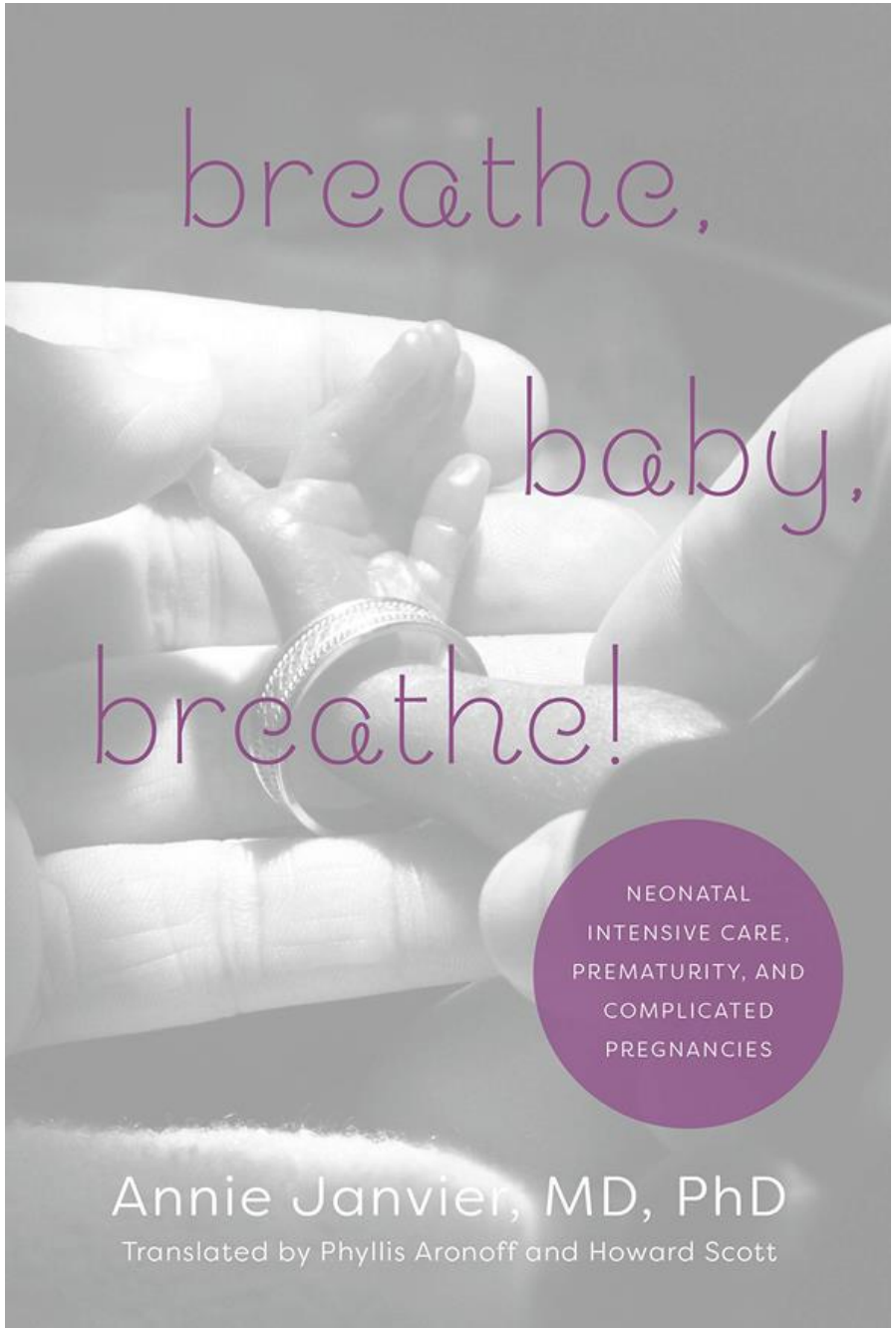
Helping parents cope when their baby is in the NICU

Annie Janvier, MD, PhD

Disclosure

No financial relationships with a commercial entity producing healthcare related products and or services.
No conflict of interest

Personal disclosure



Objectives

1. Understand the complexity of the parent/family experience
2. Identify opportunities for improvement
   - Communication
   - Flexible care models (assessing for benefit AND risk)

