallow	<u>Disorganization</u> <input type="checkbox"/> excessive protrusion beyond labial border during extension phase of sucking without interrupting sucking rhythm <input type="checkbox"/> arrhythmical movements <input type="checkbox"/> unable to sustain suckle pattern for two minutes due to: <input type="checkbox"/> habituation <input type="checkbox"/> poor respiration <input type="checkbox"/> fatigue <input type="checkbox"/> incoordination of suck/swallow and respiration which results in nasal flaring, head turning, extraneous movement	<u>Dysfunction</u> <input type="checkbox"/> flaccid; flattened with absent tongue groove <input type="checkbox"/> retracted; humped and pulled back into oro-pharynx <input type="checkbox"/> asymmetry; lateral tongue deviation <input type="checkbox"/> excessive protrusion beyond labial border before/after nipple insertion with out/down movement <input type="checkbox"/> absence of movement (% of time)

Summary and impression:

Recommendations:

 Licensed Examiner

License # _____

Table 1. Percentage of total sucks contained within sucking bursts

Post-Conceptual Age (PCA)										
31-31 6/7 weeks	32-32 6/7 weeks	33-33 6/7 weeks	34-34 6/7 weeks	35-35 6/7 weeks	36-36 6/7 weeks	37-37 6/7 weeks	38-38 6/7 weeks	39-39 6/7 weeks	40-40 6/7 weeks	41+ 6/7 weeks
0	89%	89%	87%	98%	96%	97%	98%	99%	99%	98%

Table 2. Developmental maturation of suck range of sucks in two-minute nutritive suck sample (minus isolated sucks)

Post-Conceptual Age (PCA)										
31-31 6/7 weeks	32-32 6/7 weeks	33-33 6/7 weeks	34-34 6/7 weeks	35-35 6/7 weeks	36-36 6/7 weeks	37-37 6/7 weeks	38-38 6/7 weeks	39-39 6/7 weeks	40-40 6/7 weeks	41+ 6/7 weeks
0-8	10-49	23-59	14-79	23-127	18-123	30-145	23-116	29-99	23-87	44-111

Table 3. Average number of sucks in two minute nutritive suck sample

Post-Conceptual Age (PCA)										
31-31 6/7 weeks	32-32 6/7 weeks	33-33 6/7 weeks	34-34 6/7 weeks	35-35 6/7 weeks	36-36 6/7 weeks	37-37 6/7 weeks	38-38 6/7 weeks	39-39 6/7 weeks	40-40 6/7 weeks	41+ 6/7 weeks
0	22	29	33	64	53	68	60	68	60	74

autistic spectrum disorders (ASD), and pervasive developmental disorders not otherwise specified (PDD-NOS) as well as sensory based feeding aversions based upon early neonatal nutritive sucking scores on the NOMAS®.

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Nurturing Emotional Relationships within the Newborn Intensive Care Setting

Jean Powlesland, RN, MS



View of the City of Segovia and the Cathedral from the “parador.”

What a delightful mixture of old and new did we experience in Segovia! The modern “parador” where the conference was held, is built on a hillside opposite the medieval city of Segovia. It was designed so that the public areas and the guest rooms had stunning views of the walled city and the Roman aqueduct. As we sat outside or inside the common areas, enjoying 21st century amenities, this panorama of ancient, medieval and modern integrated together constantly surrounded us.

The 25th Annual Meeting of NIDCAP Trainers and colleagues comprised 3½ days of wonderful food, incredible vistas and outings, that served as bookends to days immersed in exploring and understanding the underpinnings of the NIDCAP philosophy of relationship-based care along with implementation strategies. With each meeting I have attended, I appreciate more the theoretical and foundational work of Dr. Heidelise Als and her colleagues, which now has grown into an ever more sophisticated, nuanced and expansive program, not unlike the seamless mixture of old and new that surrounded us in the city of Segovia.

Saturday

Saturday morning’s introductory session included an overview of the current training efforts by 20 Training Sites summarized by Jim Helm, followed by self-introductions of over 120 participants who hailed from 20 different countries!

The group photos from each of the prior 24 Trainers Meeting, reproduced in the conference binders, showed how this group of clinicians, researchers, supporters and family members have changed over the years. Many of us were reminded of how young we were when we first started this work! And yet we again subjected ourselves to the scrutiny of future NIDCAPers as we posed for this year’s group photo this time with the magnificent view of Segovia as the backdrop.

Saturday afternoon was the annual NFI membership meeting where the various committees reported from the Board, and where the election for board seats whose terms were completed took place.

