



The Sick Baby in Hospital

Engaging the sick infant as a person

Assoc Prof Campbell Paul
Royal Children's Hospital and University of Melbourne
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How is the Sick baby different?

- The sick infant has the **same set of emotional and perceptual capacities** as the well baby..but may have problems in using and interpreting these capacities ...

The Sick Child Gabriel Metsu, Dutch, 1629



Working with very sick babies, in intensive care and afterwards

- The baby has a mind** from the start of baby's life
- engaging directly with the baby** can lead to a profound change; even when very sick, especially when working also with the parents.
- Neonates and very sick babies can be **responsive and receptive** to ordinary and playful communications and interventions (sometimes extraordinary) from parents and caregivers.
- Ordinary parents are often **traumatised** and so fearful such that they are unable to connect with their baby
- Babies feel and remember**

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Faith: 5 months in hospital

- Faith was born with **tetralogy of Fallot and other complex cardiac and lung abnormalities**: other complications and poor hearing and blind
- Infant mental health intervention involves helping Faith discover aspects of her own body
- and sharing this with her parents and nurses

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Who lives who dies

The doctors and nurses playing God on our behalf

The point at which premature life can be said to be overlapping the time it can be legally terminated, writes Peter Ellingsen.

SUNDAY INSIGHT

At the twilight world where Melbourne's most vulnerable babies struggle to survive, Silvana, however, seems a simple object. It has nothing to do with the scary, high-tech machines that have kept her son Francesco alive. Nor is it complex to the families that observe parents of premature babies, after five months adding the after-consider of hope that in the neonatal intensive care unit (NICU) of the Mercy Hospital, Silvana just seems to hold her own for a walk in the park. It also could get thence — born from medical intervention — in a plastic dish from around the adjacent Francis ward. It would seem to reach. Looking past the ventilators, monitors and alarms matching her son, to the picture of her son, her parents have placed on his crib, she says. "It would be a sign he'd be OK."

But today, as she stares intently at her baby, something is

That is how she feels like she is to so very sick, she has trouble in the hospital unit every day.

It is a handsome young one that can, and has, no medical such, so well as previous, again, the this occasion, here on so as her diagnosis have shown, the family members of her pull the plug. As so Venice they after 102, the first 2 1/2 hours, when she kept a few. After 102, it seems that by chance, that was a few weeks critical care. It is a grey and white, she made Silvana. It knows the routine. One day, the baby — named by his age — turned that a medical.

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'Personalisation'

- The acquisition of a personal body schema....
.. "psyche indwelling in the soma.."
- Handling**: manage the infant as if the baby's mind and the baby's body form one unit....
- Holding**: provides the basis for what gradually becomes a self-experiencing being...physical holding of the infant is a form of loving
- from D W Winnicott

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Parents' experiencing *traumatic stress symptoms* is very common



- For parents whose babies are in NICU, the rates of *acute traumatic stress symptoms*
- are as high as **34% to 45% of mothers** and between **18 and 25% of fathers**.
- The symptoms present at six and 12 months: at least 20% of mothers and more than 10% of fathers still experience traumatic stress disorder symptoms.

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Premature baby outcome



- **20% of ex-premature babies** at age 2 were in the "at risk" range for **social emotional problems** using the BITSEA scale, and remained at risk at age 5 years, independently of other risk factors. (Treyvaud 2012)
- Some **50% of very premature children** have a later mild neurodevelopmental problem, and less frequently severe disability such as cerebral palsy
- latency age children who had been in the neonatal intensive care had a **high rate of separation anxiety disorders** (Karabel 2012)
- **31% of infants with tracheo-oesophageal fistula** met of the criteria for mental health diagnosis at age 12 months, compared to 18% of the general control population

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Newborn babies can imitate and attribute the intentions of others



- The newborn baby in the first days of life is able to **imitate and copy**, by extending her own fingers, the number of digits held up by an examiner who engages with the baby
- babies even from 3 to 96 hours after birth can be **distressed and adjust their socially responsive behaviour** to a newborn version of the **still face procedure**

Emse Nagy (2008)

Imitates behaviors such as tongue and lip protrusion (Meltzoff)
Babies at least 2mth have a somatic response to mothers reaching to pick them up (Reddy 2013)

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RCH-MCRI Music therapy project



