Very preterm children are at high risk for developmental difficulties; almost half of these children will have mild-moderate problems. Early intervention has been shown to be efficacious in improving short and medium term outcomes for high-risk children and also for those with known difficulties.

There is often a long time lag between parents first becoming concerned about their children, raising these concerns with health care providers, being referred for assessment and the commencement of services. These factors in combination can mean that at-risk children do not receive intervention during critical periods in development.

It is argued that the wide range and severity of future developmental problems of preterm infants occur as a consequence of both medical complications and the parental and infant social/emotional factors.

This presentation will describe three ways in which we at the Parent-Infant Research Institute are intervening at the parent level: (i) an intense one-to-one program with parents of still-hospitalised infants (ii) therapeutic playgroups and workshops for parents and their infants between 4 and 12 months, and (iii) a research and information-based magazine for parents. All three approaches begin with the assumption that parents need and want to be educated in ways to help their premature infant.

**Disruptions to normal cognitive development**

- Improvised environment
  - stimulation
  - experience
  - interaction with peers and role models
  - Impoverished attachment relationships
- Altered brain development
  - toxins (eg. lead, radiation, drugs)
  - maternal health
  - stress & trauma (maternal & infant)
  - environment & experience
- Brain injury
Early experience and brain development

- Stress
  - animal studies - early experiences “program” the brain
- analogues in human experience
  - medical treatment
  - pain
  - disruptions of social relationships
  - medical care
- Aspects of the central nervous system are self-organising ie “plastic”
- When the CNS changes there is often an associated change in behaviour or psychological function
- These functions are known as learning, memory, emotion, skills etc.

The need for information

Parents of preterm compared with fullterm babies experience

- Emotional disturbance
- Delayed or inadequate maternal attachment
- Problems caring for the baby at home
- Higher incidence of divorce/relationship breakdown
- Higher incidence of abuse, neglect, failure to thrive

Increased stress in “PT parents”

- Fullterm babies – normal stress associated with transition to parenthood
- Preterm babies
  - unresolved grief ....
  - Lack of opportunity/unable to use the opportunity to establish an early relationship, sense of responsibility, “ownership”
  - Period of crisis – anxiety, lack of confidence, inability to cope

Preterm parents

- Perceive their babies as being “different”, comparisons are mainly “downward”
  - delayed
  - temperamentally “difficult”
  - feeding
  - developmentally
  - socially

The need for information

- Parents of premature babies transition from passive recipients of information to actively seeking it (10-20 hours per week in the first month)
- As the issues to be faced become more obvious over time, parents may seek more highly specialised information
- If sound information is not easily available they may find unreliable or inappropriate information that causes additional stress and anxiety or simply become more stressed from uninformed fear
- 72% wanted reassurance and information in both child care and child development
• Information wanted but not received included – infant colic, noisy breathing, spitting up, fussy periods, recognising early signs of illness, when to start taking the baby outside, what to expect from their baby at different ages, how to get the baby to respond to them
• Mothers who need more information were more anxious and less confident
• Mothers who were more anxious required more information
• Less confident mothers were more likely to need an “information booklet”
• Having more information helped to ease anxiety
• Multiparous mothers (86%) were more need of preterm specific information than primaparas (82%)

What kinds of information?
• Specifically about preterm infants
• Health, growth, development, feeding, sleeping, crying, behavioural cues
• (debriefing) own feelings of own and infant’s vulnerability, guilt, fear, lack of confidence
• Differences and similarities between PT and FT babies
• Need reassurance that what they are observing is (or is not) appropriate and normal

Professional educational programs protect the wellbeing of “premature parents”

1. Premiepress (2000 - present)
• Research - based and sound theoretical information written for parents
• 4 editions per year
• Subscription base still relatively small (150)
• Maternal and Child Health Centres, Early Intervention Centres, Neonatal Intensive Care Units, parents

Contents of Premiepress
• Brain development e.g plasticity, early years of development
• Psychology e.g attachment theory, mental health
• Neonatology e.g developmental care in NICUs
• Lactation/breastfeeding e.g development in PTs, melatonin
• Nutrition
• Health and safety
• Infant development e.g theory of mind, language
• Family issues e.g disability, death, multiples, parents, self-help
• How parents can help – music, reading, play ..... 
• Parents’ stories debriefing, providing role models

Style of Premiepress
• Difficult, complex information written in easy-to-read format
• High quality presentation- able to be kept as an ongoing resource
• “voice”
• Seems to appeal to both parents and professionals
• ? Use to parents with lower education
• ? Need to break up the information
The future of Premiepress

- Provide copies free of charge
- Melbourne’s Child model?
- Expand the focus, authorship and “voices”
- Enhance the size (number of pages) and the quality of presentation (more colour)
- Precarious funding basis (presently supported by the WCF Thomas Charitable Trust and William Angliss)
- ? Book
- ? Share the responsibility

2. Facilitated Playgroup - PremieHUGS

- (funded by Telstra)
- Comparison of (i) 3-hour information workshop with (ii) 8 week x 2-hour therapeutic playgroup
- Pilot playgroup

Therapeutic Playgroup

- 1. Introductory Session, “Telling your Story”
- 2. Understanding Life with a Premie
- 3. Taking care of yourself and your baby
- 4. Relaxation and baby massage
- 5. Stress Busters and Infant Temperament
- 6. Social Support, Infant Brain Development
- 7. Mindfulness for Mothers, Attachment
- 8. PremieHUGS and Beyond