The Spanish group arranged to take us on an outing to see the medieval town of Pedreza, an enchanting walled city where we had a guided tour and then enjoyed free time to explore the city under the setting sun that painted the city walls a soft golden glow. We were then driven to a restaurant in nearby Torrecaballeros where we were treated to regional specialties of lamb and pork.

Sunday

Sunday morning while the NFI Board of Directors met, the rest of the group had the opportunity to take a walking tour within the walls of the old city of Segovia and, explore the cathedral and town square, as well as get an up close and personal view of the Roman aqueduct. This magnificent antiquity built in the 1st century in the common era, was in use until the mid-19th century, bringing water from mountains 17 kilometers away. As it approaches the city and crosses a valley, the structure rises to a level of 28.5 meters with 167 arches all placed without mortar!

In the afternoon we were treated to our key note speakers. Dr. Nathalie Charpak provided fascinating follow-up data on a cohort of premature infants who received Kangaroo Mother Care as infants, and who were studied when 18-20 years old. Her preliminary data suggests that the parents of these children keep their children in preschool longer and are more invested in creating a stimulating home environment. The children were less likely to drop out of school and had better productivity as measured by higher hourly wages. Dr. Charpak is currently looking at brain maturation in this population. Dr. Miguel Marin gave us a comprehensive overview of the very complex neuro-

endocrinology of childbirth and maternal-infant attachment and how disruption of these processes may potentially effect the development of attachment and emotional issues later in life. This brought forcefully to us the need to be mindful of potential negative consequences whenever we separate infant from mother, and motivates us to consider how we can minimize those times and those negative consequences.

Dr. Nikk Conneman then led us on a reflection of compassion and empathy as we met in small groups to discuss our experiences of empathy and compassion and how this relates to being nurturing and feeling nurtured in our work.

Monday

Monday morning was dedicated to research abstract presentations. Eleven abstracts and eight posters were presented, encompassing such diverse topics as a meta-analysis of NIDCAP research, skin to skin care, developmental outcomes and attachment in premature infants, research into the sensory experiences of the infant, looking at olfaction and audition in premature infants and the role of oxytocin in parental stress. Also included were many clinical topics such as development of parental educational tools, survey of developmental care in French NICU's, feeding infants with congenital heart disease and the use of music therapy to promote relationships in the NICU.

The afternoon was devoted to a workshop to discuss how to better utilize the NIDCAP Nursery Assessment and Certification Program (NNACP) as part of NIDCAP training and consultation, as well as a reflective session on nurturing relationships between infants, families and staff in the NICU, led by our parent representatives, Mandy Daly, Silke Mader and Marni Panas.

A 25th Anniversary celebration on Monday night included a birthday cake for the NFI, cut by President gretchen Lawhon and former President and Founder Heidelise Als, followed by music, dancing and singing late into the evening.

Tuesday

Tuesday morning included a presentation from the British and Dutch groups on their work on developing a standardized introductory education course for those seeking a basic educational course that is compatible with NIDCAP philosophy. Rodd Hedlund then gave a presentation on how to use the NNACP scoring process and graphics program. The Phoenix group then wrapped up with a short presentation on the 26th Annual NIDCAP Trainers Meeting, with the infamous Elk Ceremony closing out the conference.

Many veteran participants of this meeting commented on how wonderful it was to have so much more free time in order to network and talk casually among colleagues. As we wandered around Segovia and Pedraza, or sat on the Parador's patio with a glass of sangria, you could hear many conversations, in a number of languages, concerning research and clinical work among people who only see each other at this annual event. The less packed conference schedule was emotionally nurturing to all the participants and helped us to be more engaged in the topic of emotional nurturance!

Segovia was a wonderful setting for our meeting, both literally and figuratively. While we enjoyed a relaxing and supportive time together, Segovia's blend of modern and ancient reminded us that as our organization grows there are challenges in the transformation from a small, cohesive network of colleagues, to a large international organization that covers a great diversity of systems and issues. With that growth there are bound to be challenges and differences in vision, but hopefully we will continue to blend the best of the old with the most promising of the new to meet diverse needs and forge a stronger organization.

In the town square in Segovia, I photographed the statue of Antonio Machado, a Spanish writer and poet who lived and wrote in Segovia. One of his poems contains these stanzas:

*Caminante, son tus huellas
el camino, y nada más;
caminante, no hay camino,
se hace camino al andar.
Al andar se hace camino,
y al volver la vista atrás
se ve la senda que nunca
se ha de volver a pisar.
Caminante, no hay camino,
sino estelas en la mar.*

*Wanderer, your footsteps are
the road, and nothing more;
wanderer, there is no road,
the road is made by walking.
By walking one makes the road,
and upon glancing behind
one sees the path
that never will be trod again.
Wanderer, there is no road -
Only wakes upon the sea.*



The statue of Antonio Machado in the town square of Segovia.