- Randomly assigned 3 sessions /week over 4 weeks of **music therapy intervention in Neonatal ICU** with babies with severe medical & surgical problems
- **Intervention (singing), determined by baby's state and response....was a CONTINGENT intervention designed to facilitate her ability to calm and self regulate**
- Infants who received therapy improved their NAPI scores to those of healthy controls and gained more weight than non therapy sick babies
- Small sample size
- Malloch, Shoemark, Newnham, Paul et al :IMHJ 2012

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Music therapy intervention: results



- facilitated infant development, raising the overall NAPI scores to those of the healthy, non-hospitalised infants.
- Improve ADBB (less withdrawn)
- babies did not show an escalation in irritability and crying over the 4-week period
- intervention seems to serve to **contain infant distress and support infant socialisation**
- Malloch, Shoemark, Paul, Newnham et al : IMHJ 2012

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'Personalisation' D W Winnicott



- The acquisition of a personal body schema.... ***'psyche indwelling in the soma..'***
- **Handling:** manage the infant as if the baby's mind and the baby's body form one unit....
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Baby *inhabits* his Body

- The *good-enough parents* allow and facilitate **the process of the baby inhabiting his own body**, but allow for the baby to *depersonalise, to abandon the urge to exist for a moment ..*

Winnicott

a sense of security, allowing for regression and dependence..

(..especially the sick infant...)

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RCH NICU 24+ beds in 2013

- Total admissions: 558 (in 2007 =700)
- Total number of deaths: 25 (mortality rate of 4.5%) (some babies may die later in other wards)
- extremely heterogeneous population
 - Median Length of Stay: 8 days
 - 160 infants >20 days
 - 17 infants >50 days;
 - 5 infants >100 days

Majority of infants >34weeks gestation

- Only state-wide quaternary & one of 3 tertiary NICU for 5 million pop
- Most babies with **complex cardiac disorders** are on cardiac ward or Paediatric Intensive Care Unit (PICU)



Final diagnosis: order of frequency

- meningitis (4.3%)
- hyaline membrane disease (3.6%)
- bronchiolitis
- hypoxic ischaemia
- inguinal hernia repair
- viral infection
- meconium aspiration
- gastroschisis (2.5%)
- Trachea-oesophageal fistula/atresia (2.5%)
- bile stained vomiting,
- Pierre-Robin sequence (2%)
- imperforate anus
- congenital diaphragmatic hernia (2%)
- necrotising enterocolitis (1.8%)
- duodenal atresia (1.4%)
- Hirschprung's disease
- bronchiolitis
- Volvulus
- Other

Total Discharges 2013 N=558



NICU: infant mental health

- weekly one-hour **psychosocial meeting** discussing all babies and families where likely stay more than a week
- secondary consultation** offered within the meeting, and outside the meeting
- close **liaison, and collaborative work** with social work and other professionals
- direct work with infants at risk and family** as referred by other NICU clinicians (we see about 10% of all admissions to NICU)
- tertiary consultation:** training, supporting nursing staff
- research projects:** '*Robin*': *evaluating parental reflective capacity (mentalization) in nicu*
- participation in the **development of the overall care model** in NICU: '*Cocoon*'
- (more infant-focused and parent care)



'Maddie' aged 18m teases her mother

- 18mo infant with complex cardiac problems and recent surgery
- Some medical complications
- Maddie withdrawn & fearful
- Mother sleeps in her hospital room,
- Maddie draws her mother to her with a game with her dummy/pacifier

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15mo girl : complex congenital heart disease:

Multiple procedures, operations and hospitalisations:
Distressing **traumatic stress syndrome symptoms** of crying, refusing to walk at the hospital, nightmares:

In session :

Child engages playfully with therapist, her mother watching "Off! Off!" she says and tries to pull off the blood pressure cuff

Sudden facial expression of pain

She seeks control, uses **play to communicate**

Demonstrates **embodied/procedural memory** of her physical pain

Her mother becomes **more free to hear her pain**..and joins in the play, and at home

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Engagement with the baby: techniques

The therapist respectfully and playfully uses her own self, her own body to engage the baby with:

- Gaze
- Voice
- Touch
- Spoken Word
- Use of toys
- Occasionally physical holding
- The construction of these in sequences of responsive interaction

- Must experience taking risks with the baby..take chances, as does a parent
- The process of **rupture and repair**.. Tronick, Beebe
- The therapist may seem **silly or 'sloppy'** as discussed by Stern

