H. Als, PhD  Caring for Newborns Born Prematurely and for their Families – What have we learned?
Sweeney Lectureship in Neonatology, Meetings of the American Association of Physical Therapy -Combined Sections
Anaheim, CA 20 February 2016, 0800 - 1000

Conflict of Interest Disclosure
Sweeney Lectureship in Neonatology
APTA Meetings, Anaheim, 20 February 2016
I, Heidelise Als, PhD have no financial relationships with any commercial entity producing healthcare-related products and/or services.
I am a volunteer member of the non-profit NIDCAP Federation International (NFI) Board of Directors and a Senior NIDCAP Master Trainer.

Content Attestation
Sweeney Lectureship in Neonatology
APTA Combined Section Meeting, Anaheim, CA 20 February 2016
I, Heidelise Als, PhD, hereby declare that the content for this activity, including any presentation of therapeutic options, is well-balanced, unbiased, and to the extent possible, evidence-based.

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Outline
• Magnitude of the Challenge
• Differences in Fullterm/Preterm Neurodevelopment
• Fetal Brain Development
• The Preterm Infant - Fetus Outside the Womb
• Synactive Theory of Development and Power of Behavioral Observation
• Empirical Evidence for NIDCAP Effectiveness
• Relationship-Based Care

Magnitude of the Challenge
• Prematurity rates are increasing world-wide.
• Thirteen million infants are born prematurely each year, i.e. 10% of all births.
• In the US, annually 12.7% of births are pre-term, for African-Americans the rate stands at 18.6%.
• Prematurity is the primary cause of infant mortality and morbidity.
• More than 50% of children born preterm show later learning disabilities, attention deficits, behavior and self-regulation problems, emotional dysfunction, and school failure.

Differences in Preterm and Fullterm Brain and Behavioral Development

The Brain and Development
• All sensory experience results in neural activity and impacts on developing structures.
• Consequences are greatest, when strong and unexpected experiences impact on a rapidly developing system; this results in a vulnerable if not critical period of development.

Brain Development from Conception to Term

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Development of the superficial muscles in a 20 mm embryo estimated to be 8 weeks old.


Human cerebral cortex at 7, 10, and 13 weeks.


Somatosensory cortex with representation of the various parts of the body surface (sensory homunculus). More cortical tissue is devoted to face, hand and foot than to other parts of the body.


Human Neuro-Sensory Development

<table>
<thead>
<tr>
<th>Sequential Pattern of Sensory Development</th>
<th>Weeks Post Conception</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin (Touch)</td>
<td>7.5 - 18</td>
</tr>
<tr>
<td>Taste and Smell</td>
<td>12 - 14</td>
</tr>
<tr>
<td>Audition</td>
<td>18 - 36</td>
</tr>
<tr>
<td>Movement and Position</td>
<td>20 - 25</td>
</tr>
<tr>
<td>Vision</td>
<td>38 - 2y CA</td>
</tr>
</tbody>
</table>


Early Fetal Development

Seven weeks
2.5 cm long, 2 grams


The earliest recorded fetal movement. Fetus at 8.5 weeks.


Somatosensory cortex with representation of the various parts of the body surface (sensory homunculus).


Origin and final location:

- MN Migrating Neuron
- RG Radial Glial Guides
- TR Thalamic Radiation
- VZ Ventricular Zone
- IZ Intermediate Zone
- CP Cortical Plate
- MZ Marginal Zone


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Early Fetal Development

15 weeks old
about 8 cm
about 25 g

Human cerebral cortex at 7, 10, and 13 weeks.


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Three Promised Environments
The Mother’s Womb, her Breast and Body, the Species’ Social Group

The Preterm Infant - Fetus Outside the Womb

NICU Environment Incubators and Machines Parent Separation Painful Touch Many Hands

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Going to Pieces

Falling Forever

Dying, Dying, and Dying

Loosing all Vestige of Hope for the Renewal of Contact

D. W. Winnicott
Dependence in Child Care, 1970
With good care,
going to pieces becomes relaxation and restfulness;
falling forever becomes the joy in being carried;
dying and dying and dying becomes the delicious
awareness of being alive.