How often do those of us who champion developmental care in our units feel that we are blazing the trail and breaking the path? For Machado, no one leaves a true path for another to follow; each person follows their own path, which like the wake on the water, will eventually disappear. However, the wake spreads far and wide and gently touches many before it finally dissipates.

Many of us come to this meeting emotionally, intellectually and often physically drained from the rigors of being trailblazers in our NICU practice. The emotional nurturance that was our theme of our conference is also a critical part of why we gather each year. We need this annual gathering as a chance to validate for each other what we are doing, to be inspired and renewed in our understanding of the importance of this work. The two Spanish centers, led by Dr. Maria Lopez Maestro from Madrid and Dr. Josep Perpoch from Barcelona, provided us with a nurturing, relaxed and fun atmosphere in order to learn and be renewed.

Refreshed, we returned to our home units to work with an energy that creates gentle wakes that will continue to radiate out and impact the lives of all those we work with and care for in the NICU.

See you in Phoenix, October 17-20, 2015!

The Gold Standard for Excellence in Newborn Individualized Developmental Care

What All Newborn Infants and Their Families Deserve

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The Newborn Individualized Developmental Care and Assessment Program (NIDCAP), originated in 1984 by Heide-ise Als, PhD, is the only comprehensive, family centered, evidence-based approach to newborn developmental care. NIDCAP focuses on adapting the newborn intensive care nursery to the unique neurodevelopmental strengths and goals of each newborn cared for in this medical setting. These adaptations encompass the physical environment and its components, as well as, the care and treatment provided for the infant and his or her family, their life-long nurturers and supporters.

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The Assessment of Preterm Infants' Behavior (APIB) (Als et al., 1982) is a comprehensive and systematic research based neurobehavioral approach for the assessment of preterm and fullterm newborns. The APIB provides an invaluable diagnostic resource for the advanced level clinician in support of developmental care provision in a nursery.

NIDCAP Nursery Assessment and Certification Program (NNACP)

The NIDCAP Nursery Assessment and Certification Program (NNACP) provides a comprehensive resource for the self-evaluation by a nursery system of its strengths and goals for integration of NIDCAP principles into all aspects of their functioning. External review and validation by the NFI may be sought when a nursery feels it has achieved this goal. Successful NIDCAP Nursery Certification, the ultimate goal, denotes distinction in the provision of a consistently high level of NIDCAP care for infants and their families, as well as for the staff, in a developmentally supportive environment. Nurseries that have achieved this recognition serve as a model and an inspiration to others. For information on eligibility requirements and the certification process please see: www.nidcap.org; and/or contact Rodd Hedlund, MEd, NNCP Director at: nnacpdirector@nidcap.org or 785-841-5440.



Mission

The NFI's mission is to promote the advancement of the philosophy and science of NIDCAP care and to assure the quality of NIDCAP education, training and certification for professionals and hospital systems.

Adopted by the NFI Board, May 1, 2015

Vision

The NFI envisions a global society in which all hospitalized newborns and their families receive care and assessment in the evidence based NIDCAP model, which supports development, minimizes stress, is individualized and uses a relationship-based, family-integrated approach.

Adopted by the NFI Board, May 1, 2015

Family Centered Multidisciplinary Rounds in the NICU: Do they make a difference?

Background

Multidisciplinary and family-centeredness are important and necessary elements of current, updated newborn care.¹⁻³ Fundamental to these two elements of care are collaboration and information sharing, which rest upon the establishment of effective, open and sensitive communication between caregivers and families on an ongoing basis.^{4,5}

Communication and information sharing have been underlined as critical needs of families in newborn intensive care.^{6,7,8} Yet, and in spite of the significant shift that has taken place in many NICUs towards a family-oriented model of care, parents' communication needs are not always successfully met by the professional team. Parents might remain dissatisfied with their involvement in care, physician-parent communication, and availability of information.⁹ It is therefore widely accepted that strategies conducive to improve teamwork and communication among caregivers, including parent-staff communication, are still very much needed in the NICU.^{3,10}

However, the establishment of stable structures of communication is a common challenge within complex organizational systems such as the NICU, where communication at multiple levels and in multiple directions is essential for the delivery of effective and quality care.¹ In order to put in place practices that promote communication and foster the values of multidisciplinary and family-centeredness on an ongoing basis, a proactive effort that involves planning and purpose from caregivers is usually needed.¹¹

