OPENING PANDORA’S BOX
Identifying risk of neurodevelopmental impairment in preterm infants

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Conflict of interest

Nothing to declare...
“Pandora's box had been opened and monsters had come out. But there had been something hidden at the bottom of Pandora's box. Something wonderful.

Hope.”

Lisa Marie Rice,

Breaking Danger
OUTLINE

• Why are these babies at risk?
• Why do we need to identify those at risk?
• Do we have tools available to us?
• Are we doing a good job at present?
Background
The Burden of Prematurity – WHO statistics

• ± 15 million babies born <37 completed weeks GA / yr
• This number is rising
• Preterm birth complications are leading cause of death among children <5 years of age ~ 1 million deaths in 2015
• 75% of these deaths could be prevented with current, cost-effective interventions
• Across 184 countries, the rate of preterm birth ranges from 5% to 18% of babies born

• In Canada: only roughly 8% of live births per year, but major cost to Canadian Healthcare system ~ CAD 587.1 million per year in 2014
The preterm infant

- Magnitude appreciated by gross inspection of brain:
  - 13 wks: fetal cortex smooth, no sulci or gyri
  - 26 wks: development of central & lateral sulcus, rudimentary insula
  - Gyral and sulcal formation incomplete even at 34 wks
Etiology

Dysmaturation

• Gray matter architecture distorted
• White matter connectivity altered
• Cerebellum under-developed
• Sensory system disorganization

Secondary cortical dysplasia

Premature Birth

- Majority of preterms free of major morbidity
- Greater survival at diminishing gestational ages

- Major morbidity relatively stable at 6-25%
  - Cerebral palsy
  - Vision impairment
  - Hearing impairment
  - Cognitive impairment

- 50-70% may have ‘minor morbidities’ that affect school performance
‘Minor Morbidities’

• Include:
  – Motor delays
  – Executive dysfunction
  – Attention deficit disorder
  – Language delays
  – Learning disabilities & IQ
  – Auditory dys-synchrony
  – Cortical visual impairment
  – Visual motor difficulties
  – Behavior problems*
  – Social emotional dysregulation*
‘Preterm phenotype’?

- “Prematurity Syndrome” first reported by Drillien in 1939

In most other cases the mother stated that the child was generally difficult to manage, was ‘out of hand,’ exhibited temper if thwarted, was over-dependent on his parents, and had difficulties in his relations with other children or adults.

In most cases it was obvious that the mother had little control over the child, who was being mis-managed at home.
Behavioral phenotype

Describes a constellation of behavioral, cognitive, motor, and social strengths & difficulties observed in a population with a common biological disorder

Premature survivors have a phenotype
Common biological disorder = alterations in brain development

Back SA, Miller SP. Brain Injury in Premature Neonates: A Primary Cerebral Dysmaturation Disorder? Ann Neurol 2014:75;469-86.
Behavior Problems

• Multiple studies have looked at behavioral outcome of prematurity
  
  Vohr B, Msall ME, Semin Perinatol 1997;21:202-220

• Overall, documented increased:
  – ADHD
  – Withdrawn socially
  – Anxiety
  – Depression
  – Dysregulation
Attention Deficit Hyperactivity Disorder (ADHD)

- 2.5 - 4 times greater risk in preterms
- Inattention most frequently cited

- No studies looking at stimulants and preterm infants

- Inconsistent data on whether persists into adulthood
Executive Function

• Mental processes that develop to:
  – enable self-regulation
  – problem solving
  – goal directed actions

• Internal conductor
Executive Dysfunction

• Victorian Infant Collaborative Study Group

• ELBW’s 2-3 x more likely to have executive dysfunction - ↓ GA → ↑ difficulty

• Global dysfunction, not one set pattern

• Difficulty with:
  - Starting new activities
  - Organizing information
  - Planning a sequence of activities
  - Transitioning from one task to other
### Social Emotional

<table>
<thead>
<tr>
<th>Social emotional dysregulation</th>
<th>Internalizing conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Increasingly reported</td>
<td>• Less risk taking due to:</td>
</tr>
<tr>
<td>• Children are...</td>
<td>- Underlying anxiety</td>
</tr>
<tr>
<td>emotionally labile</td>
<td>- Greater parental monitoring</td>
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<tr>
<td>have difficulty with</td>
<td>- Diminished peer relationships</td>
</tr>
<tr>
<td>transitions</td>
<td>• More likely to live at home as young adults</td>
</tr>
<tr>
<td>poor persistence to task</td>
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</tbody>
</table>
Academic Outcome

