



True Colours

Children's Health Trust

Te Oranga O Nga Tamariki



Keeping Families Standing in the Midst of Challenging Times



Cynthia Ward CEO/Nurse Specialist

True Colours Children's Health Trust

- True Colours Children's Health Trust is a child health service set up in 2004 to support seriously ill children and their families – from birth – 18 years.
- Psychological support is offered to all family members.
- Nursing collaboration/consultation is applicable when a child is seriously ill.











Parents in NICU

- Parents are often young, and inexperienced with illness and potential death.
- They carry the burden of the illness and decision-making around the treatments their child may need.
- They require information, knowledge and support to care for their child.

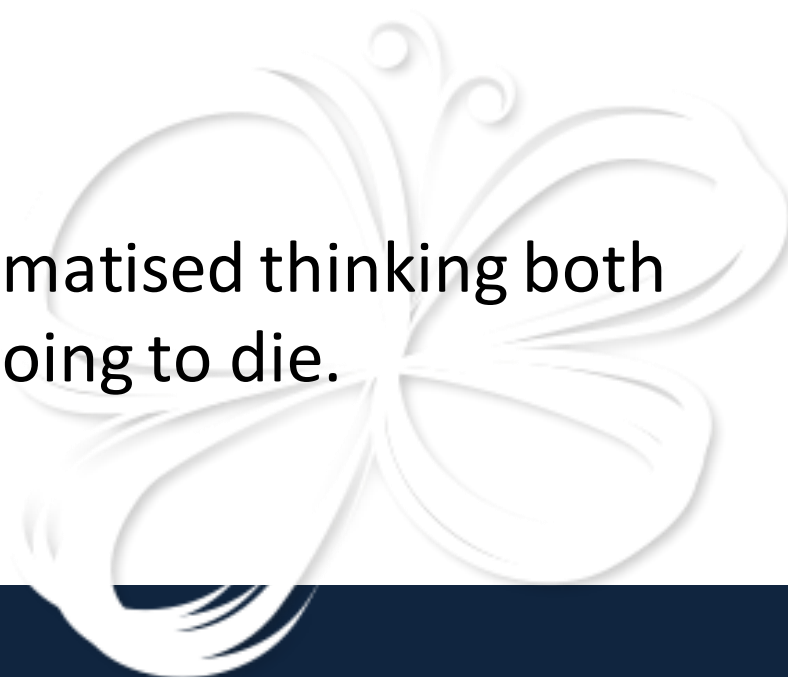


Information and knowledge

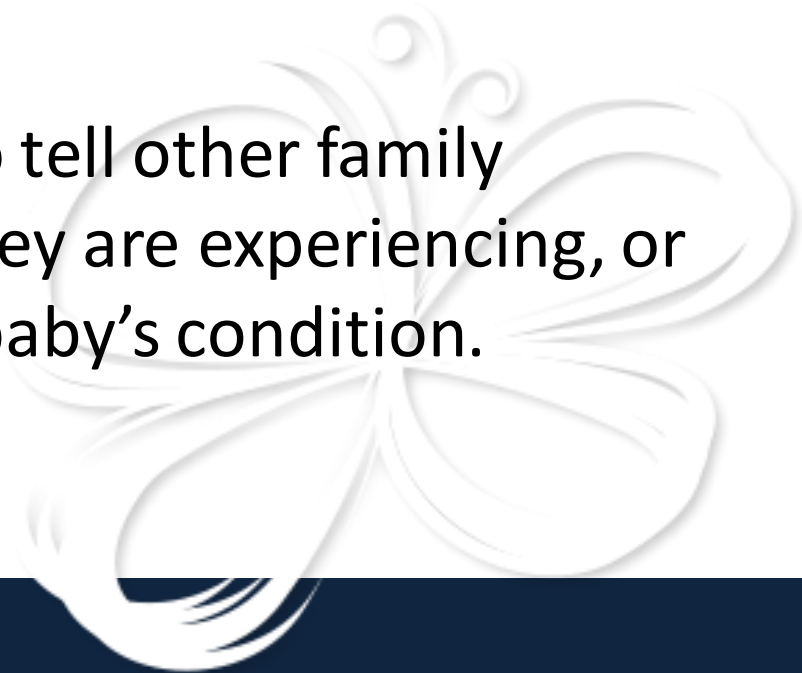
- “Parents with a baby born at the threshold of viability do not always receive sufficient counselling during an emergency admission and as a consequence, are not well-informed to accept withdrawal of treatment or quality of life decisions”.

