



Unique Considerations of the Influence of Family Planning & Structures on the NICU Experience

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Disclosures

• I have nothing to disclose

Objectives

- Describe the prevalence of perinatal mood and anxiety disorders in NICU parents and the multi-disciplinary support that is needed in this population.
- List challenges to mental health screening in the NICU, including special populations such as adoptive parents
- Describe what is known about support for the family with a history of infertility and how this experience may influence parental decision making in the NICU
- Discuss policies and ethical dilemmas in the NICU surrounding situations of gestational carriers and adoption, including decision making in diverse family structures



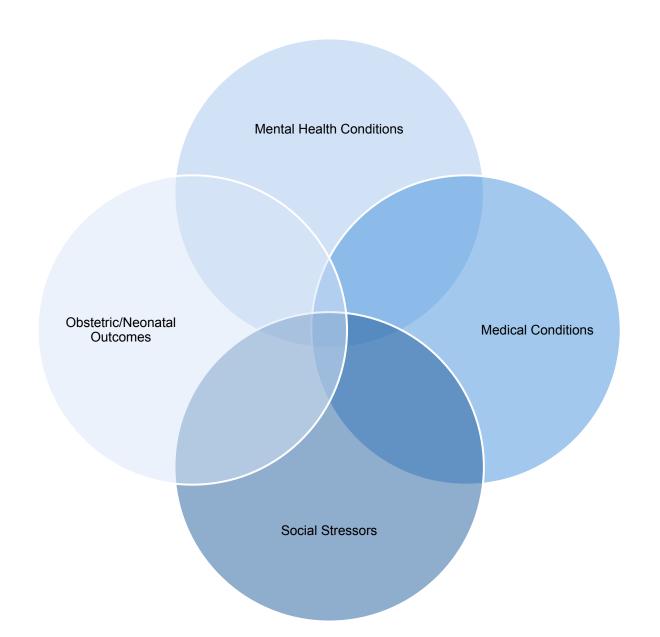


PMADs in the NICU

Define "PMAD"

- Perinatal Mood and Anxiety Disorder
- Spectrum of mental health disorders occurring during pregnancy or within the first year after birth:
 - Anxiety
 - Depression
 - Bipolar disorder
 - Psychosis
 - Obsessive-compulsive disorder
 - PTSD
- DSMD-V defines PPD as:
 - Presence of 5 or more depressive symptoms for a minimum of 2 weeks
 - The symptoms must be present either during pregnancy or within 4 weeks of delivery to be considered PPD

Who is most at risk for PMADs?



Maternal Impacts of <u>Untreated</u> PMADs

Maternal

- Cognitive Impairment/Function Impairments
- Suicide attempts/ completion
- Increased risk for relationship discord, divorce, family violence
- Increased risk for substance abuse
- Increased likelihood to engage in negative parenting behaviors
- Less likely to breastfeed
- Poorer attachment to infant

Obstetric

- Less likely to obtain proper prenatal care
- Increased risk of premature birth/ low birth weight
- Increased risk for maternal/ infant mortality

Infant/Childhood Impacts of <u>Untreated</u> PMADs

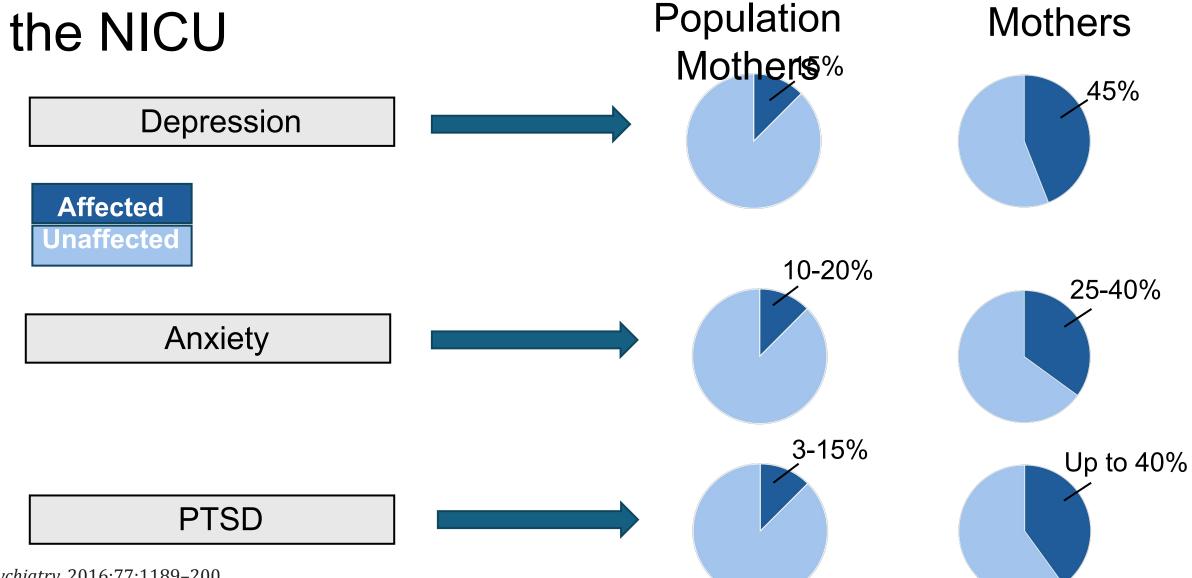
Infant

- Increased rates of infanticide
- 3 weeks- difficult to comfort, sleeping, being demanding
- 6 months- impaired bonding
- 12 months- poorer communication