• Less likely to attend 4 year college, lower scores on standardized assessments of educational achievement

• Unemployment same
  – Job income however inversely related to gestational age

Autism Spectrum Disorder – DSM V

Deficits in social communication and social interaction
• Social emotional reciprocity
• Nonverbal communication
• Difficulty making, sustaining, or understanding relationships

Restricted repetitive patterns of behavior
• Stereotyped movement patterns
• Inflexible adherence to routines
• Fixated interests with abnormal intensity and focus
Autism Spectrum Disorder & the prem

• Many studies evaluating risk factors for ASD

• Few studies evaluating prevalence of autism amidst premature survivors

• Signs may present in early infancy, can include:
  - abnormal social interactions
  - atypical communication
  - restricted interests / play
  - splinter skills may develop
  - sensory hypo/ hypersensitivity
Positive Screening for Autism in Ex-preterm Infants: Prevalence and Risk Factors

• 103 enrolled infants
  – MRI at term CA obtained
• Birth weight < 1500 g

• Follow up data:
  – Modified Checklist for Autism in Toddlers (M-CHAT)
  – Vineland Adaptive Behavior Scale (VABS)
  – Child Behavior Checklist (CBCL)
Positive Screening for Autism in Ex-Preterm Infants  Limperopoulos, Pediatrics 2008

• 26% positive on M-CHAT
• 70% of those positive found to fail 2 critical items
• Abnormal scores correlated highly with:
  - Internalizing behavioral problems on CBCL
  - Socialization and communication deficits on the Vineland Scales.

• Factors significantly associated with abnormal screen:
  - Lower birth weight or GA
  - Male gender
  - Chorioamnionitis
  - Acute intrapartum hemorrhage
  - Illness severity on admission
  - Abnormal MRI
Positive Screening on M-CHAT in ELGAN’s Kuban et al, J. Pediatrics, 2009

- 21% screened positive on M-CHAT
- 16% positive without motor, vision, or hearing impairment
- 10% positive without co-existing impairment*
Cerebellar Hemorrhage (CH)
& ASD

Limperopoulos, Pediatrics 2007

• Retrospective, case controlled (isolated CH, less than 32wk) controls matched for GA, gender, year of birth

• MRI to confirm diagnosis
• 60 infants eligible, 51 survived to study
• CH vs controls: positive ASD screener 37% vs 0%, internalizing behavioral problems 34% vs 9%
Late preterm infant
Late preterm infant

- Brain weight at 34 weeks only 65% of term brain
- Gyral & sulcal formation incomplete
- Cortical volume increases 50% between 34-40 weeks
- 25% of cerebellar development after 34 weeks GA
- Synaptogenesis & dendritic arborization incomplete
Specific long-term issues

- Medical
- Cognition
- Behaviour
- Motor deficits
Early outcome data

- 124 LPT vs 33 term infants
- Alberta Infant Motor scale (AIMS) at 6mo & Griffiths Mental Development Scales (GMDS) at 12 mo chronological age
- LPT performed significantly lower on all subscales of GMDS
- Similar scores when corrected for prematurity
• LPT infants vs term controls
• Bayley Scales of Infant Development Short Form- Research Edition (BSF-R) at 24 months chronological age
• LPT had higher odds of mental (OR 1.52) or physical (OR 1.56) developmental delay
24 month outcomes

Compared to term infants, increased odds of having:

• More severe mental delay (52%)
• Milder mental developmental delay (43%)
• Severe psychomotor developmental delay (43%)
• Milder psychomotor developmental delay (58%)
Compared to term infants:

- Risk for developmental delay or disability 36% higher
- Risk for suspension in kindergarten 19% higher
- Risk for disability in pre-kindergarten (3-4 years)
- Risk for exceptional student education 10-13% higher
- Risk for retention in kindergarten
At 6 years