The NICU parent experience

Trauma

Separation

Pain

Grief

Guilt

Disappointment

Loss

Death

Celebration

Connection

Attachment

Milestones

Confidence

Purpose

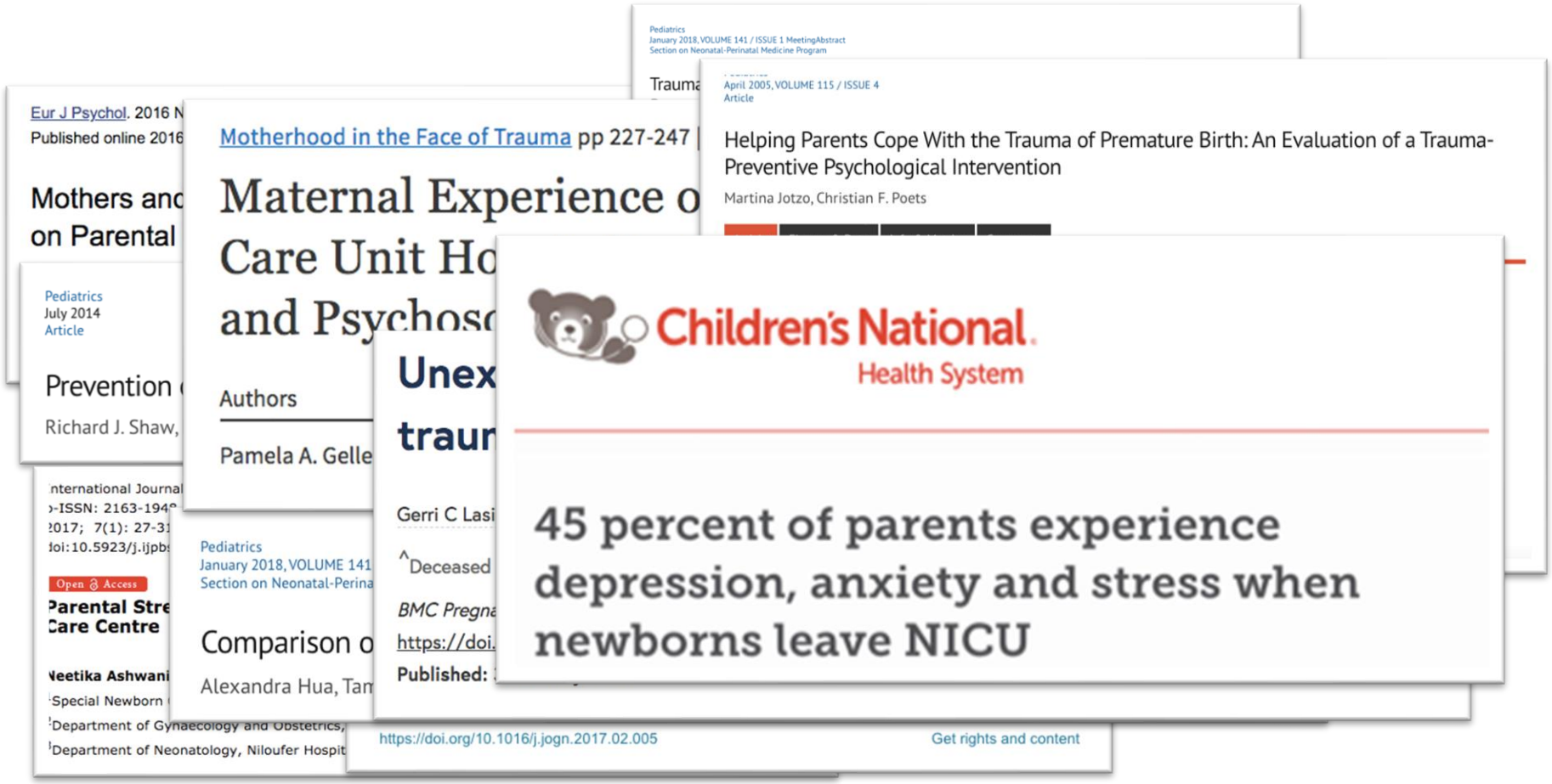
Meaning

Acceptance

Pride

Survival

The NICU changes people …



Positive transformations

- Gratitude
- Perspective
- Relationships
- Forgiveness
- Definitions of perfection
- Strength/vulnerability – knowing who you are and what you can do
- Intolerance of clinical mediocrity

Stronger and More Vulnerable: A Balanced View of the Impacts of the NICU Experience on Parents

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Opportunities for improvement: the basics

Ethics and Etiquette in Neonatal Intensive Care

Annie Janvier, MD, PhD; John Lantos, MD; for the POST Investigators

When parents voice their dissatisfaction with the neonatal intensive care unit (NICU), it is often not because they think their baby has not received good medical care. Instead, it is often because their needs have not been addressed. Policy statements and pedagogy alike urge professionals to be empathetic, compassionate, honest, and caring. However, these theoretical concepts are generally endorsed without practical suggestions on how to achieve these goals. Negative encounters for parents are generally not about the caregivers' technical expertise or knowledge and often reflect a failure in a different domain. Simple rules of etiquette are not always applied in a busy NICU or in the hospital at large. The investigators of the POST (Parents from the Other Side of Treatment) group are health care professionals who regularly communicate with parents of sick children and who were also "NICU parents." We have developed an etiquette-based systematic approach to communication with families in the NICU. These specific and practical recommendations may help parents feel well treated and respected as they go through a challenging NICU stay.

JAMA Pediatr. doi:10.1001/jamapediatrics.2014.527
Published online July 28, 2014.

Author Affiliations: Author affiliations are listed at the end of this article.

Group Information: The POST (Parents from the Other Side of Treatment) investigators are listed at the end of the article.

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A minimum for medical human interactions

Etiquette-based medicine. Kahn MW. N Engl J Med. 2008 May 8;358(19):1988-9.

- Introduce yourself
  - Sit down
- Know the name of the patient
- Why am I /are we there?
- How do you feel today?
- If physical exam needed, explain why, good time to do it?

This baseline is needed of there is to be any meaningful interaction

-many comments and criticisms

Is it really that obvious?

Appraising the practice of etiquette-based medicine in the inpatient setting, Tackett et al. J Gen internal med. 2013 Jul;28(7):908-13

Each time the physician entered a patient's room, a single observer recorded whether the "etiquette-based medicine" behaviors were performed

Results: with 30 % of the patients, none of the behaviors were performed. The average EtBM score for the physicians was 22.3 % (SD 10.9 %). Physicians who spent more time with patients were more likely to perform behaviors. Sitting down (p=0.026) and EtBM scores (p=0.019) were associated with physician-specific Press-Ganey ratings.

Conclusions: "Etiquette-based medicine" was infrequently practiced by this sample of hospitalist physicians. Improving performance of etiquette-based medicine may improve patient satisfaction.

Say your name, say my name

- Do you use the name of the baby?
- How do parents know who you are?
  - Uniforms and/or name tags?
- Do you have somewhere to sit down?
  - Do you all stand up with computers?
  - How many people are in the room/rounds?

Parental sense of competence

- Parental sense of competence scale (Gibaud-Wallston & Wandersman)
  - Associated with parental presence
- Identification of « good parent beliefs » and what is associated with them
  - Impacts on pediatric and parental outcomes
  - Chris Feudtner et al

"Good-Parent Beliefs": Research, Concept, and Clinical Practice

Meaghann S. Weaver, MD, MPH,[a] Tessie October, MD, MPH,[b,c] Chris Feudtner, MD, PhD, MPH,[d,e] Pamela S. Hinds, PhD, RN, FAAN[c,f]

Parents of ill children have willingly identified their personal beliefs about what they should do or focus on to fulfill their own internal definition of being a good parent for their child. This observation has led to the development of the good-parent beliefs concept over the past decade. A growing qualitative, quantitative, and mixed-methods research base has explored the ways that good-parent beliefs guide family decision-making and influence family relationships. Parents have expressed comfort in speaking about their good-parent beliefs. Whether parents achieve their unique good-parent beliefs definition affects their sense of whether they did a good job in their role of parenting their ill child. In this state-of-the-art article, we offer an overview of the good-parent beliefs concept over the past decade, addressing what is currently known and gaps in what we know, and explore how clinicians may incorporate discussions about the good-parent beliefs into clinical practice.

A decade and a half ago, a qualitative inquiry regarding the decision-making of parents of children with terminal cancer revealed that these parents readily defined themselves as "trying to be a good parent in making care decisions in the child's best interest."[1] When the parents specifically offered the term "good parent" to describe what they aimed to do, and to be, with their decision-making, they maintained that this term was affirming both the duty and devotion relevant to their role.

Parents of ill patients can describe a working definition of their personal set of beliefs that inform their sense of duty with regard to parenting their

clinicians were involved, a primal and personal definition that was relevant before the child's birth and lived through the longevity of parenting.[5]

Since the initial recognition of a good-parent beliefs concept, authors of a variety of research studies have explored the situations impacting the initial and longitudinal definition of the good-parent beliefs as self-defined by parents of ill children. The extent that parents of ill children achieve their personal definition of being a good parent has been described by parents as helping them cope with their child's clinical situation.[3,6] The extent that bereaved parents perceive they reached their personal definition of being

abstract

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Dr Weaver drafted the initial manuscript; Dr October revised the manuscript and critically reviewed the manuscript for important intellectual content; Drs Feudtner and Hinds conceptualized the work and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

DOI: https://doi.org/10.1542/peds.2019-4018

Accepted for publication Jan 28, 2020

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: National Institute of Nursing Research

Most frequent « Good parent beliefs » (Chris Feudtner et al)

- (1) making sure my child feels loved
- (2) focusing on my child's health
- (3) making informed medical care decisions
- (4) advocating for my child with medical staff
- (5) focusing on my child's comfort
- (6) focusing on my child's quality of life
- (7) putting my child's needs above my own when making medical care decisions
- (8) staying at my child's side
- (9) keeping a positive outlook
- (10) focusing on my child having as long a life as possible
- (11) focusing on my child's spiritual well-being
- (12) keeping a realistic outlook.

Let’s study this in Neonatology!