Humans are basically and neuro-
essentially social.
Sociare (l.) to join; joined with others
H. Als • 1995

Going to Pieces Becomes Relaxation and Restfulness

Falling Forever Becomes the Joy in Being Carried

Dying and Dying and Dying Becomes the Delicious Awareness of Being Alive.

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Relationship Implies Connectedness and Mutuality

\[ \text{re-latus (L): carrying back and forth; that which is carried back or carried in return} \]

\[ \text{[ferre] that which is carried back or carried in return} \]

H. Als • 1995

‘Each baby is from the start a person and needs to be known by someone. No one knows a baby as well as the baby’s own mother.’

Winnicott, 1964; 1987

D. W. Winnicott

The Ordinary Devoted Mother: 1966

‘When a mother has a capacity quite simply to be a mother, we must never interfere. She will not be able to fight for her rights because she will not understand. All she will know is that she has been wounded. Only the wound is not a broken bone or a gash in her arm. It is the maimed personality of the baby.’

The Synactive Theory and the Power of Behavioral Observation


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Behavior
- Continuous expression of brain function
- Always available to be observed
- Guide for environment, interaction and care

Autonomic System
- Breathing
- Color
- Visceral System

Motor System
- Tone
- Posture
- Movement

State and Attention System
- Range
- Robustness
- Transitions
Development is a Continuous Process of Dual Antagonist Integration

- Approach - Avoidance
- Towards - Away
- Flexion - Extension
- Calmness - Arousal/Agitation
- Modulation - Disorganization

The process of differential inhibition and excitation leads to continued increase in differentiation, integration, and modulation, and thus to increase in competence.

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Stijn – Video Segment

For each infant care and environment must assure
• Protection
• Predictability
• Restfulness
• Intimacy


Moving from Task-Oriented to Relationship-Based Care


Task-oriented Care
• Protocol-Based
• Staff schedule driven
• Crisis oriented
• Deficit repair model
• Technology focused
• Organ by subspecialty
• Doing-to
• O.R. and E.R. atmosphere

Relationship-Based Care
• Individualized
• Infant rhythm driven
• Development oriented
• Strength nurturing model
• Person and process focused
• Whole person
• Reflection based
• Engaging-with
• Worth, home and family atmosphere

Synactive Model of Family Focused NIDCAP Care


NIDCAP Education Model
• Conscious Awareness and Observation, Assessment and Documentation
• Framework for the Nursery’s Environment and for all Care
• Support for all Parents and Professional Caregivers, the Nursery’s Culture, and the Hospital System

Empirical Evidence for NIDCAP Effectiveness

Results of 15 NIDCAP Studies (10 RCTs)
Significant Reduction
• Ventilator Days
• Extra Oxygen Days
• Gavage Feeding Days
• Severity of BPD
• Incidence of BIV
• Weight Gain Problems
• Growth Problems
• Length of Hospital Stay*
• Age at Discharge*

Oblosoa A, Jacobs SE. NIDCAP: A Systematic Review and Meta-analysis of Randomized Controlled Pediatrics, 2015; 131:3 e881-e893. Figure 5

Significant Improvement
• Neurobehavioral Functioning*
• (2 weeks*, 9 month, 2, 3, & 8 years CA)
• EEG Coherence*: Better
• Frontal Lobe Engagement (2wCA & >5yCA)
• MRI*: Better White Matter Development in Frontal Lobe and Internal Capsule (2wCA & >5yCA)
• Parent Confidence and Competence

Ohlsson A, Jacobs SE. NIDCAP: A Systematic Review and Meta-analysis of Randomized Controlled Pediatrics, 2015; 131:3 e881-e893. Figure 5

Length of Hospitalization (Days)

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Length of Hospitalization (Days)

Postmenstrual Age (weeks) at Discharge

Bayley Mental Developmental Index at 9 or 12 mCA

Bayley Psychomotor Developmental Index at 9 or 12mCA

Very High Risk Preterm Infants <29wGA, N=107; APIB System Scores, 2wCA

Very High Risk Preterm Infants <29wGA, N = 92
Bayley Scales of Infant Development, 9m CA