• Late preterm vs term controls matched
• In adjusted models LPT birth associated with increased risk of
  - Full scale IQ <85 (aOR 2.35, 95% CI 1.20-4.61)
  - Performance IQ <85 (aOR 2.04, 95% CI 1.09-3.82)

→ LPT birth associated with lower IQ at 6 years, independent of
   maternal IQ, residential setting and sociodemographics

• Talge NM et al. Late-Preterm birth and its association with cognitive and socioemotional outcomes at 6 years of age. Pediatrics 2010; 126: 1124-1131
Threefold increased risk for developing cerebral palsy in LPT infants compared with term infants (RR 3.1, 95% confidence interval 2.3-4.2)
Children born LPT >3 times as likely as term infants to be diagnosed with cerebral palsy (hazard ratio 3.39, 95%CI 2.54-4.52)
Other

- **Executive function** deficits especially related to complex memory tasks (Baron et al, 2012)

- Higher levels of *internalizing and attention problems* (Van Baar et al, 2009; Talge et al, 2010)

- At 3, 5 & 8 yrs 20% of LPT scored in clinically significant range on **CBCL** vs expected 10% (Gray et al, 2004)

- Among LPT’s, those admitted to NICU had higher scores on CBCL at 3yrs, especially for *aggressive behavior and externalizing problems* (Boylan et al, 2014)
Social

- Slightly higher risk to receive social security benefits early adulthood (RR 1.15, 95% CI 1.12-1.17) (Teune et al, 2011)

- Helsinki Birth Cohort Study: compared with those born at term, LPT infants were more likely to...
  - be manual workers
  - have a basic or upper secondary level education
  - belong to the lowest third based on income
  - be downwardly mobile in their career
  - have lower occupations than their fathers (Heinonen at al, 2013)

- Less likely to complete high school (RR 0.96), less likely to complete university (OR 0.87) (Teune et al, 2011)
Why try to determine risk?
Early intervention

• Optimal timing < 12-15 months CA
• Maximal plasticity immediately after completion of neural migration → dendritic outgrowth & synaptic formation most active
• Mixed evidence
• Improve function
Early intervention

- Improved social and cognitive abilities
- Improved school completion
- Improved workforce productivity
- Reduced crime rates
- Reduced teenage pregnancy

- ‘The earlier in life these interventions were introduced, the higher the economic and social returns’ (Heckman, ‘Schools, Skills and Synapses’ 2010)
Early intervention

• Review of EI programs for infants at high-risk of developmental delay: improved motor and cognitive development with specific developmental programs (Blauw-Hospers et al 2007)

• Cochrane review: improved cognitive outcomes in infancy, which was sustained at preschool age, not sustained at school age - heterogeneity between studies was significant (Spittle et al 2015)
So how do we decide risk?
Clinical factors?

- Illness severity?
- Known clinical predictors:
  - Preterm: BPD, ROP, brain injury, infection, NEC
  - Late preterm: first baby, poor feeding

- Not a perfect tool – Schmidt et al cautioned ‘limited clinical usefulness of the individual risk estimates’
  - 53% of cohort who developed BPD → favorable 18 month outcome
  - 26% of infants without BPD → died / developed neurosensory impairment
Neuroimaging

Significant predictive value in specific populations: eg term HIE

Preterm population:
• Only certain markers (eg white matter injury) predictive of later neurodevelopment outcome (most commonly CP)
• Dependent on specialist training and expertise
• Interpret findings in conjunction with other clinical information
• Majority of findings on MRI NOT successfully linked to long-term impairment
• Up to 15% of children with CP: ‘normal’ MRI
• Great stress for parents of preterm infants (‘severely traumatizing’, Pearce 2012)
Screening tools
• No perfect tool exists
• General Movements (GMs), MRI, head ultrasound, Movement Assessment of Infants (MAI), neurological exam
• Normal GM assessment:
  - very high negative predictive value of 95-100%
  - negative likelihood ratio of 0
• Abnormal GMs: Pooled sensitivity 98%, specificity 91%, diagnostic odds ratio (DOR) 453 (95% CI 18-11495) for predicting cerebral palsy (CP) at 2 years of age
Predictive value of neurodevelopmental assessments used to predict CP in young children