Facilitators

- Bronwyn Leigh (clinical psychologist) – covered maternal clinical issues
- Nisha Brown (developmental specialist) – physical development of premature babies
- Carol Newnham (neuropsychologist) – brain development, babies’ needs, infant temperament, mother-infant attachment

3. VERY, early intervention Beautiful Beginnings

- Teaching parents to be parent/therapists to their still hospitalised premature infant

Aim of the program: to motivate and teach parents about how to be appropriately present and influential in their infant’s very early development

Hypothesis: this involvement will have a positive influence on infant development and maternal mental health and adjustment

Program

- Infants born < 30 weeks
- Enrolled within 2 weeks of birth (at the latest 32 weeks post menstrual age)
- Randomised-controlled trial intervention vs control (n=160)
- Intervention 13 sessions which involve primarily education, modelling, observation, skills training
Results – Pilot (n=50) Demographics- Infants

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gestational Age</td>
<td>27.48 (1.73)</td>
<td>23.7 – 30.0</td>
</tr>
<tr>
<td>Age at entry</td>
<td>30.36 (1.82)</td>
<td>26.6 – 32.1</td>
</tr>
<tr>
<td>Birthweight (gms)</td>
<td>1034.84 (257)</td>
<td>455 - 1400</td>
</tr>
<tr>
<td>Apgar 1</td>
<td>5.88 (1.96)</td>
<td>2 - 9</td>
</tr>
<tr>
<td>Apgar 2</td>
<td>7.93 (1.14)</td>
<td>5 - 9</td>
</tr>
<tr>
<td>Apgar 3</td>
<td>9.00 (0.00)</td>
<td>9 - 9</td>
</tr>
</tbody>
</table>

Results – Edinburgh Postnatal Depression Scale (Cox, Holden, & Sagovsky, 1987).

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1 - entry</td>
<td>8.86 (4.43)</td>
<td>8.40 (4.32)</td>
</tr>
<tr>
<td>Time 2 – term equivalent</td>
<td>6.00 (4.40)</td>
<td>5.17 (3.07)</td>
</tr>
<tr>
<td>Time 3 – 3 months CA</td>
<td>4.20 (4.92)</td>
<td>9.14 (6.28)**</td>
</tr>
</tbody>
</table>

Results – Parenting Stress Index - Child Domain (Abidin, 1986)

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1 (entry)</td>
<td>103.9 (11.95)</td>
<td>124.33 (17.34)**</td>
</tr>
<tr>
<td>Time 2 (term equivalent)</td>
<td>110.29 (13.92)</td>
<td>115.80 (16.21)</td>
</tr>
<tr>
<td>Time 3 (3 months CA)</td>
<td>94.50 (7.86)</td>
<td>116.00 (28.20)**</td>
</tr>
</tbody>
</table>

Parenting Stress Index – Parent Domain (Abidin, 1986)

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1 (entry)</td>
<td>126.30 (27.42)</td>
<td>118.56 (26.19)</td>
</tr>
<tr>
<td>Time 2 (term equivalent)</td>
<td>103.57 (12.07)</td>
<td>128.20 (22.47)*</td>
</tr>
<tr>
<td>Time 3 (3 months GA)</td>
<td>110.50 (20.50)</td>
<td>141.57 (65.27)*</td>
</tr>
</tbody>
</table>

Synchrony Scale for premature mothers and babies (17 subscales)

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother recognises infant stress signals and changes actions appropriately</td>
<td>1.79 (0.91)</td>
<td>0.84 (0.65)**</td>
</tr>
<tr>
<td>Overall sensitivity to infant stress</td>
<td>1.86 (0.83)</td>
<td>1.05 (0.50)**</td>
</tr>
<tr>
<td>Infant relaxed and floating</td>
<td>0.48 (0.31)</td>
<td>0.27 (0.21)*</td>
</tr>
<tr>
<td>Infant ability to be soothed</td>
<td>3.31 (1.19)</td>
<td>2.46 (0.93)*</td>
</tr>
</tbody>
</table>

New Study- Beautiful Beginnings 2

- Ready to start
- Similar protocol
- Dependent Variables
  - Brain Development
  - 2- year development
  - Maternal Adjustment
  - Mother-infant interaction
Disruptions to normal cognitive development

- Improvised environment
  - stimulation
  - experience
  - interaction with peers and role models
  - Poor relationships/interactions
- Altered brain development
  - toxins (eg. lead, radiation, drugs)
  - maternal health
  - stress & trauma (maternal & infant)
  - environment & experience
- Brain injury

Early experience and brain development

- Stress
  - animal studies - early experiences “program” the brain
- analogues in human experience
  - medical treatment
  - pain
  - disruptions of social relationships
  - medical care

A different environment

In utero (26 weeks) | Premature newborn (26 weeks)

Aetiology of neurodevelopmental impairment poorly understood

Term born infant at term | Born 23 weeks at term
Environmental effects?

Same 23 wk at term as previous photo
  - Minimal parental input, usual pattern of injury.

23 week infant at term
  - Mother at cotside almost all the time

Trauma

Parents need Information

• Normal parenting
• Normal child development
• Prematurity differences
• Parent adjustment

The future…

• Current interest in the early years and early intervention
• Need to bring parents along with us - impact of the family is still the most influential factor in child development
• Parents are an under-utilized resource
• “The focus of the TKG is to promote parent education”

We tend to intervene after a problem has become apparent

It may be more efficacious to intervene with parents before a problem develops.

For this, parents need to be educated to understand how development occurs and how they can help their child
References


Dr Carol Newnham,
The Parent Child Research Institute, Heidelberg.

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