Neuropsychological Factors at 8 YCA
< 29wGA High-Risk; C=11; E=11

Factors  P
Factor 1: Verbal and Language Abilities 0.40
Factor 2: Visual and Spatial EF Abilities 0.01
Factor 3: Automated Verbal Abilities 0.60
Factor 4: Perceptual Organization and Visual Memory 0.68
Factor 5: Verbal Expression and Memory 0.14
Factor 6: School Achievement 0.51

MANOVA, P = 2.52, df = 6, 15, P < 0.05
MANOVA, multivariate analysis of variance; df, degrees of freedom.
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EEG Coherence Factors, <29wGA, at 8yCA.  
C=9; E=10.  

- Head in vertex view, nose above, left ear to left.  
- Index electrode at lower left; frequency at lower right.  
- Background color is loading on PCA: Blue=Decreased; Red-orange =Increased.  
- Arrow color is E-group coherence: Green=decreased. Red=Increased;  
- Index electrode at lower left; frequency lower right.  


AGA Low-Risk Preterm-Born Infants (29-33wGA)  
n = 30 (14 C; 16 E)  
Newborn Period to Age Eight Years CA  
Neurobehavior, EEG and MRI

EEG Coherence Measures 2wCA AGA Preterm Infants  

\( \text{Wilks' Lambda}=0.45; \text{F}=7.69; \text{df}=4,25; \text{P} = .0001 \)


Bayley Scales of Infant Development, 2nd Edition, 9mCA  
Low-Risk AGA Infants, 28-33wGA

School Age (8-10yCA) Effectiveness of NIDCAP  
Neuropsychological Functioning  
Rey-Osterrieth Complex Figure  

ROCFT: Copy Control 9y6m22d  
Intermediate Recall Delayed Recall  

Experimental 8y4m22d

Low-Risk Preterm, 29-33wGA, School Age Outcome, McAnulty et al.  

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EEG Spectral Coherence, Low-Risk Preterms, 29-33wGA, at School Age

Control (8)
Experimental (15)

Mean Diffusivity (MD) in Cortico-Spinal Tract - School Age Low-Risk AGA
29-33wGA
Two Controls
L: 8y1m10d
R: 8y1m10d
Two Experiments
L: 8y3m21d
R: 8y3m21d

Color code: red (low) to yellow (high): measure of MD, dark orange and red: lower measure of MD

Severely IUGR  High-Risk Preterm-Born Infants (29-33wGA) n = 30 (18 C; 12 E)
Newborn Period to Age Eight Years CA Neurobehavior, EEG and MRI

Cerebellar Volume as Percent of Parenchyma

School Age
IUGR Preterms
29-33wGA

Control (11)
Experimental (7)

Bringing About Systems Change

Systems Change Core Requirements
Well-Nurtured, Continuously Well-Supported, Mutual Respect and Realization of the Multiple Simultaneous Relationships in the NICU:
- The relationships of the parents with their infants and among one another;
- The relationships of staff and professionals with the infants and the parents;
- The relationships of staff and professionals among one another and across all disciplines and services, from house-keeping to the medical director and beyond.

Each Individual’s Responsibility
Am I an agent of stress and conflict ?
Or an agent of support and nurturance?

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Summary Thoughts

- One brain for life – all experience matters.
  (Claudine Amiel-Tison)
- It matters how we listen to the voice of each newborn and how we care for each newborn and each family.
- It matters how we care for one another and for ourselves.
Caring for Newborns Born Prematurely and for Their Families: What have we learned?