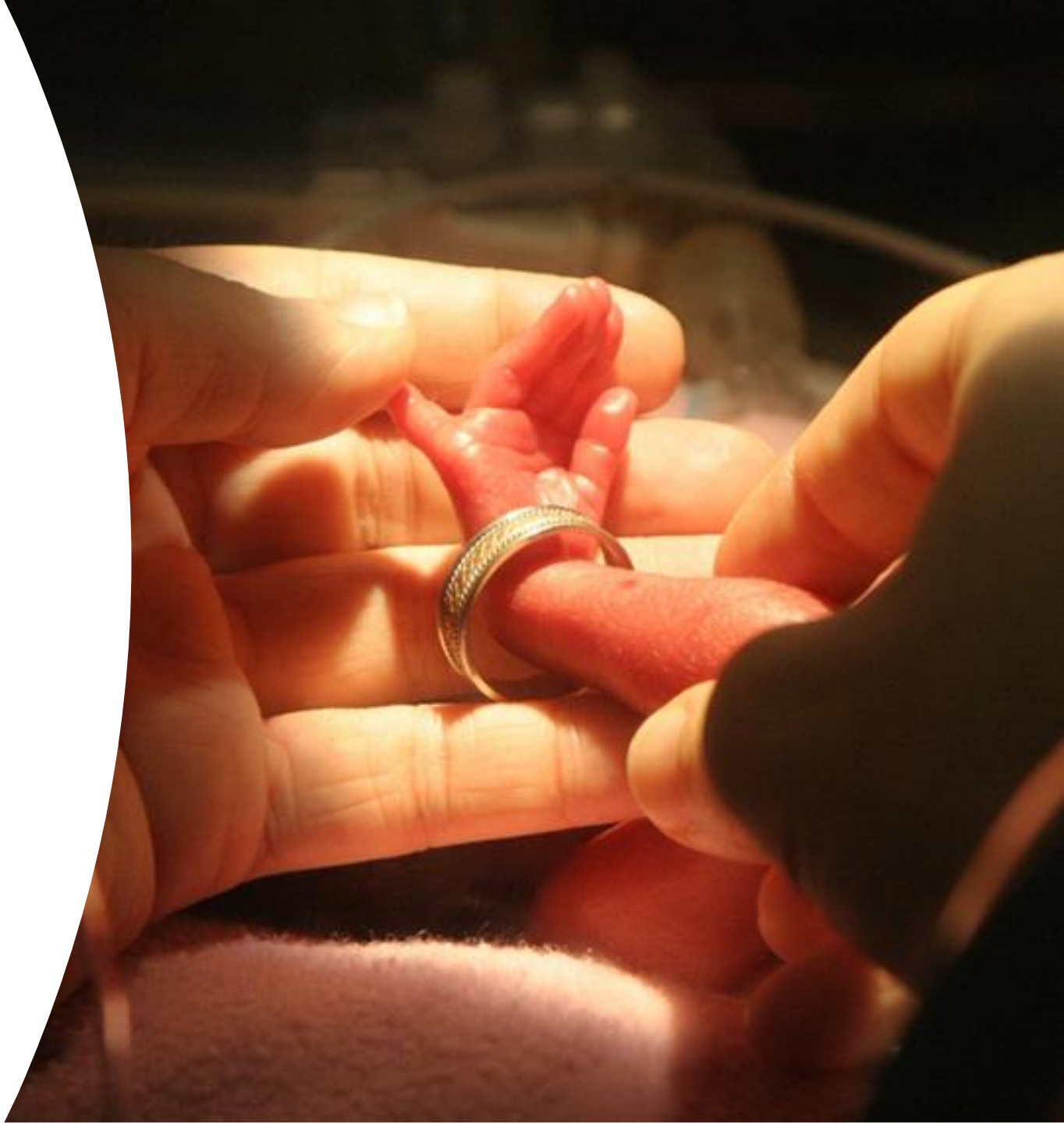
Helping Parents Cope in the NICU

Marlyse F. Haward, MD,[a] John Lantos, MD,[b] Annie Janvier, MD, PhD,[c,d] for the POST Group

abstract

Parenting in the NICU is an intense journey. Parents struggle to build intimacy with their child amid complex emotions and medical uncertainties. They need to rapidly adapt their vision of parenthood to the realities of intensive care. The psychological impact of this journey can have important effects on their psychological health. For parents of sick older children, “good parent” beliefs have been shown to foster positive growth. This concept is also essential for parents of infants in the NICU, although their path is complex.

We write as clinicians who were also families in the NICU. We suggest parents need to hear and internalize 3 important messages that overlap but are each important: you are a parent, you are not a bad parent, and you are a good parent. We offer practical suggestions to NICU clinicians that we believe will help NICU parents cope while their infant is in the NICU and afterward.



Good parent beliefs in Neonatology are different

Marlyse Haward, John Lantos, Annie Janvier on behalf of the POST group. Helping Parents Cope in the Neonatal Intensive Care Unit. Pediatrics. 2020 Jun;145(6):e20193567 (video included)

Parents need to:

- Feel like parents: support infant-parent attachment
  - Technology, what baby looks like, separation, not what parents usually experience.
- Not feel like bad parents: decrease guilt, not to inflict harm
  - Guilt associated with sick baby, “incompetent cervix”
- Feel like good parents: encourage psychological flexibility, avoid rigid family-centered care systems

How to address the guilt?

« *As a good parent, we always think about what we could have done better. You have to know there is nothing you could have done to prevent what has happened to your baby.* »

Bonding

- *« Many parents when they arrive here feel anxious, some tell us they don’t feel like parents. This is normal at the beginning but it will change and we will be with you all the way. »*
- *« All the alarms and machines can be stressful. Some parents told us they were afraid to visit. It is normal to feel like this at first. We will be there to support you. It will get better. »*

Bonding (example)

- Avoid: « *You will LOVE kangaroo care! »*
- Rather: « *Kangaroo care can help babies and mothers' milk production. For some parents, it is stressful at first, but eventually, most of them feel close to their baby during those special moments. It is normal to have many emotions and we will be with you at every step of the process*.»
- Beware of the « *congradulations* »

Empowering parents

« Thank you papa for taking him in your arms.Even if he is very preterm, he recognizes your voice, your smell and this is good for his brain. »

« Mikael is so lucky to have parents who speak to him and sing to him every day! This care is precious.»

« Suzie is lucky to have parents like you who ask all these questions and get involved.»

« Wow, Mathieu is one month old. This mean he has been receiving your milk for ONE month. You are a superwoman. This protects his life and gut better than anything we can do.»