<table>
<thead>
<tr>
<th>Test</th>
<th>Number of studies reviewed (n)</th>
<th>Number of participants (n)</th>
<th>Range of cerebral palsy prevalence (%)</th>
<th>Sensitivity [% (95% CI)] or range</th>
<th>Specificity [% (95% CI)] or range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurological assessment</td>
<td>4</td>
<td>1190</td>
<td>6.3-52.4</td>
<td>88 (55, 97)</td>
<td>87 (57, 97)</td>
</tr>
<tr>
<td>Cranial ultrasound (CUS)</td>
<td>10</td>
<td>2827</td>
<td>5.0-59.0</td>
<td>74 (63, 83)</td>
<td>92 (81, 96)</td>
</tr>
<tr>
<td>Brain magnetic resonance imaging (MRI)</td>
<td>3</td>
<td>702</td>
<td>11.5-22.8</td>
<td>86-100%</td>
<td>89-97%</td>
</tr>
<tr>
<td>Assessments of general movements (GM)</td>
<td>6</td>
<td>1358</td>
<td>6.3-52.4</td>
<td>98 (74, 100)</td>
<td>91 (83, 93)</td>
</tr>
</tbody>
</table>
General Movements

• ‘Series of gross movements of variable speed and amplitude which involve all parts of body’

  Prechtl & Nolte, 1984

• Present from 9-10 weeks post-menstrual age (PMA)

• At around 4 months corrected age are slowly replaced by more goal-directed movements
Developmental progression and age-specific characteristics of general movements

**Preterm GMs**
Extremely variable movements that include frequent pelvic tilts and trunk movements (±28 weeks to 36-38 weeks PMA)

**Writhe GMs**
Movements are now more forceful and slower, with less pelvis and trunk involvement (36-38 weeks to 46-52 weeks PMA)

**Fidgety GMs**
A continuous flow of small, elegant movements now occurring constantly, irregularly all over the body, with head, trunk and limbs participating equally. These may be superimposed on larger, faster movements (46-52 weeks to 54-58 weeks PMA)
Assessment of Quality of General Movements classification characteristics

- **Complexity** - spatial variation of movements
- **Variability** - temporal variation of movements
- **Fluency** - smooth quality of movement

‘Variation is fundamental feature of function of healthy early CNS... stereotypy hall-mark of early brain dysfunction...’ Touwen 1993, Hadders-Algra 2000
Scoring

Quality of general movement on overall impression

Is there complexity?
Is there variability?
Is it fluent?

Dichotomous classification:

**Normal GMs**
Rich in complexity, variability (& fluency)

**Abnormal GMs**
Lacking in complexity, variability (& fluency)
Available evidence

Reliability of the AQGM

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Cohen’s kappa (κ)</th>
<th>Interpretation (according to Landis &amp; Koch)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inter-rater reliability</td>
<td>1.00</td>
<td>Perfect agreement between raters</td>
</tr>
<tr>
<td>Intra-rater reliability</td>
<td>0.84 – 0.92</td>
<td>Near-perfect agreement</td>
</tr>
</tbody>
</table>

Spittle et al, 2008

Good reliability even with minimal training
• Preterm infants born <30 weeks GA
• GMs assessed during writhing & fidgety phases
• ‘Normal’ vs. ‘abnormal’
• Motor, language & cognitive function
• Strongest association: GM quality at 3mo corrected age \(\rightarrow\) CP at 2 & 4 yrs
• Association with cognitive outcomes less robust but promising...deserves further research
• Benefit of serial assessments?
Other associations

• Minor neurological deficits
• Autism spectrum disorder?
OUR STUDY

At 6 weeks CA (±6 weeks) (Writhing GM phase)

At 3 months CA (±6 weeks) (Fidgety GM phase)

At 18-24 months CA (±12 weeks)

Outcomes assessed:

- BSID-III
- Comprehensive neurological examination with diagnosis of CP
- Presence of visual or hearing impairment