Family Centered Rounds (FCRs) have been suggested as an organizational strategy that holds potential to improve communication and collaboration between families and staff.^{12,13} FCRs are defined as "interdisciplinary work rounds at the bedside in which patient and family share in the control of the management plan, as well as in the evaluation of the process itself".¹¹ This general conceptual framework has been more specifically articulated in different clinical frameworks. Mittal¹² defines FCRs in the pediatric setting as multidisciplinary rounds that involve complete case discussion and presentation in front of the patient and family, so as to involve them in the decision-making. About a decade ago, the American Academy of Pediatrics advocated for bedside rounds with the family present as the standard of care.¹⁴ Nevertheless, evidence on implementation of FCRs in pediatric contexts is limited and mostly not specific to the NICU setting.



The infant's mother and nursery caregivers sharing observations with one another.

Moreover, most of the evidence pertains to observational studies or quasi-experimental study designs, and controlled studies are very scarce.

Evidence on FCRs

In a recent prospective study comparing families with a child admitted to a general pediatric ward team with or without formal training in FCRs, families who experienced FCRs were more likely to report consistent medical information, the option of discussing the care plan, participation in decision-making, physicians listening carefully to their concerns, and showing respect for them. No difference was found in number of medications, discharge time and hospital charges. The authors concluded that FCRs were associated with higher parent satisfaction with no additional burden to health service use, and emphasized the need to assess this rounding modality in different settings of care.¹⁵

A multidisciplinary improvement team in a pediatric acute care unit published a case report on a process that allowed families to decide whether they want to be part of attending-physician rounds.¹⁶ This team concluded that family involvement in rounds seemed to improve communication and shared decision-making, as well as to offer a new learning framework for residents and students.

A quasi-experimental study to determine the impact of family-centered multidisciplinary rounds on an inpatient

pediatric ward, reported no differences in family satisfaction between conventional rounds and FCRs. Nevertheless, a positive effect was found for the staff, who reported better understanding of the patients' medical plans, better ability to help families, and a greater sense of teamwork with FCRs as compared to conventional rounds. The authors attributed the lack of effect on parent satisfaction to the small sample size, and underscored the positive impact on staff satisfaction as the most significant finding in their study.¹⁷

The intervention study conducted by Voos and colleagues¹⁸ is among the very few published on the implementation of family-centered rounds specifically in the NICU setting. This team assessed the impact of FCRs both on staff satisfaction and on parent satisfaction and stress. An increase in a compound measure of collaboration and satisfaction was reported by newborn nurse practitioners and medical fellows following FCRs implementation, while no other professional group reported a decrease in satisfaction. Although parents' overall satisfaction scores did not change following implementation of FCRs, items related to communication (meeting with physicians and obtaining information about their infant condition and long term expectations) did show a significant increase. Parental stress scores did not vary following implementation of FCRs. One of the main limitations of this study was the low return rate of parents' questionnaires.

The views of parents and health-care providers regarding parental presence at bedside rounds in the NICU has been recently explored in a Canadian study,¹⁹ which surveyed nurses, residents and senior medical students. The majority of parents reported that attending rounds reduced their anxiety (84%) and increased their confidence in the health-care team (88%). A small minority (8%) found the discussion during rounds was more confusing than helpful, and some (17%) thought too many medical terms were used. Nurses were more likely than medical trainees to support parental presence at rounds, and felt that parent presence results in less time being spent outside rounds explaining the child's condition and plan of care. Yet, about three-quarters of medical trainees and nurses thought discussion is inhibited, and two-thirds of trainees felt there is less teaching - when parents attend rounds.

In a quality improvement project conducted in our NICU in Israel,²⁰ nurses' perceptions were more positive after implementation of FCRs, specifically regarding the parents' right to participate in rounds, the contribution of FCRs to parents' understanding of the infant's condition and plan of care, and the contribution to nurses' understanding of infant and parents' needs. Parents, in turn, felt better understood and perceived that their opinion was further taken into account, after implementation of FCRs.

Overall, a range of benefits from involving families during FCRs have been reported in the last decade and include improved parental satisfaction, staff satisfaction, communication, coordination of care, teamwork, discharge planning, and improved trainee education.^{16,17,21-26} Despite this growing body of literature and the fact that the vast majority of families will prefer to be present on rounds when given the choice,^{16,27} a more thorough scrutiny, implementation and evaluation of this important component of family-centered care is apparently needed, most specially in the NICU setting.