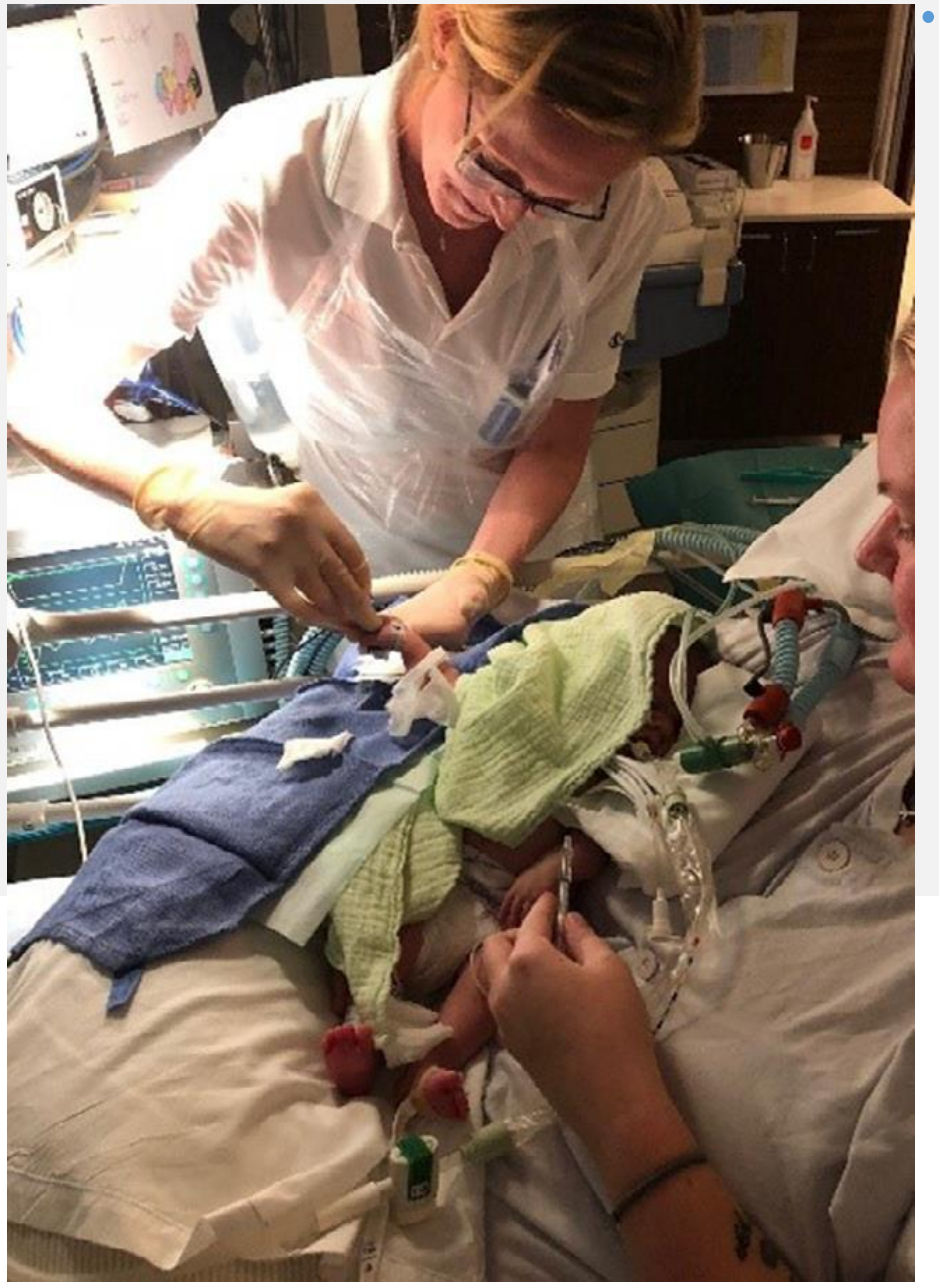
« The most important thing in Samuel's life at the moment is to have parents who love him and are there like you are.»

Opportunities for improvement: Family integrated care

- Philosophy of care has changed in Neonatology
  - Parents are part of the team
- « Transfer of care » from admission to discharge
- Already done for years in many NICUs

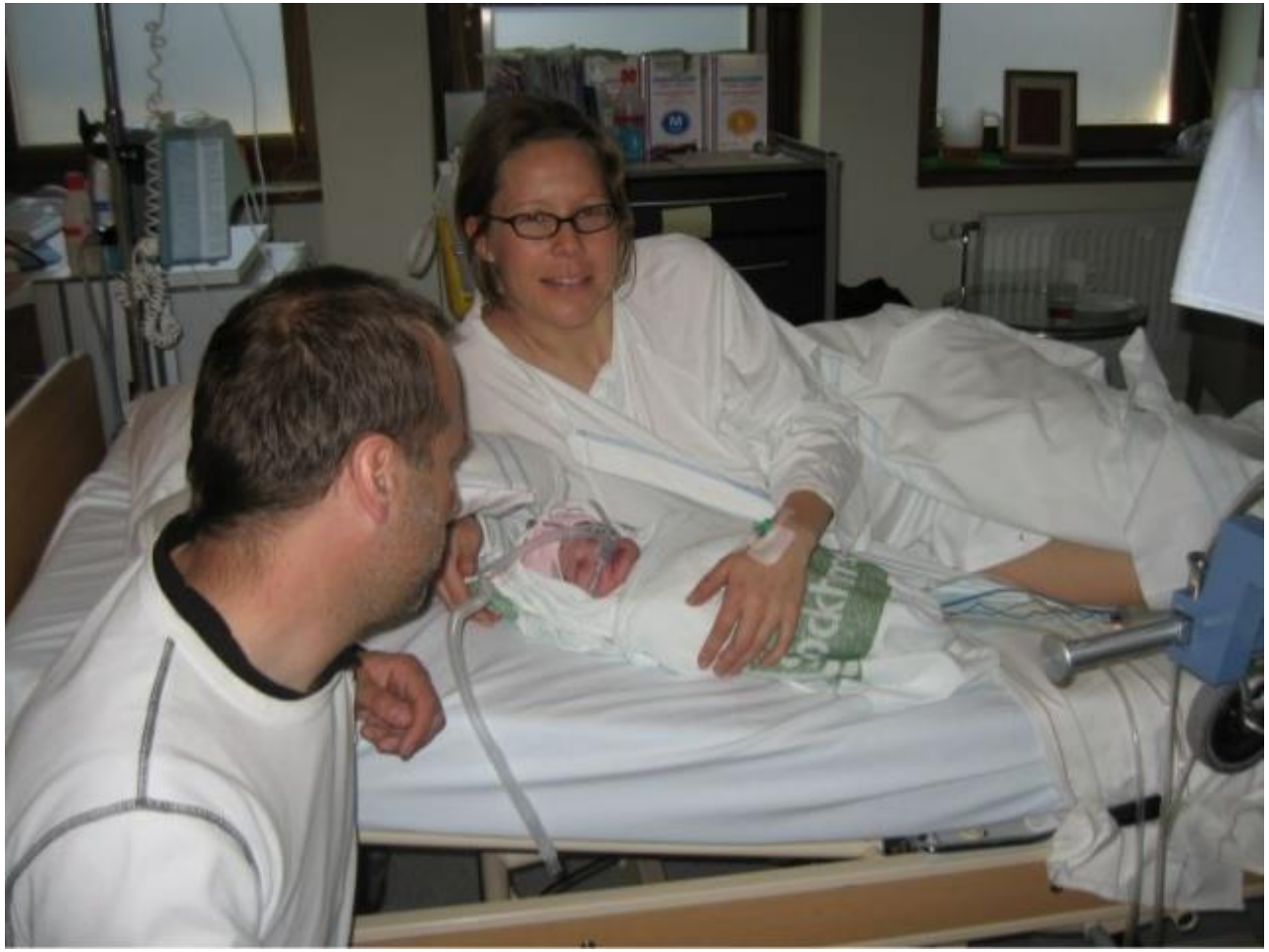
The Swedish approach to nurturing extremely preterm infants and their families: A nursing perspective
Blomqvist t al. Seminars of Neonatology, 2022

Picture 1 – Collaboration with the family; parent holding his sick newborn, while an older sibling watches a children's show, and has a snack.