Schroeder, 2008

- Husbands/partners often traumatised thinking both their partner and baby were going to die.



- A woman may grieve the loss of her pregnancy, not being able to hold her baby, or to breastfeed.
- A father may not know how to relate to his partner, or to his baby.
- Parents may not know how to tell other family members and friends what they are experiencing, or how to inform them of their baby's condition.



- Parents may feel isolated from other members of the family and homesick.
- Parents maybe fearful, sleep deprived, anxious, suffering from post-traumatic stress, and fear of the unknown.

Holditch-Davies et al., 2003; Obeidat et al., 2009

- Parents fear the death of their baby, with anxiety impeding their ability to interact with the baby.

Guillaume et al., 2013

- Parents feel separated from their baby when admitted to NICU, the technology acting as a barrier.

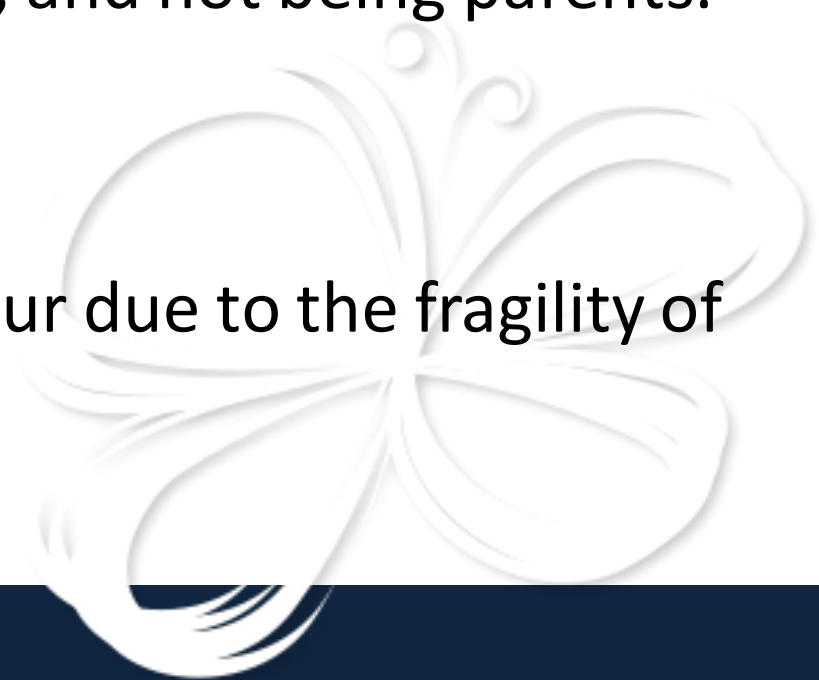
Treherne et al., 2017

- Parents feel overwhelmed and disorientated, a liminal state of being parents, and not being parents.

Lasiuk et al., 2013

- Emotional separation can occur due to the fragility of the baby.

Flacking et al., 2012



Long term impact of experiences in NICU

- Parental stress emanating from the NICU experience potentially influences parenting behaviour and long-term emotional problems and health alteration.
- Evidence suggests that emotional stress may not abate over time and that parents are at risk for delayed response.