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Importance of humour: 'Clowning' and Playfulness

- 'Infants respond to the absurd behaviour of others and *smile and laugh back* from age 3 months on, responding to different forms of "clowning": an odd face to hidden finger; infants develop their own form of clowning

Mireault et al Johnson Johnson State University and Reddy, V

Play is woven throughout the intervention, even with a sick baby...eg gaze play, peek a boo

(dummy game of 18mo Maddie)

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The hospital-based infant mental health clinician works :

- directly with **the infant** and
- the **infant's parents, their relationships and the extended family**
- medical and nursing staff** caring for the child
- the **overall hospital ecology** (Minde 2000)
- the **world of the child external** to the hospital.

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Parental Mentalization

- Mentalization is the capacity to *envision mental states in the self or the other*
- This begins with a parent's capacity to hold her baby in mind, and by doing so, it enables the baby to understand that they have a mind
 - Therefore, the mother mentalizing about the baby is crucial in the child's developmental of mentalization capacities

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Thinking about RF in NICU:

- The concept of **reflective functioning** has not been systematically studied within a NICU environment
- we have been using our own capacity for reflective functioning clinically to
 - Hold the baby in mind when we are present with the baby**
 - Help parents hold babies in mind within an environment characterised by trauma and distress**
 - Help parents in getting to know and connect with their baby as a person**
- anxiety and stress can impact on a person's reflective capacity
- having higher reflective capacity can be protective in circumstances of trauma.

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Goals of the process of engagement with the baby

Why make a specific connection with the infant in her own right?

- Acknowledge the importance of the infant's own self and identity, the baby as a person
- Acknowledge the infant's own capacities for understanding and giving meaning to behaviour
- The interview becomes the *infant's interview, as if it was her own possession* (see Winnicott (1971) on the role of the therapeutic consultation)

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Neonatal Behavioral Observation NBO @thewomens Melbourne



Meeting the baby & Relationship Building

The 18 items include observations of the infant's:

- capacity to **habituate** to external light and sound stimuli (sleep protection)
- the quality of **motor tone and activity level**
- capacity for **self-regulation** (including crying and consolability)
- **response to stress** (indices of the infant's threshold for stimulation)
- **visual, auditory and social-interactive capacities** (degree of alertness and response to both human and non-human stimuli)



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Parental Embodied Mentalizing Shai & Belsky (2011)



Parental reflective capacity/mentalizing:

- Parents capacity to appreciate, even unconsciously, their infant's mental states...Not just measured with semantic and verbal expression, **but includes** :
Embodied Mentalizing Capacity : which is to
 - implicitly conceive, comprehend and extrapolate the infant's mental states from the infant's whole-body movement*
 - adjust their own kinaesthetic patterns accordingly.*

<To engage with the baby or toddler the therapist could do the same>



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Gaze

- From the moment of meeting the **therapist looks to the baby** to see how she looks to the therapist as well as her parents and other family.
- There is the process of **looking at** versus **seeing**(to understand some meaning)
- The baby in the therapist should be able to share a **range of emotional experiences**: joy fear, anxiety, anger, shame, surprise



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Conclusions



- Acknowledge the baby has a *mind* from the start of our therapeutic work: *the start of baby's life*
- In the context of overall therapy plan **the baby is the subject of our relationship intervention**
- Work directly with the sick baby and her embodied mind, *this may seem to intensify psychic pain*, but maybe it will make living with illness, near death or despair easier
- Many parents are *extraordinary devoted parents* (but not perfect or totally loving)
- Allow for **hatred and anger**
- **There are risks to direct engagement but**
- **Therapist should be directly engaging the baby in play, even when very sick**



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Necessary Parental Protective Emotional Distance: Reduced Reflective Capacity



- 'Ordinary good-enough' parents faced with new or old **trauma** may need to distance themselves from the emotional experience and inner world of their own baby (see Winnicott)
- This **may be protective in the short term**, but problematic in the long term
- The emotional pain may be too overbearing, distressing and disorganising
- The baby may be 'left alone' and poorly regulated
 - Some stressed parents may have had persistent **complex trauma** themselves
 - Or a "**disorganised attachment dyadic relationship**" in the face of the memory of a **frightened-frightening** caregiver of their own infancy



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