Child

- 4 years-insecure attachments/behavior difficulties
- 16 years- academic troubles/cognitive development delays (2-fold increase)
- 18 years- anxiety/depression (7-fold increase)

Maternal Mental Health in the NICU



General

NICU

J Clin Psychiatry. 2016;77:1189–200.

J Obstet Gynecol Neonatal Nurs. 2017;46:576–87

Clin Pediatr. 2020;59:163-9

Which parents are at highest risk during NICU stay?

- 45% of parents reported depressive symptoms
- 43% reported elevated perceived stress
- Odds of depression were 7.87 for parents of infants with gestational age ≥37 weeks compared with gestational age <28 weeks
- Parental NICU stress was higher in younger parents (P < .01).
- Depressive symptoms were positively associated with parental stress
 - Each 1-point increase in PSS:NICU score was associated with a 2.1-point (95% CI, 1.6-2.9; P < .001) increase in CESD-10 score.
- Social support was inversely associated with depressive symptoms

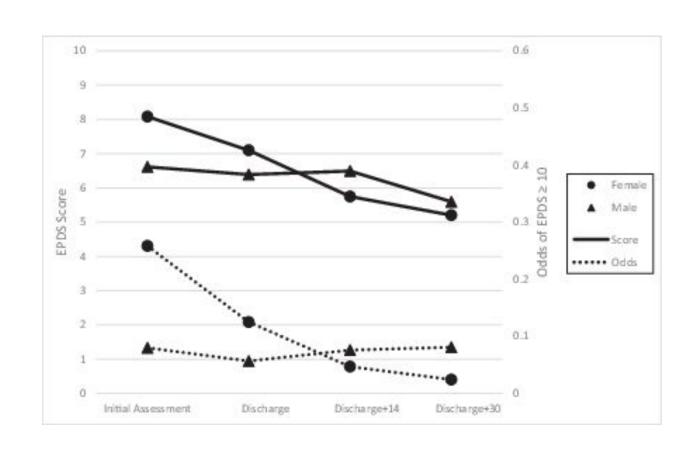
participants categorized	by pare	ntal depre	ssion score
Characteristics	All (n = 300)	Elevated (score ≥10) (n = 135)	Normal (score <10) (n = 162)
Parent characteristics			
Age, y, mean \pm SD	30 ± 7	30 ± 7	30 ± 6
Female sex, n (%)*	267 (89)	121 (90)	143 (88)
Race, n (%)*			
Caucasian	117 (39)	54 (40)	62 (38)
African American	133 (44)	53 (39)	79 (48)
Asian	17 (6)	8 (6)	9 (6)
American Indian/Pacific Islander	8 (3)	5 (4)	3 (2)
Mixed race/not reported	25 (8)	15 (11)	9 (6)
Hispanic, n (%)*	23 (8)	10 (7)	13 (8)
Education level, n (%)*	1.7	,	
High school diploma or less	77 (25)	36 (27)	41 (25)
Trade/vocational training/	87 (29)	43 (32)	42 (26)
some college	\/	1-1-	
College/university degree	136 (45)	56 (41)	79 (49)
or higher			
Married partner/spouse,	160 (53)	70 (52)	89 (55)
n (%)*	, ,	, ,	, ,
Pre-NICU employment,	212 (71)	98 (73)	112 (69)
n (%)*		,	,
No other children at home,	129 (43)	58 (43)	70 (43)
n (%)*	, ,	, ,	, ,
Infant characteristics, n (%)*			
Female sex [†]	126 (42)	67 (50)	59 (37)
Gestational age category [†]	, ,		, ,
<28 wk	30 (10)	7 (5)	22 (14)
28-33 ^{6/7} wk	60 (20)	23 (17)	37 (23)
34-36 ^{6/7} wk	40 (13)	18 (13)	21 (13)
37+ wk [‡]	170 (57)	87 (65)	82 (51)
Birth weight category			
<1000 g	32 (11)	10 (7)	21 (13)
1000-1499 g	31 (10)	12 (9)	19 (12)
1500-2499 g	63 (21)	24 (18)	38 (23)
2500+ g	174 (58)	89 (66)	84 (52)
LOS quartiles		, ,	, ,
1-7 d	78 (26)	38 (28)	40 (25)
8-17 d	73 (24)	29 (21)	42 (26)
18-47 d	75 (25)	40 (30)	35 (21)
48-181 d	74 (25)	28 (21)	45 (28)