Challenges to FCRs

Several concerns have been raised regarding family-centered multidisciplinary rounds and their feasibility in clinical contexts.^{11,12,28,29} Time investment emerges as one of the main concerns raised by professionals in different settings, and is definitely relevant to the complex, often unpredictable nature of the work at a NICU. Even when the culture of care in a unit resonates with principles of multidisciplinary and family centeredness, genuine concerns about the extra time required for a new rounding modality are often expressed by the staff. The time commitment for family-centered multidisciplinary rounds and conventional rounds was examined in a short term quasi-experimental study conducted in an inpatient pediatric ward. The average time for discussing each patient was 10.2 and 7.5 minutes, respectively. Although the rounding period during FCRs took longer, the difference was not found to be statistically or clinically significant.¹⁷ In a case report from an acute pediatric care setting, it was found that FCRs took approximately 20% longer than traditional rounds.¹⁶ Participating staff, however, believed that their time was used more efficiently and that the new rounding modality saved time later in the day. Of great significance was the improvement in discharge timelines as a result of FCRs implementation. In line with this findings, most practitioners in an adult cardiothoracic setting found that even if the new rounding modality may require an additional investment of time up front, it saved time during the course of the day.³⁰ In the NICU, both nurses and medical trainees thought that rounds take longer when parents are present, yet only less than one-third of them perceived that as an actual problem.¹⁹ Overall, it appears that the evidence about time allotted for rounds is not conclusive, and there are also reports that parental participation was not associated with an increase in time in the pediatric setting.^{29,31}

Another concern relates to the belief that FCRs could be intimidating or overwhelming for families.^{11,12,32} This is not clearly supported in the literature, and different studies have actually shown families' explicit wish to participate in rounds.^{27,33} In a randomized controlled trial of bedside versus conference room presentation in a pediatric intensive care unit, parents' satisfaction was significantly higher during bedside case presentations, they preferred this modality of patient presentation, and were more comfortable attending bedside teaching. When asked for their preference for next case presentations, most parents desired that it be performed at the bedside.³⁴ In a survey of community-based clinic patients following bedside presentations and discussions, the group reported that listening to their concerns being discussed with another physician made them more comfortable, and they also demonstrated a preference for listening to interactions in future visits.³⁵ Responses from preterm infant parents are in line with these findings. A study about parent-staff communication in the NICU addressed parents' desire to be present during rounds.⁸ Moreover, experiencing FCRs helped parents to feel less worried about their infant,¹⁹ and parental stress did not increase.^{18,36} Certainly, the provision of a relaxed and sensitive atmosphere, as well as the use of clear and simple lay terminology to explain complex medical concepts, are among the various factors that shape parents' satisfaction and comfort during FCRs.^{16,22,37}

Concerns have also been raised about staff discomfort with bedside discussions when parents are present, as well as the possibility that rounds with families might constrain bedside teaching.^{21,38} However, higher satisfaction has been reported by staff members (including attending physicians, residents, nurses and medical students) when rounds were held with the family, both in pediatric¹⁷ and in newborn¹⁸ settings. Moreover, residents-in-training reported to be equally comfortable with presenting the clinical case and satisfied with the teaching received, when clinical presentations were held with families at the bedside.³⁴ In line with this finding, medical residents tend to believe that teaching is better when families are present and that learning occurs in a way that is not possible when rounds are held in the conference room.¹⁶ While presumably not all teaching activities can occur when families are present in rounds, educational benefits unique to FCRs include learning through increased patient encounters, attending role modeling, and direct observation and feedback.²⁵

Privacy and confidentiality are other concerns, especially in multiple-bed room units,^{28,39} where private rooms, that are becoming increasingly common in NICUs worldwide,⁴⁰ cannot be afforded. Sensitivity and flexibility towards parents' desires, as well as an open discussion of the unit's limitations concerning privacy, seem to be key in overcoming environmental constraints. When aware of these limitations, families can explicitly express their own choices regarding the participation in FCRs. Positive experiences with family-centered rounds have, in fact, been reported in newborn intensive care units with multiple-bed rooms.¹⁸

Finally, the concomitant presence of several caregivers at the bedside can be an additional challenge of FCRs in the NICU. Beyond the need to maintain a quiet environment during rounds, the provision of multidisciplinary viewpoints within the time constraints imposed by a realistic and feasible clinical round at the bedside, can be a challenge in itself. This challenge has not received much attention in the literature, yet from our experience with the implementation of FCRs in our unit, we learned that periodic debriefing of rounds are important in order to facilitate the participation of all disciplines involved. Especially important is to assure the availability of the bedside nurse during FCRs,⁴¹ an issue that has to be carefully and proactively addressed, especially in settings where the work load of bedside nurses is high.