Heidelise Als, PhD

The Jane Sweeney Lectureship in Neonatology

American Physical Therapy Association Combined Sections Meeting

Anaheim, CA

Saturday, 20 February 2016

0800 - 1000

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Introduction

Preterm birth is an increasing global perinatal challenge. Given recent advances in perinatology and the accompanying dramatically increased survival rates, assurance of appropriate life quality is recognized as a key responsibility that goes beyond the assurance of survival. The research results gained over the last thirty years increasingly support the importance of improved understanding of early born infants’ strengths, vulnerabilities, thresholds to stress and disorganization, functional regulation to improve future prognoses and life quality. This lectureship provides a framework for the recognition of the infant’s individual neurobehavioral development, the delivery of care from a neurodevelopmentally supportive perspective, and the effects of the newborn individualized developmental care and assessment program (NIDCAP) on the futures of preterm newborns and their families.

Neurodevelopmental Framework

Preterm infants are fetuses, who develop in extra-uterine settings when their brains are growing more rapidly than at any other time in the individuals’ life time. Human infants expect three securely inherited environments, their mother’s womb, their mother’s breast and body, and their family and community’s social group. (Hofer, 1987) Preterm delivery removes the fetus from the evolutionary promised, expected environment. The preterm born infant’s immature organs require care available only in highly specialized, medical technological environments, i.e. newborn intensive and special care nurseries (NICNs and SCNs) with their well-known iatrogenic side-effects including bronchopulmonary dysplasia (BPD), intraventricular hemorrhage (IVH), retinopathy of prematurity (ROP), and necrotizing enterocolitis (NEC). Moreover, these environments stand in massive sensory mismatch with the fetal brain’s expectation for the womb and thus provide significant brain developmental challenges that influence the infant’s brain structural, neurophysiological and neuropsychological development and challenge the infants’ parents’ confidence and competence.

Behavioral Language of the Preterm Infant

Observation of the preterm infant’s behavior provides a way to infer from the observed behavior the infant’s current developmental goals and assess current functional competence and equilibrium. Even very early born, very fragile infants display reliably observable behaviors along three main systems, the autonomic, the motor, and the state system with the emerging attention system. The self regulation system reflects the infant’s current success and efforts in returning to subsystem re-integration and balance. These systems express themselves in detailed behavioral communication signals. Autonomic system signals include breathing patterns, color fluctuations, and visceral responses such as spitting up, gagging, hiccoughing, bowel movement strains and actual defecation, among others. Motor system signals include muscle tone of trunk, extremities and face with flaccidity and/or hyper tonicity, postures and movement patterns, such as finger splays, arching, grimacing, and tucking, among others. The state system, i.e. the infant’s level of arousal and awareness, includes sleep, wakefulness, and upset, transition patterns between the states, and the robustness and modulation of each of the states. The regulatory system expresses its efforts and successes, for instance, by hand clasp, bringing the hands to the mouth, efforts to suck, curling up into a tucked position, moving onto the side from supine, and others. These reliably observable behavioral communications provide information for the parent and the professional caregiver how best to structure and adapt care and
interactions and the environment in order to enhance the infant’s own competence and strengths and to prevent and/or diminish the infant’s signals of stress, discomfort, and pain. (H. Als, 1982) The immature infant seeks continuous co-regulatory support, a function fulfilled by the womb, and in the NICN/SCN best fulfilled by the parent/family caregiver in collaboration with the professional caregiver.

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP)

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) is an approach to environmental support and care based on reading each preterm infant’s behavioral cues, and on formulation of a plan of care, which enhances the infant’s strengths, and supports the infant sensitivities and vulnerabilities. (www.nidcap.org) (H Als, 1986 rev 2015) NIDCAP’s goal is the improvement of long term child and family outcome. It applies from delivery room to the first few months at home. The NIDCAP model aims to create a relationship-based developmentally supportive environment for preterm infants and their families. Figure 1 schematically depicts the Synactive Theory, (H. Als, 1982) (Figure 1) which underlies the NIDCAP formulation and proposes that environment and care interactions, when adapted to each infant’s subsystem thresholds from modulation and strengths to disorganization, are supportive of long-term outcome. The assurance of the parents and family as their child’s primary nurturers is critical to the infant’s developmental outcome. Figure 2 depicts the NIDCAP model of family-focused developmental care. (H. Als, 1992) Parents and infants seek respectful, supportive, and consistently nurturing environments that help them grow competence and mutually supportive trust in their relationship. The transformation that developmentally supportive care demands is the paradigm shift from protocol-based to relationship-based care. The key concept of relationship-based care is co-regulation, based in the neuro-essentially interconnected nature of human beings. A co-regulatory framework of care requires that caregivers are mindful of one another and the personhoods of infants and the family members. Such a framework for medical intensive care is highly demanding, and requires reflection in action, a challenge and responsibility in developmentally effective intensive care settings. For its realization considerable staff education and support are indicated. In the well-functioning NICN/SCN mutual consistent reliable co-regulation must permeate all care, interaction, education, supervision and environmental aspects.
NIDCAP Research: Evidence-Based Practice