Busse et al 2013



- Evidence of post-traumatic stress disorder is identified in some parents following preterm birth and experiences in NICU.
- The high levels of stress can last beyond the baby's first year of life and have long-term effects between baby and parent.

Sweet & Mannix 2012

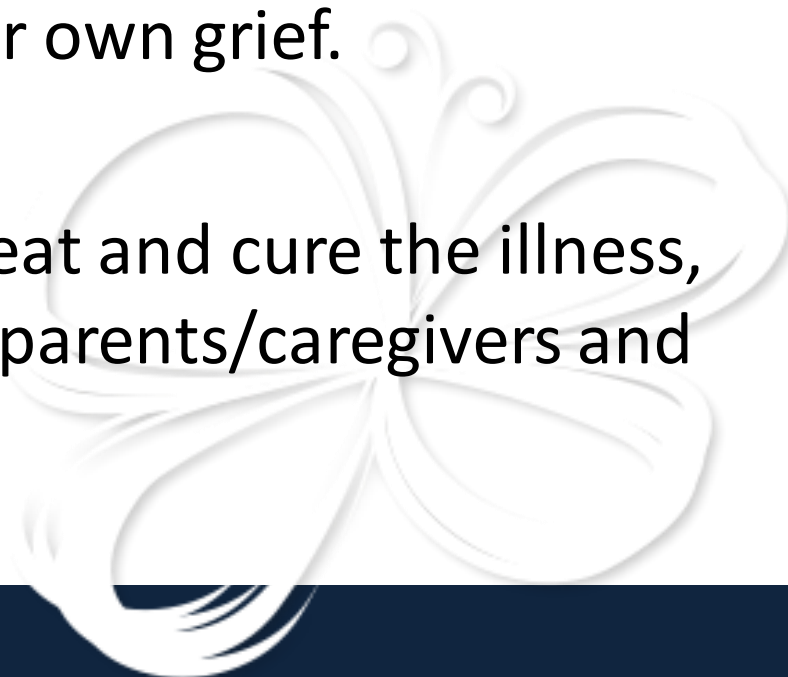


- Parents express anguish, feeling excluded from being with their baby, not having information about their babies care and the decisions required.
- Grief and loss of not having a healthy baby, full term, losses along the way.

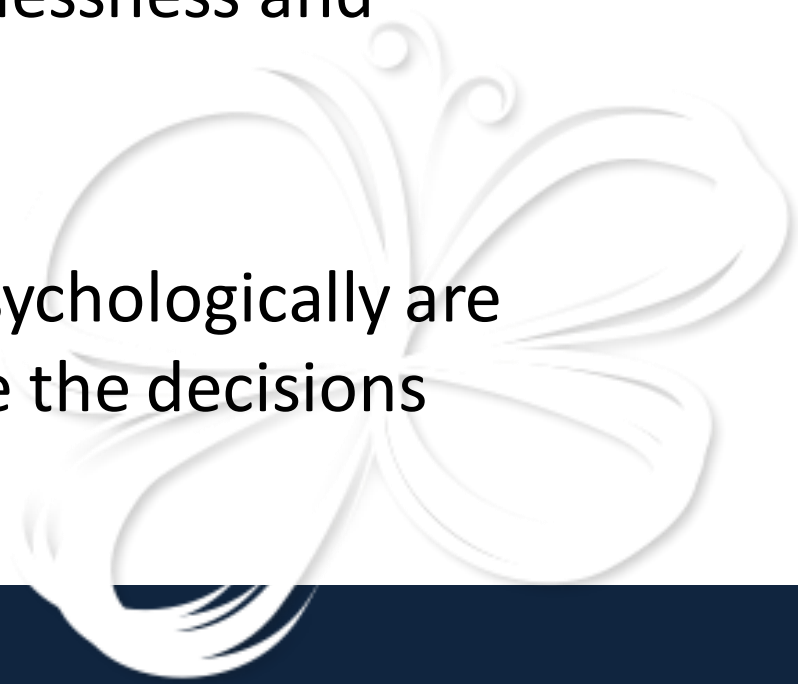


The impact on health professionals

- Health professionals often find it challenging to care for the baby who may possibly die.
- We are often confronted with feelings of helplessness and powerlessness, needing to confront our own fears of dying and our own grief.
- Faced with inadequacies to treat and cure the illness, while supporting the grieving parents/caregivers and the baby.