The Swedish approach to nurturing extremely preterm infants and their families:
A nursing perspective
Blomqvist et al. Seminars of Neonatology, 2022

Single patient/family rooms (evidence based?)



Single patient (family) room

- **Decreases infections and noise ☺**
- **Increases parental presence (average) ☺**
  - Not for all patients
- Worse: less « Meaningful noise », associated with worse language outcomes for certain patients
- More reported maternal isolation
- Increased maternal stress the first month
- Decreases nursing mentorship and the time nurses spend with families

« the parent needs to want to come at the bedside »

Published in final edited form as:
J Perinatol. 2012 July ; 32(7): 545–551. doi:10.1038/jp.2011.144.

The Single Patient Room in the NICU: Maternal and Family Effects

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Abstract

Objective—To explore differences in maternal factors, including visitation and holding, among premature infants cared for in single patient rooms (SPR) compared to open-bay in the neonatal intensive care unit (NICU).

Study Design—Eighty-one premature infants were assigned to a bed space in either the open-bay area or in a SPR upon NICU admission, based on bed space and staffing availability in each area. Parent visitation and holding were tracked through term equivalent, and parents completed a comprehensive questionnaire at discharge to describe maternal health. Additional maternal and medical factors were collected from the medical record. Differences in outcome variables were investigated using linear regression.

THE JOURNAL OF PEDIATRICS • www.jpeds.com ORIGINAL ARTICLES

Auditory Exposure in the Neonatal Intensive Care Unit: Room Type and Other Predictors

Roberta Pineda, PhD, OTR/L[1,2], Polly Durant, MSOT[1], Amit Mathur, MD[2], Terrie Inder, MD[3], Michael Wallendorf, PhD[4], and Bradley L. Schlaggar, MD, PhD[2,5,6,7,8]

Objective To quantify early auditory exposures in the neonatal intensive care unit (NICU) and evaluate how these are related to medical and environmental factors. We hypothesized that there would be less auditory exposure in the NICU private room, compared with the open ward.

Study design Preterm infants born at ≤ 28 weeks gestation (33 in the open ward, 25 in private rooms) had auditory exposure quantified at birth, 30 and 34 weeks postmenstrual age (PMA), and term equivalent age using the Language Environmental Acquisition device.

Results Meaningful language ($P < .0001$), the number of adult words ($P < .0001$), and electronic noise ($P < .0001$) increased across PMA. Silence increased ($P = .0007$) and noise decreased ($P < .0001$) across PMA. There was more silence in the private room ($P = .02$) than the open ward, with an average of 1.9 hours more silence in a 16-hour period. There was an interaction between PMA and room type for distant words ($P = .01$) and average decibels ($P = .04$), indicating that changes in auditory exposure across PMA were different for infants in private rooms compared with infants in the open ward. Medical interventions were related to more noise in the environment, although parent presence ($P = .009$) and engagement ($P = .002$) were related to greater language exposure. Average sound levels in the NICU were 58.9 ± 3.6 decibels, with an average peak level of 86.9 ± 1.4 decibels.

Conclusions Understanding the NICU auditory environment paves the way for interventions that reduce high levels of adverse sound and enhance positive forms of auditory exposure, such as language. (*J Pediatr 2017;■■:■■-■■*).

FiCare is becoming the norm

- O Brien et al, Lancet Child Adol 2018
  - Improves breastfeeding rates, parental anxiety and depression
  - **BUT** inclusion criteria: minimal parental presence of 8h per day

- Exemples of QI projects since this publication: “goal that X% (60-80%) of parents”
  - Present their baby at clinical rounds
  - Are there during interventions
  - Tube feed their baby
  - Verify IV sites
  - Skin-to-skin care in the first 2h after birth
  - etc

Implementing flexible FICare

- Our PAF group refused to be part of the FiCare RCT
  - Inclusion criteria, FICare items for parents, etc
- Passionate people disagreed
- « Partnering with families » QI project was born

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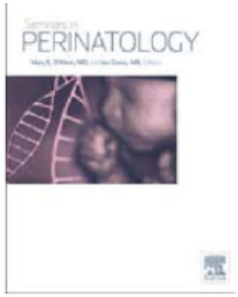
www.seminperinat.com



The ethics of family integrated care in the NICU: Improving care for families without causing harm

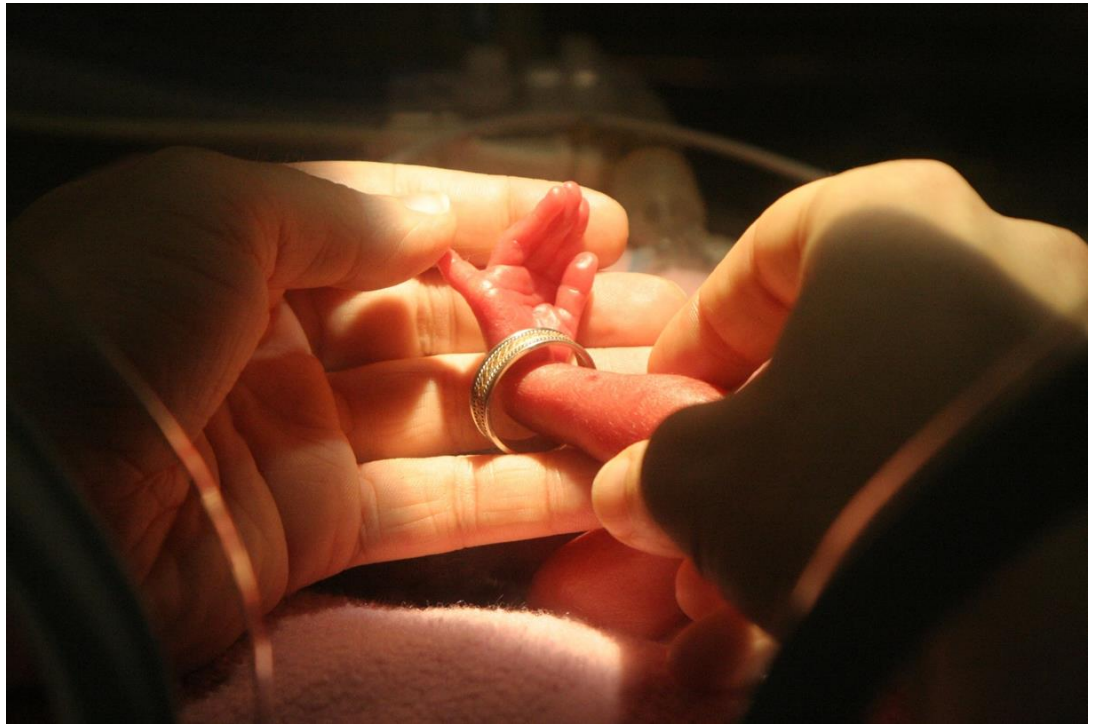
Annie Janvier[a,b,c,d,e,f,g,h,], Michael-Andrew Asaad[a,b], Martin Reichherzer[b], Catherine Cantin[b,h], Maia Sureau[i], Josée Prince[i], Thuy Mai Luu[a,c], and Keith J Barrington[a,b,c]*

Objective

- Examine the perspective of all stakeholders regarding FICare in the NICU
- Implement changes that are meaningful and important.