Conclusions

Family-centered rounds emerge as a key component of Family-Centered Care. There is now growing evidence on the inclusion of parents as active participants in bedside rounds in the pediatric setting,^{12,13} and this practice has been recommended by important professional organizations.¹⁴ Most recently, a couple of studies have focused on FCRs in the NICU.^{18,19} Review of the evidence provides preliminary support for various benefits of this rounding modality both for families and staff. By potentially providing a consistent venue for family engagement, FCRs arise as a promising framework to further foster communication and collaboration between parents and caregivers in the NICU. Since there are many different ways to conduct FCRs, each unit should determine how to best incorporate it and tailor it to its own clinical setting. Several studies have provided recommendations

on how to more optimally conduct FCRs, and offer valuable insights about the factors that hinder and facilitate their implementation.^{16,22,37,42}

Finally, it should be noted that FCRs are to be articulated as an additional and complementary structure of communication between parents and staff, and not perceived as a "stand alone" practice. To fully exert their potentially positive influence on different aspects of infant and family caregiving, FCRs should be embedded in a NICU's comprehensive family-centered culture of care.^{3,23}

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Joke Wielenga, RN, PhD

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Conferences

NIDCAP: Developmental Care for NICU Infants and Families from Admission through Discharge

Location: Raleigh, North Carolina
Date: August 3, 2015
www.nidcap.org

The Fragile Infant Feeding Institute 2015

Location: Sheraton Denver West Hotel, just outside of Denver, Colorado
Date: August 24 – 28, 2015
www.fragileinfantfeedinginstitute.com and
www.fragileinfantfeedinginstitute.org

1st Congress of joint European Neonatal societies (jENS)

Location: Budapest
Date: September 16-20 2015
www.jens2015.eu

The 9th International Conference on Brain Monitoring and Neuroprotection in the Newborn.

Location: Cork, Ireland
Date: October 1-3, 2015
www.newbornbrain2015.com

2015 Premie Parent Alliance Summit Innovation & Sustainability: Future Trends for Fragile Families

Location: Dallas, Texas, USA
Date: October 19 -21, 2015

National Association of Neonatal Nurses: 31st Annual Educational Conference

Location: Dallas, TX, USA
Date: October 22-25, 2015
www.nann.org/education/content/conference.html

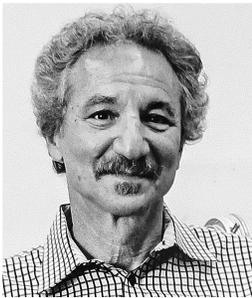
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Websites and Downloads

www.premievoicesbook.com

www.redesignhealthcare.org/2014/11/18/the-garfield-innovation-center/

We invite you to send in information that you may encounter, such as upcoming conferences, websites, books, journals, articles, videos, etc., that may be shared with our readers. Please send items for inclusion in the Developmental Observer to Joke Wielenga, RN, PhD at: developmentalobserver@nidcap.org.



Associate Editor for Science

We are pleased to announce that Jeffrey R. Alberts, PhD, Professor of Psychological and Brain Sciences at Indiana University, has joined the editorial board of the *Developmental Observer*. His research program has long emphasized perinatal development and parental behavior of rodents. Through a grant from the U.S.'s National Institutes of Health, he received NIDCAP Training from Linda Lacina, MSN at the NIDCAP Training and Research Center at Cincinnati Children's, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA, where he now pursues research in the NICU, currently on sleep promotion, feeding, skin to skin contact, and the mother-infant microbiome, all of which connect with his laboratory (animal) research. Jeff's research with pregnant rats launched into orbital spaceflight by NASA has yet to connect directly with NIDCAP.

He joined the NFI Board in 2011 and has been working mainly in areas of Advancement, Governance, fund raising, and the establishment of scientific support of NIDCAP activities. He values diversity on the board and enjoys the challenges of NFI unity across different medical and social settings.

Welcome Jeff! We are looking forward to working with you as you share your vast scientific knowledge and experience with us, while we continue to advocate for the science-based NIDCAP approach to caring for infants and their families.

Developmentally yours,

The Editorial Board, *Developmental Observer*

Our Son: Nicolò Leon Gargano

Marcella, Giovanni e Cecilia Meraviglia Gargano



Nicolò cherished through many NICU challenges.