Table I. Characteristics of parent and infant study

Table V. NICU stress (PSS:NICU) among parents with elevated vs normal CESD-10 scores					
PSS:NICU scores	All participants (n = 296)	Elevated CESD-10 (n = 135)	Normal CESD-10 (n = 161)		
Total score Subscales	3.0 (2.4-3.6)	3.3 (2.7-3.7)	2.8 (2.1-3.4)		
Sights and sounds	2.0 (1.4-2.8)	2.2 (1.6-3.2)	1.8 (1.3-2.6)		
Infant appearance and behavior	3.3 (2.5-4.0)	3.7 (2.9-4.3)	3.1 (2.2-3.9)		
Parental role alteration	3.4 (2.6-4.1)	3.8 (3.0-4.3)	3.1 (2.2-4.0)		
Parental relationships with staff*	2.0 (1.4-3.0)	2.3 (1.5-3.0)	2.0 (1.2-2.7)		

Parental Screening Trends Over NICU Stay

- 33% of mothers and 17% of fathers had a positive EPDS screening
- Over time, mothers decreased 10.96 times (CI: 2.99–38.20; P 5 .0003); fathers decreased at a nonsignificant rate
- Admission or discharge screening improved 30-day depressive symptom prediction compared to using demographics only
 - · Demographics alone are poor predictors
 - Ability to predict depression at 30-days post-discharge is still increased by screening during the NICU stay
- Mothers of premature infants PPD risk (28% to 40%) is nearly double that of mothers of term infants, with rates typically decreasing over time yet remaining higher in the infant's first year.

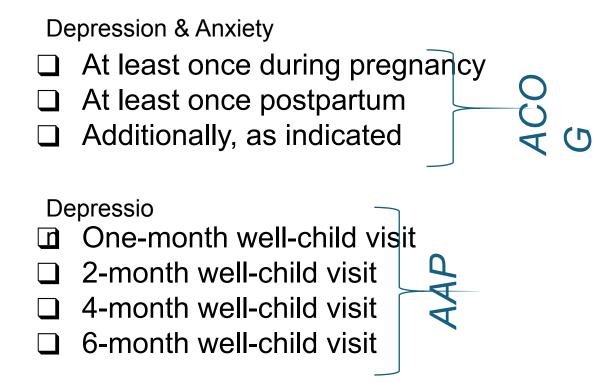






Screening Recommendations

Screening Recommendations



Validated Screens for Depression

PHQ-9 and EPDS

- 9 and 10 items, respectively
- Sensitive/ specific
- Always review last question

Validated Screens for Anxiety

GAD7 and EPDS-3A

- 7 and 3 items, respectively
- Sensitive/ specific
- Many mothers do not make their postpartum follow up with OBGYN
- Families with longer NICU stays will miss screening at well-baby visit

Why inclusive, formal screening is important, & at regular intervals

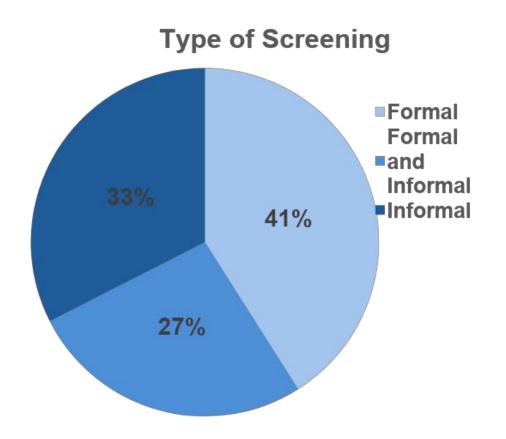
- Kaiser-Cali OB:
 - Identification of a new depression diagnosis increased from 8.2% to 11.5% (P<.001).
 - Depressive symptoms improved at 6 months
- At UMinn NICU:
 - Standardized PMAD screening in NICU parents resulted in <u>an additional 2 referrals per week</u>, identified more NGP with MH symptoms, and was viewed positively by parents and providers.
 - 31% birthing parent & 22% NGP were positive
 - 7 parents had suicidal ideation (4 birthing parent & 3 NGP)
 - Rates highest at 6 months
 - Previous children (p=0.009), term infants (p=0.005), and preterm infants < 24 weeks (p=0.028) were associated with positive EPDS
 - There were significant differences in EPDS-3A positive rates between insurance types (p=0.021).