Participants

- **R**ecruited during a period of 3 months:



All **clinicians** working in the NICU:

- residents, fellows and neonatologists
- NICU nurses
- Other professionals:

RT, SW, psych, clerks, pharmacy, etc.

Parents:

- In the NICU > 1month or
- at follow-up visit at < 1year after discharge

Questionnaire

- Co-constructed by providers and NICU parents, included a long list of family integrated care items.

- For each item, 2 questions were asked:

In the NICU, AT THE PRESENT TIME, can parents (*item*), if they wish to?“

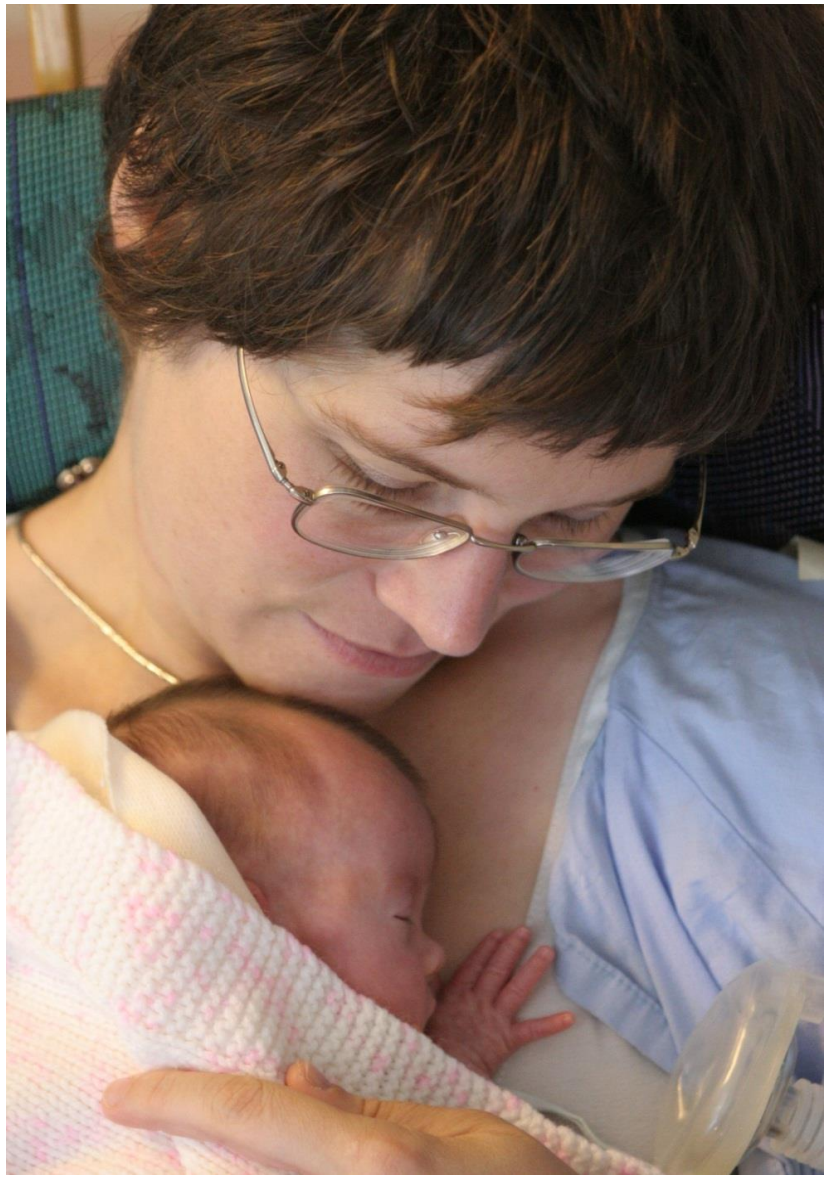
"IDEALLY, should parents be able to (*item*)?“

SUR L'UNITÉ EN CE MOMENT, **Si la condition du bébé le permet, les parents font ces soins s'ils le désirent**			**IDÉALEMENT** **Les parents DEVRAIENT POUVOIR faire ces soins s'ils le désirent**	
	Oui	**Non**	**Oui**	**Non**
Donner le bain	❑	❑	❑	❑
Changer la couche	❑	❑	❑	❑
Donner le boire au biberon	❑	❑	❑	❑
Allaiter	❑	❑	❑	❑
Donner le gavage	❑	❑	❑	❑
Donner les médicaments déjà préparés par le tube de gavage	❑	❑	❑	❑
Donner les médicaments déjà préparés par la bouche	❑	❑	❑	❑
Ajuster l'oxygène après approbation par l'équipe soignante	❑	❑	❑	❑
Prendre bébé non intubé sans cathéter ombilical	❑	❑	❑	❑
Prendre le bébé intubé	❑	❑	❑	❑
Prendre le bébé qui a un cathéter ombilical	❑	❑	❑	❑
Vérifier le site de l'intraveineuse	❑	❑	❑	❑
Changer les capteurs et le saturomètre (souvent après le bain)	❑	❑	❑	❑
Toucher leur bébé en tout temps	❑	❑	❑	❑
Lire une histoire ou chanter au bébé	❑	❑	❑	❑
Utiliser des effets personnels de la maison (doudou, pyjamas, mobile, etc)	❑	❑	❑	❑
Les parents peuvent être présents pendant				
- Une pose d'intraveineuse	❑	❑	❑	❑
- Un vaccin	❑	❑	❑	❑
- Une ponction lombaire	❑	❑	❑	❑
- Une intubation	❑	❑	❑	❑
- Une ventilation au masque lorsque bébé dé sature	❑	❑	❑	❑
- Une réanimation	❑	❑	❑	❑
- L'examen des yeux	❑	❑	❑	❑
- Les déplacements dans l'hôpital (Scan, salle d'opération, etc	❑	❑	❑	❑

« Please tell us how we can optimize the integration of parents in the unit »

Results

- 331 participants: 102 parents and 239 providers.
- For “basic care” items almost all participants answered FICare occurred in the NICU and should be standard of care



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Donner les médicaments déjà préparés par le tube de gavage	❑	❑	❑	❑
Donner les médicaments déjà préparés par la bouche	❑	❑	❑	❑
Ajuster l'oxygène après approbation par l'équipe soignante	❑	❑	❑	❑
Prendre bébé non intubé sans cathéter ombilical	❑	❑	❑	❑
Prendre le bébé intubé	❑	❑	❑	❑
Prendre le bébé qui a un cathéter ombilical	❑	❑	❑	❑
Vérifier le site de l'intraveineuse	❑	❑	❑	❑
Changer les capteurs et le saturomètre (souvent après le bain)	❑	❑	❑	❑
Toucher leur bébé en tout temps	❑	❑	❑	❑
Lire une histoire ou chanter au bébé	❑	❑	❑	❑
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- L'examen des yeux	❑	❑	❑	❑
- Les déplacements dans l'hôpital (Scan, salle d'opération, etc	❑	❑	❑	❑

Give bath,
Change diapers,
Touch baby at any time,
Kangaroo care,
Read to baby,
Sing to baby,
Be there for vaccinations,
Express their opinion,
Be there at rounds,
Ask questions during rounds
Be informed about baby's care and plans of care, etc

For more medical items:

Parents are all different

but all physicians want more

- The majority of physicians (>80%) wished for increased parent involvement, generally more than other clinicians and parents
  - 42% of parents do not want to tube feed their child
  - 45% do not want to present their child at rounds
  - 53% of parents do not want to be at resuscitations
    - 85% of physicians think parents should be there (vs 30% of nurses)

Parents identified important features of FICare: intimacy, proximity, "taking ownership" of their baby, being a family,

"being a good parent"

- *"I really enjoy doing these things, it made me feel like a real mother at first, and then at some point, like a good mother. I have failed my birth, but I can help her heal and be in charge a bit." (mother)*
- *"I think of doctors and nurses as the specialists of everything that happens to my baby, the medical stuff. I want to become a specialist of my baby, for all the non medical aspects" (mother)*
- *"It helped me become a father for real" (father)*
- *"He is supposed to be inside me at the moment. My uterus is supposed to do all these things, not machines. When I give him this kind of attention, I get this closeness back, the sense that I am doing my job" (mother)*

Downsides: FiCare or Family Imposed Care?