The literature to date reports sixteen trials regarding the effectiveness of NIDCAP. Of these, six are historically controlled trials (HCT),(H. Als et al., 1986; Becker, Grunwald, Moorman, & Stuhr, 1991, 1993);(Brown & Herman, 1997; Parker, Zahr, Cole, & Brecht, 1992; Stevens, Petryshen, Hawkins, Smith, & Taylor, 1996; J.M. Wielenga, Smit, Merkus, & Kok, 2007) six randomized controlled trials (RCT) focused on newborns <29 weeks gestation at birth (wGA),(H. Als et al., 1994; Fleisher et al., 1995) and four RCTs focused on newborns 28-33wGA, two samples with appropriate in growth (H. Als et al., 2004; Buehler, Als, Duffy, McAnulty, & Liederman, 1995) and two with intrauterine growth restricted (IUGR) newborns.(H. Als et al., 2012; H. Als et al., 2011) The trials, which focused on <29wGA, extremely low birth weight, medically high risk infants found improved lung function, reduction in intraventricular hemorrhage, better feeding and growth, and decreased lengths of hospital stays for the experimental NIDCAP groups in contrast to the standard care control groups. For the 28-33wGA groups health outcome was comparable for both groups. However, for all samples, <29wGA and 29 - 33wGA preterm infants, neurodevelopmental outcome for the NIDCAP groups in comparison to the respective control groups was improved at 2w corrected age (CA), and at 9 months, as well as at 1, 2, 3 and 5 years CA(A Kleberg, Westrup, & Stjernqvist, 2000; A. Kleberg, Westrup, Stjernqvist, & Lagercrantz, 2002; Westrup, Böhm, Lagercrantz, & Stjernqvist, 2004) and at school age(McAnulty et al., 2010) as measured with neurobehavioral/neuropsychological, spectral coherence (EEG), and magnetic resonance imaging (MRI) methodologies. Additionally, motor system improvement was identified in several other motor system measure focused studies.(Mouradian & Als, 1994; Ullenhag, Persson, & Nyqvist, 2009) Moreover, parental stress was lowered, and parental competence enhanced for the experimental groups as compared to the controls.(H. Als et al., 2003; van der Pal et al., 2008; J. M. Wielenga, Smit, & Unk, 2006)

NIDCAP Training, System Change, and the NIDCAP Federation International (NFI)

The NIDCAP training program, see www.NIDCAP.org focuses on education and training of multi-disciplinary developmental specialist teams in NICUs.(H Als, 1986 rev 2015) Internationally currently twenty-one NIDCAP Training Centers provide training, with the most recent being the Modena University Hospital NIDCAP Training Center in Modena, Italy. Seven nurseries internationally (USA-3; France-1; Israel-1; Denmark-1; and Sweden-1) at this point serve as models of full NIDCAP system integration. The NIDCAP Federation International (NFI) safeguards the quality of all training and is the certifying agency for NIDCAP training centers and NIDCAP nurseries. System-wide introduction and integration of NIDCAP involves considerable investment at all levels of an organization. It may require physical changes and architectural adaptations in the nursery’s structure and lay-out. Foremost, however, it requires substantive educational efforts and changes in staff interaction and staff support, professional role definition, conceptualization and perception of infant and family, as well as in care practices. NIDCAP thus is evidence based, compelling ethically and in direct keeping with family-integrated care. As such it is rapidly become the aspired standard of care for all NICUs world-wide.
References