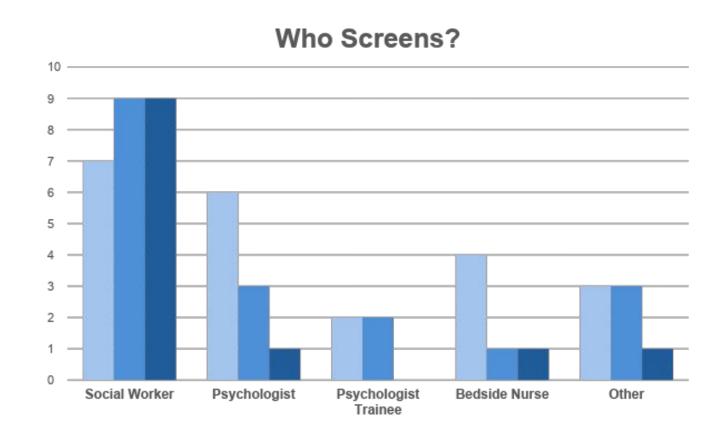
Presence of dedicated mental health professionals in the NICU beyond social work is rare

Survey conducted within CHNC centers showed that the majority of the 34/44 centers responding were without additional mental health support

Site factors	N (%)	Median (Q1, Q3)
Beds in NICU		60.00 (43, 84.00)
FTE licensed social workers in NICU		3.00 (2.00, 4.00)
Number licensed social workers/20 NICU beds		1.00 (0.79, 1.15)
Centers with psychologists in NICU *	13 (38)	0.80 (0.40, 1.00)
Centers with psychology trainees in NICU	7 (21)	0.30 (0.25, 0.45)
Centers with psychiatrists in NICU	1 (3)	0.50 (0.50, 0.50)
Centers with mental health counsellors in NICU	3 (9)	0.60 (0.35, 1.05)
Cumulative Mental Health Professionals		3.00 (2.00, 4.50)

Less than half of Level IV NICUs standardize formal screening with validated tools





Centers with more mental health professionals are more likely to screen formally

Mental Health Work FTEs per 20 beds	formal alone (N = 14)	formal and informal (N = 9)	informal alone (N = 11)	Kruskal-Wall is rank sum test p-value
Social Worker site FTE Median (Min, Max)	1.05 (0.43, 1.55)	0.95 (0.76, 1.67)	1.00 (0.19, 1.33)	0.904**
Combined (SW, Psychologist, Psychologist Trainees, Psychiatrist,	1.27 (0.51, 2.24)	0.95 (0.76, 3.64)	1.00 (0.19, 1.33)	0.331**

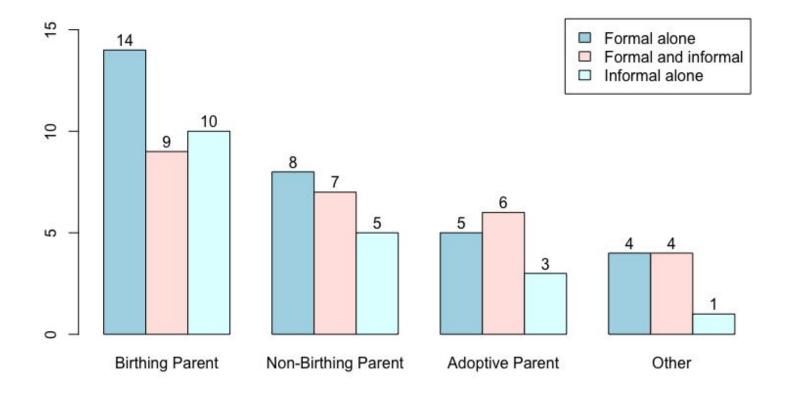
Mental Health Work FTEs per 20 beds	formal alone (N = 14)	informal alone (N = 11)	Kruskal-Wallis rank sum test p-value
Combined (SW, Psychologist, Psychologist Trainees, Psychiatrist, MHC) * Median (Min, Max)	1.27 (0.51, 2.24)	1.00 (0.19, 1.33)	0.089**

Tables: FTEs (Social Worker, all MHW) grouped by screening (formal, formal and informal, informal)

^{*}Mediam Malive MHW FTEs (SW+other MHPs)

^{**}Results in differences in FTE (social worker, all workers) in sites due to screening method. A comparison of combined FTES for sites with formal alone vs Informal alone results in a KW p-value is 0.089 which at 10% significance level can be considered significant and indicative of some evidence that sites with more MHW are more likely to screen formally.

Whom is Screened?



Screening Practices across NICUs

- Nearly one-quarter of the NICUs did not provide any PMAD screening
- Despite consensus that postpartum psychosocial care is essential, routine mental health care of primary caregivers in the NICU remains inadequate

Table 3. Provision of routine mental health education, screening, and treatment, by NICU characteristics.

	Education ^a n (%)	Screening b n (%)	Treatment n (%)
Geographic Region			
Midwest ($n = 15$)	8 (53%)	8 (83%)	12 (80%)
West $(n = 18)$	8 (44%)	10 (56%)	14 (78%)
South (<i>n</i> = 18)	9 (50%)	9 (50%)	14 (78%)
Northeast $(n = 24)$	10 (42%)	6 (25%)	20 (83%)
Hospital Type ^c			
Independent Children's Hospital vs. Not			
Children's hospital $(n = 28)$	15 (54%)	14 (50%)	23 (82%)
Non-children's hospital ($n = 47$)	20 (43%)	19 (40%)	37 (79%)
Academic vs. Community Hospital			
Academic $(n = 39)$	21 (54%)	20 (51%)	32 (82%)
Community $(n = 36)$	14 (39%)	13 (36%)	28 (78%)
NICU Level			
I–III (<i>n</i> = 53)	22 (42%)	20 (38%)	42 (79%)
IV (<i>n</i> = 22)	13 (59%)	13 (59%)	18 (82%)
Patient Volume (per month)			
$0-50 \ (n=38)$	16 (42%)	14 (37%)	30 (79%)
51+ (n = 37)	19 (51%)	19 (51%)	30 (81%)