“Every day, a nice nurse would ask me if I would come back in the evening. I had 2 other small children at home who reacted to my absence and an exhausted husband. So I ended up every night either crying at home missing my baby, or crying in the NICU missing my other kids. Family integrated care occurs at home too. I wish they understood […] sometimes just asking us hurts.”

« I don’t know, this is not what I see myself doing as a parent. Like, inserting a tube myself so my baby can eat. This is a medical thing and I want to be a dad.[…] The goal is that she will go home without these tubes. So I really want to focus on being there, with her, not learn to become a nurse. »

Answer to open-ended question

- Many positive things
- 82% of parents wanted to meet other parents (in the unit and « old parents »)
- Parents appreciate clinicians, are generally happy
  - Thank the nurses more than all other clinicians
- Physicians are totally for more FiCare, everywhere
- Half the nurses want to increase parent participation

BUT

Half the nurses are critical towards FiCare iniatitives

When explaining their reservation, several themes were invoked: responsibility and role of parents and safety of patients

- *« This is my patient, and it is their baby. It is not their responsibility to do these things (such as hold baby for LPs!!). They should do the caring part parents do: change diaper, kangaroo = be parents. »*
- *« Parents do not have a nursing degree, they should not do these things. They don't have a professional order they subscribe to. »*
- *« I did not do a nursing degree for parents to do my job. »*
- *« There are just not things parents do, it is not safe and will cause stress on many mothers. »*

The biggest irritant for parents: variation of care in nursing practice

- Parents felt judged when this happened
- Leads to polarisation: good vs bad nurse
- « *The day nurse tells me my son is too fragile for kangaroo, after the change of shift, the evening nurse asks me why we did not do kangaroo today, that it is good for Ludo. What?? I was here all day. Who is the bad nurse there? Is one too scared and junior, or is the other one too cowboy and dangerous?* »
- *« What I find the hardest at the moment is to have different opinions on how much I should come here to breastfeed, what they think of bottles because my milk is not sufficient, and when I should place her on the breast. It makes me feel so incompetent. I am so mixed up. I don't know who to believe.* »

What did we do in our unit?

- Worked on the areas where parents are most dissatisfied and where team is least resistant to change:
  - Variations of nursing practice addressed: several protocols developped
  - Improve discharge planning

What did we do in our unit?

- Waiting to implement what is not as important to parents and where there is high resistance to change from team:
  - Parents giving tube feeds
  - monitoring IV site
  - Changing oxygen

- Speaking to parents differently about their preferences for more medical items (ex, presence during interventions)

How to ask parents?

« Just asking: « do you want to be here during the intubation? » makes me think that I need to be there. That this is what good parents do. And I want to be a good mother, or show them I am good. What kind of parent wants to leave their child when asked if they want to stay? If there is no good answer, they should say something like: « some parents want to be there during the intubation, it makes them feel in control, for these parents, imagining is worse than seeing. For other parents, it is different, seeing an intubation on their child is too stressful and it does not help them or their family. What kind of parent are you? »

(Mother of 25 week baby)

Information for parents

-Prenatal support group (Ombrelles)

-Welcome book written with parents, for parents

-Videos: visit of the unit, survival guide to parents

-Book “breathe baby breathe” and many other books available on loan

Stories of other families (mur de l'espoir) and integrating resource parents

REGULAR ARTICLE

ACTA PEDIATRICA WILEY

Peer support groups for families in Neonatology: Why and how to get started?

Sonia Dahan[1,2,3] | Claude Julie Bourque[1,2,4,5,6] | Martin Reichherzer[2] | Josée Prince[7] | Ginette Martha[7,8] | Melissa Savaria[3] | Annie Janvier[1,2,3,4,5,6,9]

Abstract

Aim: To describe the development of peer-to-peer support meetings between parents of children in neonatal intensive care unit (NICU) and veteran resource parents

Other stories

Art:
« les prématurés »
RedM©

Educational workshops for parents

- "Being a parent in the NICU"
- Organization and money
- Breastfeeding and nutrition
- Transfer to intermediate care
- Discharge
- My baby's lungs
- Prenatal educational workshop; Boutillier et al 2023 https://pubmed.ncbi.nlm.nih.gov/37761531/

THE JOURNAL OF PEDIATRICS • www.jpeds.com ORIGINAL ARTICLES

Community, Hope, and Resilience: Parental Perspectives on Peer Support in Neonatology

Sonia Dahan, MD, MSc[1,2,3,4], Claudia Julie Bourque, PhD[1,2,3,4], Martin Reichenbach, BSc[5], Jessie Prince, MSc[3], Ornella Martha[3,6], Melissa Saviolia, IBCLC[3], and Annie Janvier, MD, PhD[1,2,3,4,5,6,7]

Objectives To describe the perspective of parents who participated in peer-to-peer support meetings with parents of children in a neonatal intensive care unit (NICU) and veteran resource parents with previous NICU experience.

Study design During a longitudinal evaluation in a tertiary care NICU, participating parents were asked to evaluate meetings with open-ended questions; they were asked about their perspectives. Results were analyzed using mixed methods.

Results Forty-five NICU parents participated over a 10-week study period. They were followed longitudinally after attending at least 1 of the 10 meetings offered; 95% of parents (43 of 45) reported that the meeting was useful to them and gave an overall evaluation of 8.7 out of 10 (average). For each meeting, all the subjects on the checklist of the moderators (veteran resource parents) were discussed with new parents. When describing why and how the meetings were useful to them in their answers to open-ended questions, NICU parents reported 3 major themes: (1) decreasing isolation and being a community (73%), (2) hope and resilience (65%), and (3) getting practical "parent" information (32%). Sharing stories with parents who also had experienced loss, sadness, and grief, NICU parents trusted that it was possible to adapt and thrive. The meetings normalized parents' emotions (82%), decreased negative emotions (eg, anger, sadness, guilt), empowered them in their parental role, and helped them communicate with loved ones and providers.

Conclusions Peer support meetings are a unique and useful means to support parents. Future investigations will investigate whether and how this type of intervention can improve clinical outcomes. J Pediatr 2023;253:86-93.