Normal AQGM

Abnormal AQGM

Normal AQGM

Abnormal AQGM

Normal AQGM

Abnormal AQGM
# NEURODEVELOPMENTAL OUTCOME CATEGORIZATION

<table>
<thead>
<tr>
<th>Diagnostic criteria</th>
<th>Normal or mild impairment</th>
<th>Moderate impairment</th>
<th>Severe impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>BSID-III cognitive composite score &gt; 85</td>
<td>BSID-III cognitive composite score 70-85</td>
<td>BSID-III cognitive composite score &lt; 70</td>
</tr>
<tr>
<td>Motor</td>
<td>BSID-III motor composite score &gt; 85 or No diagnosis of CP</td>
<td>BSID-III motor composite score 70-85 or Diagnosis of CP with GMFCS level 1-2</td>
<td>BSID-III motor composite score &lt; 70 or Diagnosis of CP with GMFCS level 3-5</td>
</tr>
<tr>
<td>Language</td>
<td>BSID-III language composite score &gt; 85</td>
<td>BSID-III language composite score 70-85</td>
<td>BSID-III language composite score &lt;70</td>
</tr>
<tr>
<td>Vision</td>
<td>Mild visual impairment (visual acuity better than 20/200 in both eyes)</td>
<td>Bilateral blindness (visual acuity &lt; 20/200 in strongest eye)</td>
<td>Bilateral blindness that cannot be corrected</td>
</tr>
<tr>
<td>Hearing</td>
<td>Mild hearing loss (not requiring amplification / in just one ear)</td>
<td>Bilateral hearing loss (requiring amplification)</td>
<td>Severe to profound hearing impairment (no functional hearing with amplification)</td>
</tr>
</tbody>
</table>
Table 12: Unadjusted and adjusted odds ratio for association of AQGM trajectories, maternal and neonatal characteristics, short-term neonatal morbidities and NDI

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Unadjusted OR (95 % CI)</th>
<th>Adjusted OR (95 % CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A-A vs N-N</td>
<td>2.5 (1.2, 5.3)</td>
<td>1.7 (0.8, 3.6)</td>
</tr>
<tr>
<td>A-A vs N-A</td>
<td>2.4 (1.1, 5.4)</td>
<td>2.0 (0.9, 4.6)</td>
</tr>
<tr>
<td>A-A vs A-N</td>
<td>2.2 (1.1, 4.4)</td>
<td>2.5 (1.2, 5.1)</td>
</tr>
<tr>
<td>A-N vs N-N</td>
<td>1.1 (0.5, 2.8)</td>
<td>0.7 (0.2, 1.7)</td>
</tr>
<tr>
<td>A-N vs N-A</td>
<td>1.1 (0.4, 2.8)</td>
<td>0.8 (0.3, 2.2)</td>
</tr>
<tr>
<td>N-A vs N-N</td>
<td>1.0 (0.4, 2.8)</td>
<td>0.8 (0.3, 2.4)</td>
</tr>
</tbody>
</table>

Maternal characteristics
- Maternal age at delivery (years) 1.0 (0.95, 1.0)
- Maternal education (post-secondary) 0.5 (0.2, 1.1)
- Home language (not English) 1.1 (0.6, 2.0)
- Parental circumstance (single parent household) 1.8 (0.8, 3.9)

Neonatal characteristics
- Gender (male) 2.1 (1.3, 3.3)
- Gestational age (weeks) 0.8 (0.7, 0.9)
- Birth weight (grams) 0.9 (0.8, 0.9)
- Mode of delivery (Caesarian section) 1.0 (0.6, 1.6)
- Multiple birth 1.2 (0.7, 2.0)

Short-term neonatal morbidities
- Presence of BPD ± received postnatal steroids 3.8 (2.2, 6.8)
- Presence of intraventricular hemorrhage 2.2 (1.1, 4.3)
- Presence of retinopathy of prematurity 1.8 (0.2, 14.8)
- Presence of necrotizing enterocolitis 1.2 (0.4, 3.5)
- Presence of PDA requiring ligation 5.8 (2.3, 15.0)
**Table 14: Association between AQGM score at 6 weeks (writhing phase) and 3 months (fidgety phase) and motor impairment**