On the 1st of January 2014, more than halfway through my pregnancy, I entered the hospital due to premature rupture of my membranes. Luckily, we were able to delay delivery until the 23rd of January, when at 30 weeks and 4 days, Nicolò Leon decided it was time to come into the world. He weighed 1420 grams and was admitted to the NICU. Nicolò was a tiny little boy full of energy and he did well, for the first four days of life.

Then, this tale turned into a nightmare, Necrotizing Enterocolitis (NEC), a very severe sepsis which required the surgeons to operate. From that moment, the onslaught of signing forms started, and the sorrow of repeating the same words:

*“Yes, we understand that it is difficult for him to survive...
Yes, we understand that he could die...
YES! For God’s sake....we understand!”*

Nicolò had such a will to survive. He endured disease, infection, more complications including sepsis, DIC, renal and heart failure...all this during his first 7 days of life. He survived all of this.

He was who he was...the expression of our love...and the work, dedication, efforts and the “experiments” of all the NICU family together. Leon bounced back again and again. Then, ROP grade IV was diagnosed and surgery was needed. Nevertheless, Leon lived on...it would be okay.

The nurses naturally took good care of the babies. It was amazing how they are able to help parents understand how their babies are doing. It’s sort of a mixer, where diseases and therapies are served as fruit on a dish, and all of a sudden, everything is in the mixer and soon everything is mixed up. We must keep up the pace, we must understand it, because in a while it could be okay or it could not be. We had to be strong.

We always thoroughly trusted all the NICU staff taking care of Nicky and the staff was therapeutic for us, as well. The respectful nature of each caregiver was so clearly genuine that

we felt at home, throughout the 109 days that Nicky was living in the nursery. We felt protected, helped and supported, and we shared some nice moments, full of smiles, talking and drinking a lot of coffee together. We felt honoured with our best gift, our son, Nicolò Leon Gargano.

If on the 23rd of January, we were totally unaware of the existence of the NICU, by the 12th of May, when Nicolò Leon was discharged, we were experts on monitors, therapies, blood samples, staff shifts, the nurses’ favorite foods and the names of their children.

Our son is the son of all the people who took care of him... spending hours and hours around his crib:

“All those people who knew that he may die...they strenuously fought to save his life.

All those people who experienced fear and joy...who tried everything possible to stave off death.

All those people who proudly emphasized all of Nicky’s successes.”

The Modena NICU is a family to us, we felt like a family and we want to tell this to everybody. Nicolò is the son of all the NICU people, as well. I proudly say this.

Also the two of us, as parents, are a part of the nursery, because the NICU is always a parent, proud to be part of the team, whatever the result.



Being together.

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National NIDCAP Training Center
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Children's Hospital at Westmead
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email: kaye.spence@health.nsw.gov.au

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Director, National NIDCAP Training Center
email: heidelise.als@childrens.harvard.edu

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email: mandy.daly@yahoo.co.uk

Kathleen VandenBerg, PhD

NIDCAP Master Trainer
Director, West Coast NIDCAP and
APIB Training Center
email: kathy.vandenberg@ucsf.edu

Rodd Hedlund, MEd

Director
NIDCAP Nursery Assessment and
Certification Program
NIDCAP Trainer
email: nnacpdirector@nidcap.org

Sandra Kosta, BA

Financial Operations and
Administration Director
email: sandra.kosta@childrens.harvard.edu

NIDCAP On the Web



The NFI is pleased to announce the launch of its NIDCAP Blog. The Blog will offer observations from many different perspectives on NIDCAP and its implementation, such as NIDCAP and APIB training, Nursery Certification, the science behind the approach, the family experience with NIDCAP, the NFI, and much more. The first blog was written by founder, Heidelise Als, PhD and our second blog post was written by Vicki Batkin-Bjornson, a parent of a premature infant, and a former NFI Board Member. We encourage you to visit the NIDCAP Blog and to leave comments for our bloggers and our NIDCAP community in general.