- The role we have as health professionals is to support and guide the parents to optimize care of their baby to support quality of life.
- Support given to parents to care for their baby decreases the feelings of helplessness and powerlessness.
- Basic needs physiologically, psychologically are important for parents to make the decisions required.



- Professional collaboration is important in caring for the baby.
- The family is an essential part of this collaborative care – partnership of care is paramount.
- Nurses have a professional responsibility to parents.

Trajkovski et al 2012



- Establishing relationships with the parents and families will contribute to high quality care.
- Parents feel less stressed when health professionals make them feel welcome in the unit. This can assist in helping them bond with their baby.

Gibbs et al., 2015

- Nursing actions that reduce parental stress improve both parental health and behaviour.

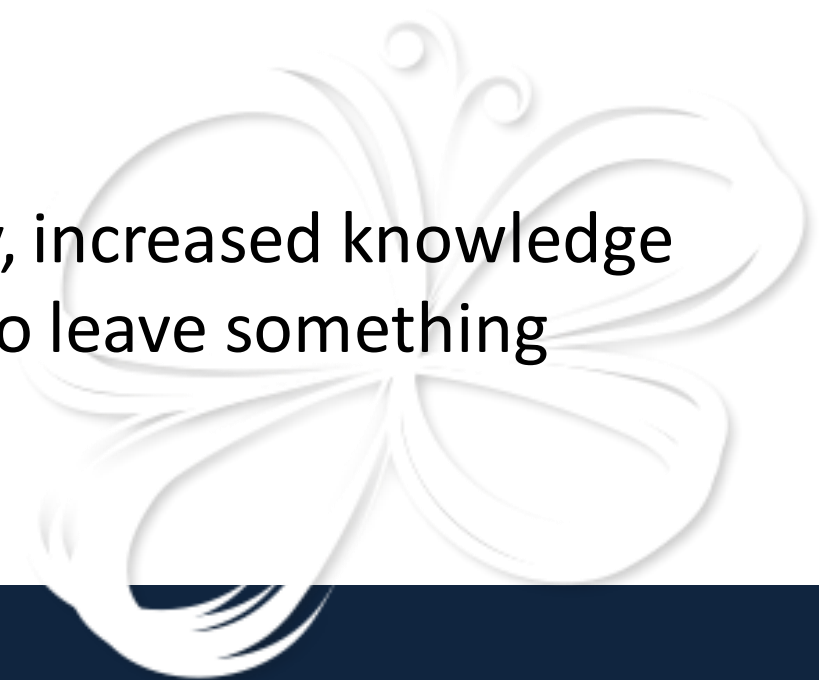
Busse et al 2013



What worked well for parents in NICU

- Communication is the key to partnerships working well between parents and health professionals.
- Networking and having an openness to share knowledge and information widens the safety net for families caring for their baby.
- Physical closeness to the baby, increased knowledge with contact, and being able to leave something personal with the baby.

Guillaume et al., 2013



- *“the skin-to-skin, I loved it . . . feeling her, having her pressed against me. I said to myself, she's really my baby, mine, today. I felt that I was her mother before the skin-to-skin, but there . . . that's it, she was lying there, peaceful”.*
- *"I arrive, there are 3 physicians in the room, a blue sheet over my baby. And there, I panic! The doctors say to me, "You can't come in." I say to myself, they've put this sheet so that I can't see. . . They're taking her to the morgue. Fortunately, there was someone who saw that I was stunned and explained to me: They're changing the catheter““*

Guillaume et al., 2013



What do parent's need?