Resource parents in the unit: decreases isolation and gives hope to new parents

Table III. What new NICU parents found positive about parent peer support meetings moderated by veteran resource parents: Main themes and illustrative quotes

Hearing stories and sharing (61%)
- *"Parents telling their stories"*
- *"Listening to other parents' stories and sharing"*

Friendliness and laid-back atmosphere (31%)
- *"The location in the kitchen, informal"*
- *"I liked that the meeting was like a casual conversation where everyone can express oneself without fearing judgment."*
- *"Good friendly atmosphere"*
- *"Straight talk and sense of humor of the 2 moderators"*

The presence of resource parents (33%) answers was often associated with resilience
- *"I liked that the moderators were people who had been through the same place, they are believable."*
- *"Sharing our story with someone who experienced the same situation and understands us."*
- *"I liked the fact that it was moderated by parents; they have a message of hope."*

« Seeing is believing. I lost one of my twins and what helps me the most at the moment is to be in a room with with all the other NICU parents and the ressource parent who has lost 2 of her triplets. We all have lost something. Even when I speak to the psychologist, it is not the same thing. The groups make it clear I can really be OK in the end, that real life can come back, that it will not always be like this. We just feel stronger. Others made it through, we are together, and we will too. »

So many interventions, limited evidence

MANY interventions can help parents cope in the NICU:

- Mindfullness
- Yoga for families: in person and online
- Massage for parents
- Parent navigator app
- Parent support groups: online, in person, on the phone, buddies, etc
- Coping kit for parents
- Beads of courage
- etc

Unpublished but amazing programs

- Papa pizza night
- Running parent group
- Fathers who knit
- Boxing room
- Lavender room
- Free gym membership

Lack of « robust » evidence: a problem or not?

- In most of these studies, less than half the parents participate
- In our peer-to-peer groups, many parents did not
  - *« I am not a group person »*
  - *« I get support elsewhere »* (clinicians, family, online, friends, etc)
- Mainly quantitative measures and babies outcomes, but if parents report they feel better, is this enough?
  - Those who do benefit do so in various ways
- GOAL: perhaps a « catalog » of interventions?
- Interventions also depend on positive leaders in units

Any ideas for your unit?

Plan-Do-Check-Act cycle

- Who should be on the team?
- How to go about gathering information as to what needs to be improved? (defining the local ecosystem)
- What are the best solutions for your unit? The easiest? Who are your champions?
- What to check/measure?

Keeping in mind potential harm

- Some parents report experiencing guilt from their feeling of non-optimal involvement.
  - Avoid QI goals such as “80% of mothers feed from the breast”, “80% of parents present at rounds”, “80% of parents are present during resuscitations”, “90% skin-to-skin the first hour” etc
- Changes need to respect the reality of each NICU, with implementation priorities identified by parents.
- This will be affected by social and familial characteristics
- Gradual changes and a flexible philosophy of care will ensure FICare is not perceived as "family-imposed care".

Choosing your battles?

- Working hard for parents to present at rounds when there is no parental leave in your state, the parking is 20$
  - Yes, you can do something
- Abandonning rounding standing up with computers is easier and probably has more impact than having parents present at rounds
  - Are daily large multidisciplinary rounds really optimal ?
- Systems changes: are there chairs in the single rooms, uniforms, do residents/consultants enter whenever they want to examine a baby?

Take home message

- The NICU is a place of trauma and celebration
- « NICU Families » also experience positive transformations
- Supporting parenthood and helping parents feel like « good parents » is an important goal
- Careful implementation of Family integrated care models are promising
  - Each NICU is different
- Veteran resource parents can help new « NICU parents »

Questions? Comments?

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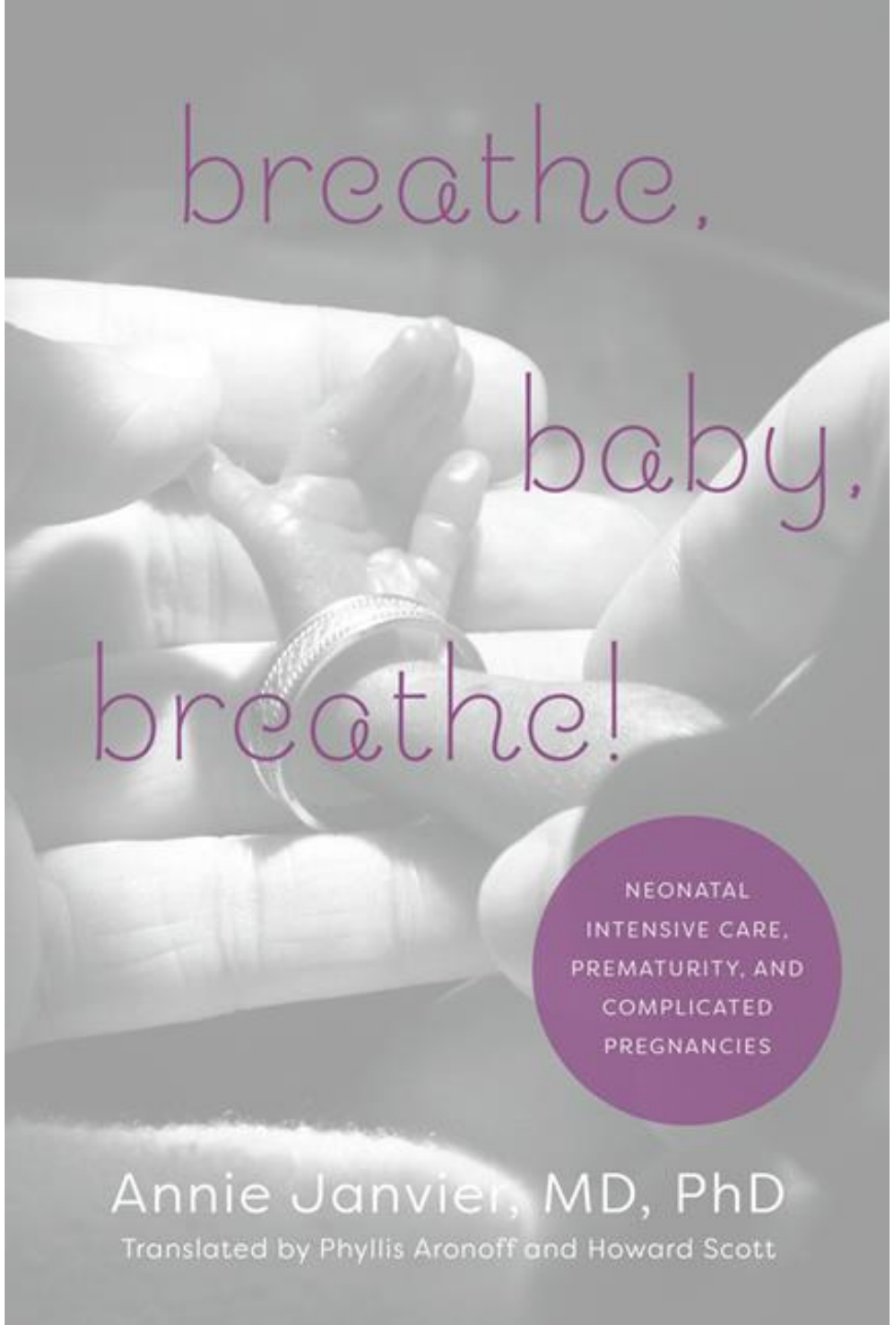

Fragments of humanity:

Violette’s coping work of art (lungs) made with medical devices used in the NICU (and PICU)