Mental Health Treatment in US NICUs

Table 4. Mental health treatment referrals and services offered (n = 60).

	n (%)	
Referrals		
Referral to therapist in the community	39 (65%)	
Referral to therapist in hospital system	34 (57%)	
Referral to psychiatrist in hospital system	29 (48%)	
Referral to psychiatrist in the community	27 (45%)	
Services		
Support groups	32 (53%)	
Individual supportive psychotherapy	19 (32%)	
Couples/Marital counseling	6 (10%)	
Cognitive behavioral therapy	4 (7%)	
Family therapy	3 (5%)	
Problem solving skills training (PSST)	2 (3%)	

- 76% of the participating NICUs provided referrals for outpatient treatment
- 53% of NICUs provided some psychosocial support services within the NICU most often caregiver support groups
- Most NICUs had a social worker as a psychosocial support staff.
 - Few NICUs met the NPA's recommendations for employing at least one doctoral level psychologist in NICUs with 20 or more beds.
- Access to a psychiatrist or psychologist was more common in NICUs providing universal screening

Challenges & Barriers in the NICU

- NICUs that did not provide regular universal screening were more likely to perceive significant barriers related to conceptual issues
 - Time (16% vs. 53%; p = 0.002)
 - Medical team or social work support (6% vs. 26%; p = 0.03)
 - Lack of evidence-based psychosocial approaches (3% vs. 21%; p = 0.03)
- Multidisciplinary collaboration is needed when designing PMAD screening programs in the NICU

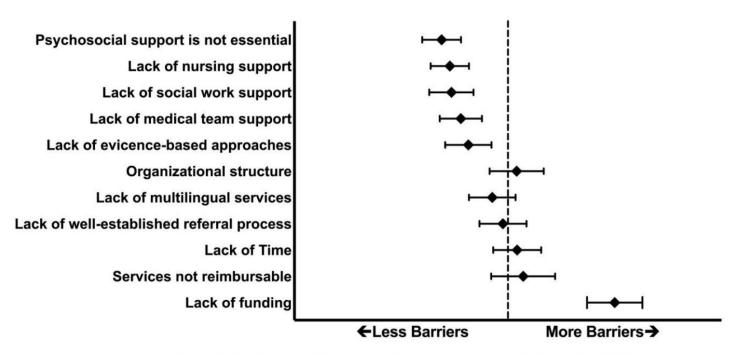


Figure 1. Challenges and Barriers to Caregiver Psychosocial Care in the NICU.

Many barriers exist to screening AND supporting parents/caregivers in the Level IV NICU

No reimbursement for mental health support of caregivers in the pediatric setting "We don't know what to do with the results"

- •Where do you chart?
- •Lack of support for parents that screen positive

We don't have enough staff/time to screen



Parents are not our patients



Liability of having this information and long term impact of discoverable information in patient chart



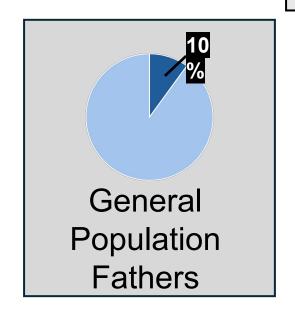


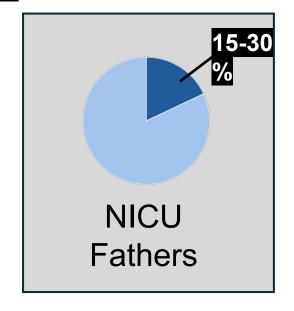
Non-Birthing Parent Mental Health Considerations

Non-Birthing Parent Mental Health Challenges in the NICU

Especially in the NICU setting, partner mental health may be overlooked

Depression







PMAD Risk Factors in Adoption

- Low family income
- Low occupational status
- Depression during pregnancy
- Pregnancy and delivery complications
- Biological changes associated with giving birth

- Mother's quality of sleep
- Children's behaviors (Colic, screaming)
- Low marital satisfaction
- History of depression

- Infertility
- Time to parenthood
- Journey to parenthood

PMADs in Adoptive Mothers

	Postpart	um mothers	Adoptive	e mothers		
	Mean	SD	Mean	SD	F_a	$p^{ m b}$
DAS						
General depression_	36.9	11.9	35.3	11.1	4.4	0.007
Dysphoria	17.0	7.0	16.7	6.5	3.6	0.013
Lassitude	11.8	4.3	11.1	3.8	2.3	0.052
Insomnia	11.4	4.9	11.1	5.2	2.2	0.057
Suicidality	6.4	1.3	6.5	1.2	2.1	0.064
Appetite loss	4.2	2.3	4.0	1.9	1.8	0.085
Appetite gain	6.3	3.2	5.7	2.6	2.2	0.058
Ill temper	8.7	3.8	8.2	3.2	1.1	0.174
Well-being	23.5	6.4	26.6	6.0	12.9	< 0.001
Social anxiety	7.0	2.9	6.3	2.1	8.4	< 0.001
Panic	9.7	3.2	8.6	2.1	7.2	<0.001
Traumatic intrusions	5.8	2.5	4.9	2.2	6.8	< 0.001
PDS	6.5	4.9	5.4	4.5	2.4	0.046
	n	%	n	%	χ^2	p
EPDS Scores >13 ^d	11	7.5	13	8.8	0.81	0.670