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National NIDCAP Training Center

Boston Children's Hospital and Brigham and Women's Hospital
Boston, Massachusetts, USA
Director: Heidelise Als, PhD
Contact: Sandra M. Kosta, BA
email: nidcap@childrens.harvard.edu

Sooner NIDCAP Training Center

University of Oklahoma Health Sciences Center
Oklahoma City, Oklahoma, USA
Co-Director: Andrea Willeitner, MD
Co-Director and Contact: Eleanor (Bunny) Hutson, RN
email: bunny-hutson@ouhsc.edu

West Coast NIDCAP and APiB Training Center

University of California San Francisco
San Francisco, California, USA
Director and Contact: Kathleen VandenBerg, PhD
Associate Director: Deborah Buehler, PhD
email: kathy.vandenberg@ucsf.edu

Carolina NIDCAP Training Center

WakeMed, Division of Neonatology
Raleigh, North Carolina, USA
Director and Contact: James M. Helm, PhD
email: jhelm@wakemed.org

Colorado NIDCAP Center

University of Colorado Denver
School of Medicine and The Children's Hospital
Aurora, Colorado, USA
Director and Contact: Joy V. Browne, PhD, PCNS-BC, IMH (IV) Mentor
email: joy.browne@childrenscolorado.org

St. Luke's NIDCAP Training Center

St. Luke's Children's Hospital
Boise, Idaho, USA
Co-Director: Beverly Holland, MSN, RN, NE-BC
Co-Director and Contact: Karen M. Smith, RNC, BSN, MEd
email: smithka@slhs.org

Karolinska NIDCAP Training Center

Astrid Lindgren Children's Hospital at Karolinska University Hospital
Stockholm, Sweden
Director: Björn Westrup, MD, PhD
Contact: Ann-Sofie Ingman, RN, BSN
email: nidcap@karolinska.se

French NIDCAP Center

Medical School, Université de Bretagne Occidentale and University Hospital
Brest, France
Director: Jacques Sizun, MD
Co-Director and Contact: Nathalie Ratynski, MD
email: nathalie.ratynski@chu-brest.fr

Sophia NIDCAP Training Center

Erasmus MC-Sophia Children's Hospital
Rotterdam, The Netherlands
Director: Nikk Conneman, MD
Co-Director and Contact: Monique Oude Reimer, RN
email: nidcap@erasmusmc.nl

Centro Latinoamericano NIDCAP & APiB

Fernández Hospital
Fundación Dr. Miguel Margulies and Fundación Alumbrar
Buenos Aires, Argentina
Director and Contact: Graciela Basso, MD, PhD
email: basso.grace@gmail.com

Children's Hospital of University of Illinois (CHUI) NIDCAP Training Center

University of Illinois Medical Center at Chicago
Chicago, Illinois, USA
Director: Beena Peters, RN, MS
Contact: Jean Powlesland, RN, MS
email: jpowlesl@uic.edu

NIDCAP Training and Research Center at Cincinnati Children's

Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio, USA
Director: Whitney Brady, MSN, RN
Contact: Linda Lacina, MSN
email: nidcap@cchmc.org

The Brussels NIDCAP Training Center

Saint-Pierre University Hospital
Free University of Brussels
Brussels, Belgium
Director: Inge Van Herreweghe, MD
Co-Director: Dominique Haumont, MD
Contact: Delphine Druart, RN
email: delphine_druart@stpierre-bru.be

NIDCAP Norway, Ålesund Training Center

Ålesund Hospital, Ålesund, Norway
Director: Lutz Nietsch, MD
Contact: Liv Ellen Helseth, RN
email: nidcap@helse-mr.no

The Barcelona-Vall d'Hebron NIDCAP Training Center Spain

Hospital Universitari Vall d'Hebron
Barcelona, Spain
Director and Contact: Josep Perapoch, MD, PhD
email: jperapoc@vhebron.net

Hospital Universitario 12 de Octubre NIDCAP Training Center

Hospital Universitario 12 de Octubre
Madrid, Spain
Director: Carmen Martínez de Pancorbo, MD
Contact: María López Maestro, MD
email: nidcap.hdoc@salud.madrid.org

St. Joseph's Hospital NIDCAP Training Center

St. Joseph's Hospital and Medical Center
Phoenix, Arizona, USA
Co-Directors: Bonni Moyer, MSPT and Marla Wood, RN, MEd
Contact: Windy Crow
email: stjosephnidcap@dignityhealth.org

Italian Modena NIDCAP Training Center

Modena University Hospital, Modena, Italy
Director: Fabrizio Ferrari, MD
Contact: Natascia Bertocelli, PT
email: natafilli@yahoo.com

Danish NIDCAP Training and Research Center

Aarhus University Hospital
Aarhus N, Denmark
Director and Contact: Hanne Aagaard, RN, MScN, PhD
Co-Director: Eva Jörgensen, RN Newborn and
email: hanne.aagaard@skejby.rm.dk

São João NIDCAP Training Center

Pediatric Hospital at São João Hospital
Porto, Portugal
Director: Herculíia Guimarães, MD, PhD
Co-Director and Contact: Fátima Clemente
email: saojoanonidcap@chs.j.min-saude.pt

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