- 11 dimensions of care identified by parents that were important:
- Assurance, caring, communication, consistent information, education, environment, follow up care, pain management, participation, proximity and support.

Conner & Nelson, 1999



Dimensions of care

- Assurance, care and support is something that makes all the difference to how a parent feels when in a place of personal crisis.
- Communication, education, information, allows parents to make the decisions they need to for their baby and their families.



Core principles of family centred care

- Listening and respecting, sharing of information.
- Flexibility, recognising and building on strengths of individuals and their families.
- Providing formal and informal support systems.
- Collaboration at all levels.

Heffernan et al., 2014



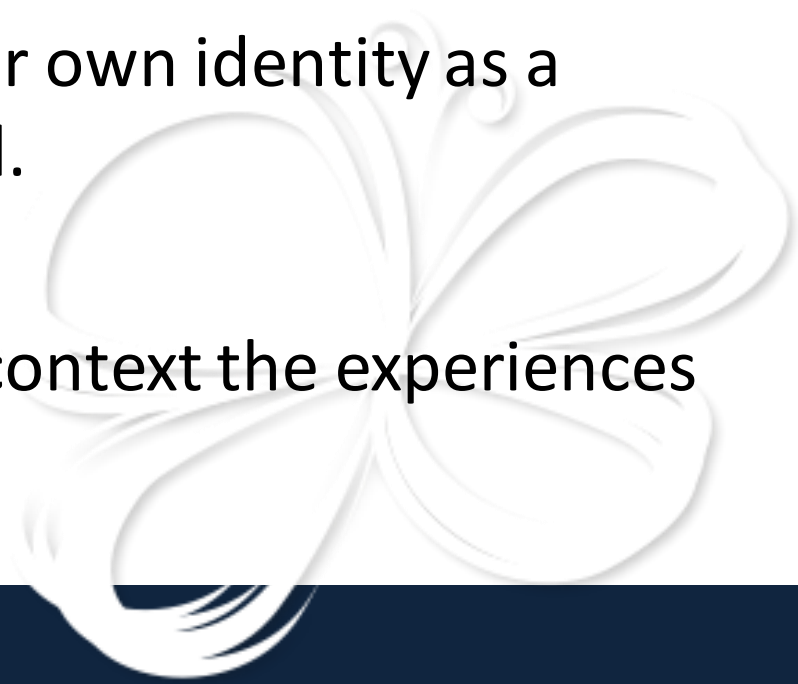
Empathetic and compassionate care

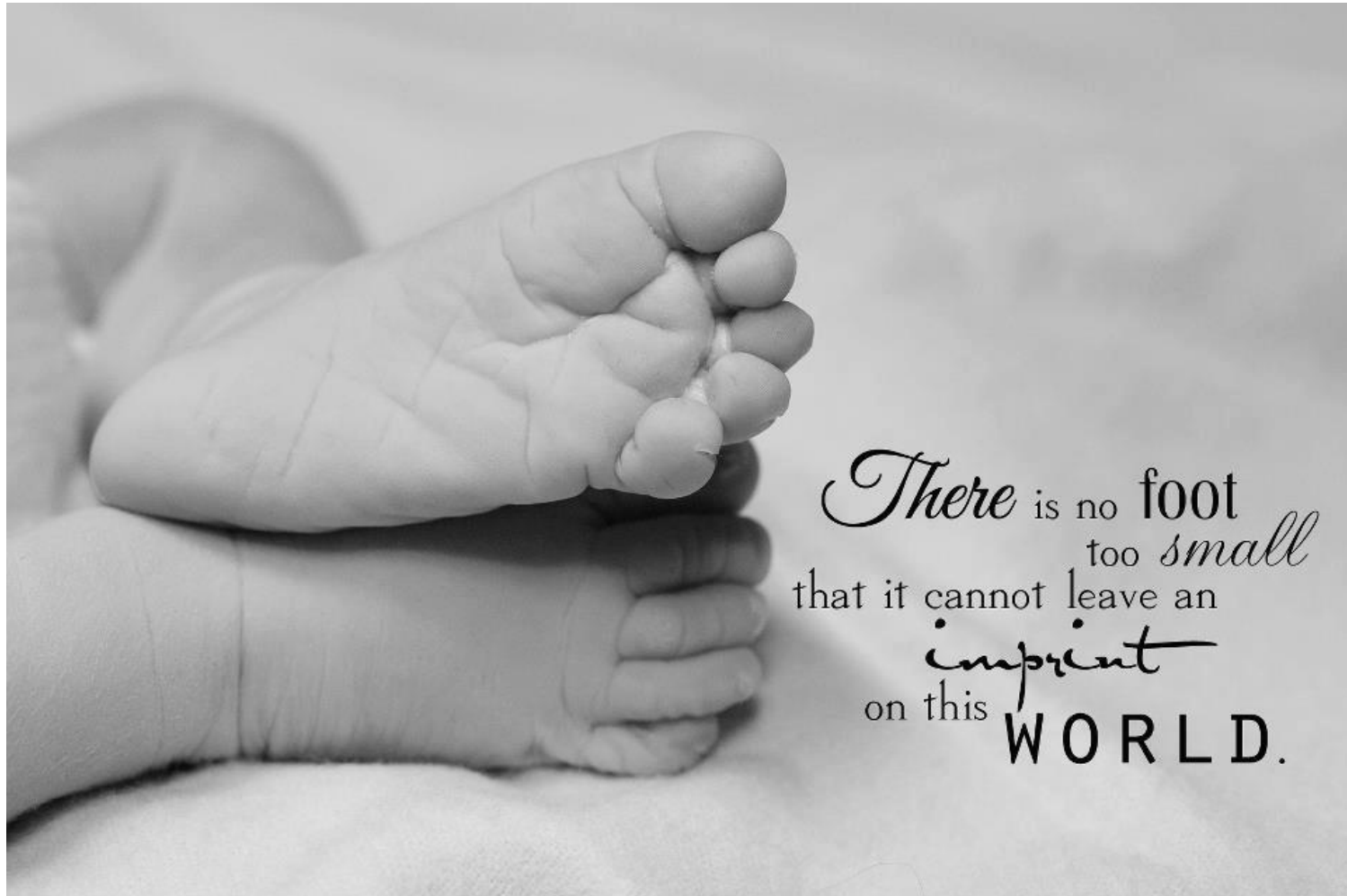
- To view the parent's world and their experiences of their fragile baby.
- To be non-judgmental and able to understand parent's perspectives and emotional stressors, and to communicate this understanding.
- Partnerships with parents that are empathetic and compassionate.



Resiliency and courage

- Determining a family's strengths and highlighting these strengths in ways that build their resiliency and hope in the unexpected and uncertain times of their NICU experiences.
- Assisting a parent to view their own identity as a parent as well as an individual.
- Normalising within the NICU context the experiences of parents.