- Postpartum and adoptive mothers experience comparable levels of depressive symptoms
 - Adoptive women experienced significantly fewer symptoms of anxiety, including social anxiety, panic, and traumatic intrusions
 - Experienced greater well-being than the postpartum women
 - The groups in this study appear to have an equal vulnerability to depressive symptoms

Risk Factors in Adoptive Mothers

- In the first year following adoption:
 - Greater sleep deprivation
 - A history of infertility
 - Self-reported past psychological disorder diagnosis
 - Lower marital satisfaction
- Associated with more depressive symptoms

Factors associated with women's depressive symptoms following adoption (n=147)

		<i>r</i> _a	β <u>b</u>	p	R^2	ΔR^2	p
Model 1					0.08	0.08	0.016
	Age	-0.10	-0.05	0.55			
	Education	0.02	0.04	0.66			
	Income	-0.23	-0.26	0.003			
Model 2					0.16	0.09	< 0.001
	Age	-0.10	-0.05	0.51			
	Education	0.02	0.01	0.91			
	Income	-0.23	-0.19	0.03			
	Past psychological disorder	0.36	0.30	< 0.001			
Model 3					0.35	0.19	< 0.001
	Age	-0.10	-0.01	0.96			
	Education	0.02	0.07	0.37			
	Income	-0.23	-0.11	0.19			
	Past psychological disorder	0.36	0.18	0.03			
	Duration of adoption process	-0.71	-0.12	0.15			
	Difficulty with adoption process	0.17	0.05	0.52			
	Sleep deprivation	0.42	0.25	0.004			
	How much infertility bothers her	0.23	0.18	0.03			
	Time spent on infertility treatments	0.01	-0.10	0.19			
	Marital adjustment	-0.42	-0.24	0.004			

Longitudinal Risk in UK Adoptive Parents

- Prospective, longitudinal design, investigated anxiety and depression symptoms in 96 British adoptive parents over four time points in the first four years of an adoptive placement
- Depression and anxiety symptom scores were relatively stable across time, however parents' scores indicated higher rates of clinical symptoms of depression and anxiety compared to the general population using the same measure
- Support for adoptive families primarily focuses on child adjustment professional awareness of parental mental health post-placement may be necessary, and interventions aimed at improving parents' sense of competency may be beneficial
- Underscores the need to support parental mental health over the early years of parenting, for example, and for this to include adoptive parents

Higher child internalizing scores and lower parental sense of competency at five months post-placement

Higher initial levels of parental depressive symptoms

Lower parental sense of competency

Higher initial levels of parental anxiety symptoms

What we know—or don't know

- Paucity of data regarding MH outcomes of fathers, co-mothers, extended family, and stepparents in the NICU
- Available data indicate partners do experience increased MH symptomatology

- Little research exists about the experiences of lesbian, gay, bisexual, transgender and gender nonconforming individuals in the NICU
- These populations continue to be affected by barriers to care such as poor provider knowledge, stigma, and inadequate access, despite known disparities in MH and obstetric care

- Parents with limited English proficiency have also been understudied
- Language barriers contribute to suboptimal healthcare delivery, including MH services

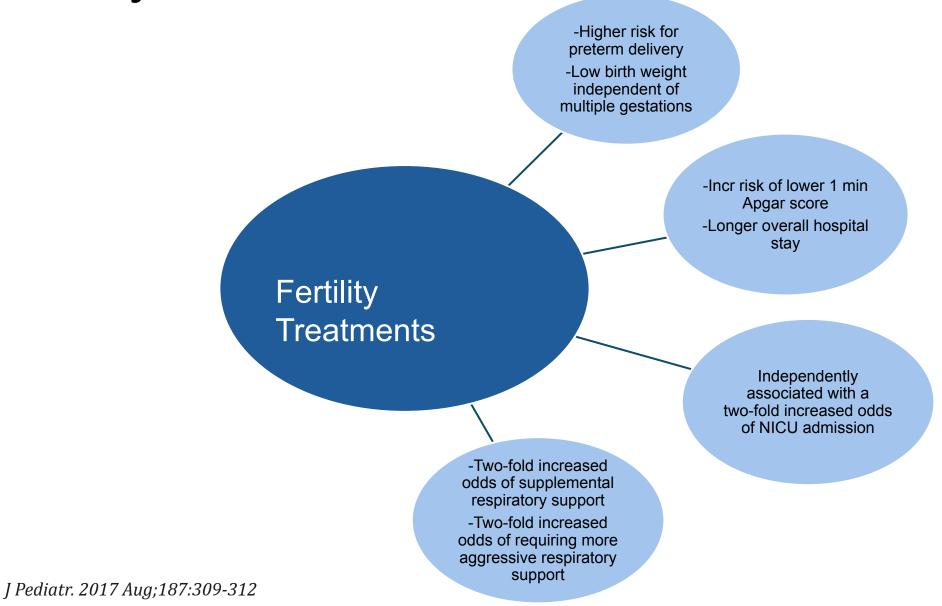
 Adoptive parents may have specialized needs that are unrecognized in the NICU