<table>
<thead>
<tr>
<th></th>
<th>Unadjusted OR (95 % CI)</th>
<th>Adjusted OR for 6 weeks CA (95 % CI)</th>
<th>Adjusted OR for 3 months CA (95 % CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AQGM score</strong></td>
<td></td>
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<tr>
<td>A vs N at 6 weeks CA</td>
<td>2.1 (0.9, 4.6)</td>
<td>1.8 (0.7, 4.5)</td>
<td></td>
</tr>
<tr>
<td>A vs N at 3 months CA</td>
<td>2.9 (1.3, 6.3)</td>
<td></td>
<td>3.4 (1.4, 7.9)</td>
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<tr>
<td><strong>Maternal characteristics</strong></td>
<td></td>
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<td><strong>Neonatal characteristics</strong></td>
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<tr>
<td>Gender (male)</td>
<td>2.0 (1.0, 3.7)</td>
<td>1.8 (0.9, 3.7)</td>
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</tr>
<tr>
<td>Gestational age (weeks)</td>
<td>0.8 (0.7, 0.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birth weight (grams)</td>
<td>0.9 (0.8, 1.0)</td>
<td>1.0 (0.9, 1.2)</td>
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<td>3.6 (1.2, 10.5)</td>
</tr>
<tr>
<td>Presence of intraventricular hemorrhage</td>
<td>8.9 (4.2, 18.8)</td>
<td>7.8 (3.6, 17.1)</td>
<td>8.3 (3.7, 18.5)</td>
</tr>
<tr>
<td>Presence of retinopathy of prematurity</td>
<td>7.1 (0.9, 58.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence of necrotizing enterocolitis</td>
<td>0.3 (0.04, 2.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence of PDA requiring ligation</td>
<td>4.4 (1.7, 11.2)</td>
<td>3.7 (1.3, 10.6)</td>
<td>3.6 (1.2, 10.5)</td>
</tr>
</tbody>
</table>
Hammersmith Infant Neurological Examination (HINE)

- Recommended in *International Clinical Practice Early Diagnosis of Cerebral Palsy Guidelines*, particularly in situations where the most predictive tools (General Movements and MRI) not able to be used
- Infants 2-24 months of age
- A HINE score < 57 at 3 months 96% predictive of cerebral palsy (sensitivity 96%; specificity 87%)
- >5 months age (corrected) it has 90% predictive accuracy for detecting the risk of cerebral palsy
So...do we have a clear answer then?

- Not really...
- In this case: less isn’t more
- Combine clinical data + imaging + reliable screening tools appropriate for the chosen population
- Future research: clinical prediction rules for specific neonatal populations?
**Neonatal Follow-Up Program: Visit Schedule**

The different stages at which you will visit the NFUP and what to expect at each visit.

### 4 - 8 weeks
- **Goals:** Discuss how to transition home safely.
- **What to expect:**
  - Meet with the team
  - Answer a questionnaire about how you’re feeling
  - Review your child’s feeding and sleeping
  - Learn about “homework”

### 4 months
- **Goals:** Check on your mental health, and start to work with you on helping your child move!
- **What to expect:**
  - A check-in on how you’re doing
  - A check-in on your child’s feeding and sleeping
  - A chance to ask the team your questions to help with tummy time

### 8 months
- **Goals:** Work on your child’s motor development as he/she starts to move!
- **What to expect:**
  - The team will watch you and your child doing tummy time
  - Get advice on how to help your child achieve his/her mobility goals
  - Advice on what to expect next and how to help your child achieve the next steps

### 12 months
- **Goals:** Help your child feed him or herself and look at his/her social development
- **What to expect:**
  - A check-in on how feeding is going and tips on how to help your child learn to self-feed
  - Get tips on how to encourage healthy social development

### 18 months
- **Goals:** Continue to look at your child’s social development and review the accomplishments!
- **What to expect:**
  - Play games with your child to assess how he/she is doing
  - Look for your child’s strengths and any areas he/she may be struggling with
  - Get tips on how to help you work around any areas of challenge
  - Discuss and review questions you may have on behavior management or discipline

### 36 months
- **Goals:** Start preparing your child for school!
- **What to expect:**
  - Learn about what resources are available in your community
  - Discuss behavior management now that your child will have to sit, listen to another adult and play with other children
  - Get tips on how to promote your child’s behavior skills
  - Feel comfortable that you know your child’s strengths and challenges
  - Discuss possible future challenges, ways you can monitor them and any concerns you might have
Parental mental health

Post-traumatic Symptomatology in Parents with Premature Infants: A Systematic Review of the Literature