There is no foot
too *small*
that it cannot leave an
imprint
on this **WORLD.**

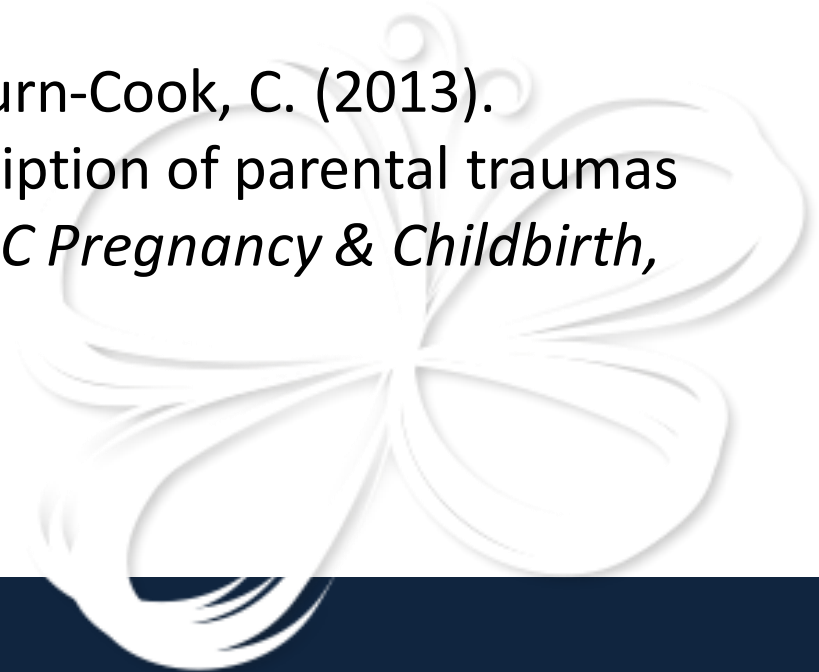
References

- Busse, M; Stromgren, K; Thorngate, L. & Thomas, L. (2013). Parents' Responses to Stress in the Neonatal Intensive Care Unit. *Critical Nurse Journal* 33(4). 52-60
- Blust, L., (2010). Health Professional Burnout. End of life/Palliative Education resource Centre.
- Catlin, A. & Carter, B. (2002). State of the Art: Creation of a Neonatal end of life Palliative Care protocol. *Journal of Perinatology* 22. 184-195.
- Conner, J.M, & Nelson, E.C. (1999). Neonatal Intensive Care: Satisfaction Measured from a Parent's Perspective. *Paediatrics* 103(1). 336-349.



- Flacking, R., Lehtonen, L., Thomson, G., Axelin, A., Ahlqvist, S., Moran, V. H., ... Dykes, F. (2012). Closeness and separation in neonatal intensive care. *Acta Paediatrica*, 101(10), 1032–1037.
- Gibbs, D., Boshoff, K., & Stanley, M. (2015). Becoming the parent of a preterm infant: A meta-ethnographic synthesis. *British Journal of Occupational Therapy*, 78(8). 475–487.
- Guillaume, S., Michelin, N., Amrani, E., Benier, B., Durrmeyer, X., Lescure, S., Bony, C., Danan, C., Baud, O., Jarreau, P., Zana-Taieb, E., & Caeymaex, L. (2013). Parents' expectations of staff in the early bonding process with their premature babies in the intensive care setting: a qualitative multicentre study with 60 parents. *Pediatrics*, 13. 18.

- Heffernamm J. Gustafson, K., Packard, S., & Tooley, L. (2014). What works: All in the family- How a family advisory council promotes family-centred care in the NICU. *American Nurse Today*, 9(6).
- Holditch-Davis, D., Bartlett, T. R., Blickman, A. L., & Miles, M. S. (2003). Posttraumatic stress symptoms in mothers of premature infants. *Journal of Obstetric Gynaecology & Neonatal Nursing*, 32.161–171.
- Lasiuk, G. C., Comeau, T., & Newburn-Cook, C. (2013). Unexpected: An interpretive description of parental traumas associated with preterm birth. *BMC Pregnancy & Childbirth*, 13(1).13.



- Obeidat, H. M., Bond, E. A., & Callister, L. C. (2009) The Parental Experience of Having an Infant in the Newborn Intensive Care Unit. *Journal Perinatal Education*, 18. 23–29.
- Schroeder, J. (2008). Ethical Issues for Parents of Extremely Premature Infants. *Journal of Paediatrics & Child Health*, 44(5). 302-304
- Treherne, S. C., Feeley, N., Charbonneau, L. & Axelin, A. (2017). Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU. *JOGNN*, 46. 737–747.