Decision Making in the NICU

Fertility Treatments and NICU Admission



IVF and Decision Making

- For Anna and Mark the environment combined with their circumstances lead to feelings of loss: "I was just so alone... you're isolated ...we had nothing normal. There was nothing normal about this pregnancy, about getting pregnant... there was nothing normal about giving birth."
- For this couple it was a loss of their hopes and dreams for a normal conception as the twins were conceived via in vitro fertilization, loss of the normal pregnancy as Anna was on bed rest for a shortened cervix early in the pregnancy, and then loss of normal, healthy labour and delivery as the twins were delivered by an emergency caesarean section.
- For Anna and Mark, their childbearing journey was nothing that they had expected and they experienced culture shock



Jaimie and John Florio via Women's Health Mag

Neonatal Nurses Perspective



- When the baby is born through IVF and is also born extremely prematurely, it creates a crisis situation for the parents
- Examined parental anguish from caregiver perspective of the neonatal nurse who supports the parents through this very difficult time
- Neonatal nurses' understanding of "parental anguish" and "overwhelming sadness" in parents whose baby was conceived by IVF, and was also born extremely prematurely
- The theme of 'seeking parenthood' was synthesized from two sub-themes – 'longing for a baby' and 'the desperation to become parents'
- The time, effort and money required to achieve a pregnancy does not mean that the baby will be spared the outcomes of extreme prematurity and the risk factors associated with IVF
- The parents may be left empty handed
- The word precious becomes a metaphor for the IVF baby as the neonatal team try desperately to give the parents their much longed baby
- Witnessing parental anguish can be a major source of stress for the neonatal nurses. Neonatal nurses need to develop strategies not only to help the parents but also to prevent the parents' overwhelming sadness from affecting their ability to function in the neonatal intensive care unit

Provider Bias

- Anonymous questionnaire given to nurses, physicians, and students
- Scenarios of 3 sets of parents
 - 16-year-old teenager
 - A couple who were lawyers
 - A couple with a history of in vitro fertilization, about to deliver at 22 5/7 weeks, 24 weeks, or 27 5/7 weeks
- Respondents were asked whether active intervention is in the infant's best interests and whether they
 would comply with family decisions
- At 22 5/7 weeks' gestation:
 - 21% of the respondents thought that resuscitation was in the infant's best interest
- At 27 5/7 weeks' gestation:
 - Estimates of best interest, and willingness to comply, varied significantly by parental characteristics
- At 22 5/7 weeks' gestation:
 - 17% of respondents believed that resuscitation was in the best interest of the teenaged mother's infant
 - 26% of respondents who believed that resuscitation was in the best interest for the infants of the others; this difference persisted at 24 weeks.
- At 22 5/7and at 24 weeks' gestation, compliance with active care despite believing that it not in the infant's best interest was significantly more frequent for the in vitro fertilization couple and the lawyers than for the teenaged mother.

Decision Making in Diverse Family Structures: Providers

- Qualitative interviews with Neonatologists and Obstetricians
- Involvement Matters
 - Partners should be included in the decision-making process only when they intended to coparent
 - Some providers emphasizing intended involvement was as important or more important than marriage or biological relationship
 - For many providers, marriage appeared to be an indicator of involvement
- This theme was repeated in the legal case vignette when providers were prompted to think about who should have the ultimate decisional authority under a variety of scenarios.
- Providers overwhelmingly agreed that Mr K should not have decisional authority if there were no intention to coparent

TableII. Provider responses to the partner involvement questions

"Should partner's decisional authority be affected	Yes	No
if the partner is married to the pregnant person?"	16 (53.3%)	14 (46.7%)
if the partner is biologically related to the child?"	18 (60.0%)	12 (40.0%)
depending on the amount of involvement the partner has had with the pregnant patient during the pregnancy?"	18 (60.0%)	12 (40.0%)
depending on the amount of involvement the partner intends to have in the child's life? (ie, whether they intend to co-parent)"	20 (66.7%)	10 (33.3%)

Table III. Provider responses regarding decisional authority and nonheteronormative family structures