Athanasios Karatzias, PhD¹, Zoë Chouliara, PhD², Fiona Maxton, PhD³, Yvonne Freer, PhD⁴, and Kevin Power, PhD⁵

Risk of psychological distress in parents of preterm children in the first year: evidence from the UK Millennium Cohort Study

Claire Carson, Maggie Redshaw, Ron Gray, Maria A Quigley

State-of-the-Art

Screening parents of high-risk infants for emotional distress: rationale and recommendations

MT Hyman¹, KO Mounts² and DL VandeBilt³

Postnatal Depression, Mother–Infant Interactions, and Child Development

Prospects for Screening and Treatment

Lynne Murray, Pasco Fearon, and Peter Cooper

Paternal Depression in the Postnatal Period and Child Development: Mediators and Moderators

Leticia Gutierrez-Galve, PhD⁴, Alan Stein, FRCPsych⁵, Lucy Hanington, BM, BCh⁶, Jon Heron, DPhil⁷; Paul Ramchandani, DPhil⁸
Edinburgh Postnatal Depression Scale (EPDS)

Since you are either pregnant or have recently had a baby, we want to know how you feel. Please place a CHECK MARK (✓) on the blank by the answer that comes closest to how you have felt IN THE PAST 7 DAYS—not just how you feel today. Complete all 10 items and find your score by adding each number that appears in parentheses ( ) by your checked answer. This is a screening test, not a medical diagnosis. If something doesn't seem right, call your health care provider regardless of your score.

Below is an example already completed:

I have felt happy:
- Yes, all of the time [✓]
- Yes, most of the time
- No, not very often
- No, not at all

This would mean: "I have felt happy most of the time" in the past week. Please compare the other questions in the same way.

1. I have been able to laugh and see the funny side of things:
   - As much as I always could
   - Not quite so much now
   - Definitely not so much now
   - Not at all

2. I have looked forward with enjoyment to things:
   - As much as I ever did
   - Rather less than I used to
   - Definitely less than I used to
   - Hardly at all

3. I have blamed myself unnecessarily when things went wrong:
   - Yes, most of the time
   - Yes, some of the time
   - Not very often
   - No, never

4. I have been anxious or worried about no good reason:
   - No, not at all
   - Hardly ever
   - Yes, sometimes
   - Yes, very often

5. I have felt scared or startled for no good reason:
   - Yes, quite a lot
   - Yes, sometimes
   - No, not much
   - No, not at all

6. Things have been getting to me:
   - Yes, most of the time I haven't been able to cope at all
   - Yes, sometimes I haven't been coping as well as usual
   - No, most of the time I have coped quite well
   - No, I have been coping as well as ever

7. I have been so unhappy that I have had difficulty sleeping:
   - Yes, most of the time
   - Yes, sometimes
   - No, not very often
   - No, not at all

8. I have felt sad or miserable:
   - Yes, most of the time
   - Yes, quite often
   - Not very often
   - No, not at all

9. I have been so unhappy that I have been crying:
   - Yes, most of the time
   - Yes, quite often
   - Only occasionally
   - No, never

10. The thought of harming myself has occurred to me:
    - Yes, quite often
    - Sometimes
    - Hardly ever
    - Never

TOTAL YOUR SCORE HERE

Thank you for completing this survey. Your doctor will score this survey and discuss the results with you.

Verbal consent to contact above mentioned MD witnessed by:
School readiness
# High Rates of School Readiness Difficulties at 5 Years of Age in Very Preterm Infants Compared with Term Controls

Gehan Roberts, PhD,†‡‖ Jeremy Lim, BIIthSc (Hons),†§ Lex W. Doyle, MD,†‖ Peter J. Anderson, PhD†§

<table>
<thead>
<tr>
<th>School Readiness Domain</th>
<th>Individual Measures</th>
<th>VPT (N = 195)</th>
<th>Control (N = 70)</th>
<th>Mean Difference (95% CI)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health and physical development</td>
<td>PEDE-QI score</td>
<td>87.7 (16.0)</td>
<td>95.4 (7.1)</td>
<td>-7.7 (-10.5 to -4.8)</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td></td>
<td>Movement-ABC percentile</td>
<td>23.1 (23.1)</td>
<td>44.5 (26.5)</td>
<td>-21.4 (-28.6 to -14.2)</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td></td>
<td>Visual-motor integration score</td>
<td>94.4 (14.2)</td>
<td>100.2 (15.5)</td>
<td>-5.8 (-9.8 to -1.8)</td>
<td>.05*</td>
</tr>
<tr>
<td>Social-emotional skills</td>
<td>Total difficulties score, SDQ</td>
<td>9.6 (5.7)</td>
<td>7.1 (4.3)</td>
<td>2.5 (1.2 to 3.8)</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Approaches to learning</td>
<td>Global composite score, BRIEF-P</td>
<td>54.6 (13.1)</td>
<td>47.2 (10.6)</td>
<td>7.4 (1.6 to 4.2)</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td></td>
<td>Digit recall, WMTB-C</td>
<td>89.5 (15.5)</td>
<td>101.3 (16.0)</td>
<td>-11.8 (-16.2 to -7.4)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>Nonword recall, WMTB-C</td>
<td>98.9 (19.4)</td>
<td>109.3 (15.0)</td>
<td>-10.4 (-15.0 to 5.8)</td>
<td>&lt;.001*</td>
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<tr>
<td>Communication</td>
<td>Expressive language score, K-SEALS</td>
<td>97.0 (13.8)</td>
<td>105.8 (12.5)</td>
<td>-8.9 (-12.5 to -5.2)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>Receptive language score, K-SEALS</td>
<td>97.6 (13.0)</td>
<td>107.2 (9.6)</td>
<td>-9.6 (-12.5 to -6.7)</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Cognition and general knowledge</td>
<td>Number skills score, K-SEALS</td>
<td>97.4 (12.6)</td>
<td>104.5 (9.9)</td>
<td>-7.1 (-10.4 to -3.8)</td>
<td>&lt;.001</td>
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<tr>
<td></td>
<td>Letter/word skills score, K-SEALS</td>
<td>96.6 (16.5)</td>
<td>107.0 (14.9)</td>
<td>-10.4 (-14.8 to -6.0)</td>
<td>&lt;.001</td>
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<tr>
<td></td>
<td>Early academic composite score, K-SEALS</td>
<td>96.9 (12.9)</td>
<td>106.4 (10.9)</td>
<td>-9.5 (-12.9 to -6.0)</td>
<td>&lt;.001</td>
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<tr>
<td></td>
<td>Nonverbal general ability score, K-BIT 2</td>
<td>96.1 (12.7)</td>
<td>102.9 (10.1)</td>
<td>-6.7 (-10.1 to -3.4)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
Knowledge of Educators

Educators (n=138) less knowledgeable about outcomes of prematurity
- 75% aware and/or knowledgeable about ADHD/ADD
- 62.5% aware and/or knowledgeable about learning disabilities
- 60.6% aware and/or knowledgeable about ASD
- 24.8% aware and/or knowledgeable about developmental outcomes of prematurity

Factors that enhanced educators’ knowledge
- Having experience with a child born preterm
- Having a child with an individualized education plan
- Additional educator qualifications

Kids with late birthdays can wait a year for kindergarten if needed, Toronto school board says

With new data pointing to the problems young children face adapting to education, Canada’s biggest school board wants to remind parents of their options, Caroline Alphonso explains.
So what am I supposed to take away from this?

• Have a structured approach to following premature infants
• Use all tools available to you – MRI / US, GMA, a structured neurological exam (HINE)
• If concerned (you OR parents) → REFER for intervention
• Educate parents on risks and expectations, empower them to advocate
• Educate teachers whenever possible!
• Don’t forget to assess parental wellness
Resources

• Edinburgh Postnatal Depression Scale
  http://med.stanford.edu/content/dam/sm/ppc/documents/DBP/EDPS_text_added.pdf

• Provincial Council for Maternal and Child Health (PCMCH)
  http://www.pcmch.on.ca/ontario-neonatal-follow-program/

• Sunnybrook Health Sciences Centre Neonatal Follow-up Clinic website – parent and provider resources
  http://followup.sunnybrook.ca/

• Neoknowledge
  http://www.neoknowledge.org/
Thank you!

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