"Who should have the ultimate decisional authority in the following scenarios?"	Ms H	Mr K	Mr and Mrs O	Mr and Mrs B	Declined to answer
If Ms H and Mr K are not married, but Mr K is planning to coparent?	28 (93.3%)	1 (3.3%)	N/A	N/A	1 (3.3%)
If Ms H and Mr K are not married and Mr K is not planning to coparent?	29 (96.7%)	1 (3.3%)	N/A	N/A	0
If Ms H and Mr K are not married and Mr K is not the biological father, but he intends to coparent?	29 (96.7%)	1 (3.3%)	N/A	N/A	0
If Ms H and Mr K are the biological parents, but have selected Mr and Mrs O as adoptive parents?	20 (66.7%)	1 (3.3%)	9 (30%)	N/A	0
If Ms H is a gestational carrier (surrogate carrying their embryo) for Mr and Mrs B who are the biological parents?	9 (30.0%)	0	N/A	20 (66.7%)	1 (3.3%)
Mrs K is both the pregnant patient (carrier) and biologically related mother (egg donor).*	26 (86.7%)	1 (3.3%)	N/A	N/A	3 (10.0%)
Mrs K is the pregnant patient (carrier) and Mrs H is the egg donor/biologically related mother?*	22 (73.3%)	5 (16.7%)	N/A	N/A	3 (10.0%)

Provider Perspective

- Greater uncertainty among providers when probed to think about how to adjudicate disagreement in <u>nonheteronormative family</u> <u>situations</u>
- This theme was not evident with disagreement among heterosexual couples, where providers overwhelmingly agreed that the pregnant patient should have decisional authority.
- When prompted to think about who should have ultimate decisional authority in making resuscitation decisions, providers expressed the need for legal guidance
- A pregnant person's partner can influence decisions around prenatal care, delivery, and other health-seeking behaviors, but without specific guidelines and training on the partners' roles, health care systems and providers can easily exclude them from the decision-making process

Decisional Dynamics in Diverse Family Structures: Families

- Experienced and prospective dyads with interviews on conflict resolution and decisional authority for periviable resuscitation decision making
- Included a clinical case vignette portraying a married, heterosexual couple hospitalized at 22 weeks' gestation for a threatened periviable delivery
- Participants were asked to consider how Mrs. H and Mr. K should:
 - · Navigate this disagreement
 - Determine who should have ultimate decisional authority
 - Discuss whether the healthcare team should play a role in conflict resolution
- Seven additional scenarios exploring decisional authority in non-traditional family structures where H and K represent diverse familial contexts such as surrogacy (gestational carrier), adoption, same-sex relationships, and unmarried co-parents.

Table 1. Demographic characteristics of prospective and experienced parents. N = 120.

	Prospective	Experience
Mean Age (Range)	30.02 ± 5.04	36.01 ± 6.86
	n (%)	n (%)
Race		
White	51 (85%)	41 (68%)
Black/African American	6 (10%)	11 (18.3)
Asian	2 (3.3%)	1 (1.7%)
Native Hawaiian, Pacific Islander	0	3 (5%)
American Indian, Alaskan Native	0	1 (1.7%)
Multiracial	3 (5%)	7 (11.7%)
Other/Prefer not to disclose	1 (1.7%)	0
Ethnicity		
Non-Hispanic/Latinx	54 (90%)	54 (90%)
Hispanic/Latinx	5 (8.3%)	4 (6.7%)
Prefer not to disclose	1 (1.7%)	2 (3.3%)
Sex at Birth		
Male	29 (48.3%)	26 (43.3%)
Female	31 (51.7%)	33 (55%)
Prefer not to disclose	0	1 (1.7%)
Gender		
Cis-gender male	28 (46.7%)	26 (43.3%)
Cis-gender female	29 (48.3%)	33 (55%)
Trans-gender male	1 (1.7%)	0
Trans-gender female	0	0
Non-binary	2 (3.3%)	0
Prefer not to disclose	0	1 (1.7%)
Sexuality		
Heterosexual	50 (83.3%)	57 (95%)
Gay	1 (1.7%)	0
Lesbian	1 (1.7%)	0
Bisexual	5 (8.3%)	2 (3.3%)
Other	2 (3.3%)	0
Prefer not to disclose	1 (1.7%)	1 (1.7%)
Marital Status		
Single, never married	52 (86.7%)	9 (15%)
Married/partnered	8 (13.3%)	49 (81.7%)
Divorced/separated	0	2 (3.3%)

Presents demographic characteristics of both prospective and experienced parent participants.

Marriage, Biology, & Involvement As Factors that Affect Partners Decisional Authority

	Overall			Prospective			Experienced		
Should decisional authority be affected:	Prospective (n = 60)	Experienced (n = 60)	p- value	Birthing parent (n = 30)	Partner (n = 30)	p- value	Birthing parent (n = 30)	Partner (n = 30)	p- value
If the partner is married to the pregnant person?	18 (30%)	25 (41.7%)	0.18	9 (30%)	9 (30%)	1.0	12 (40%)	13 (43.3%)	0.79
If the partner is biologically related to the child?	38 (63.3%)	40 (66.7%)	0.70	19 (63.3%)	19 (63.3%)	1.0	20 (66.7%)	20 (66.7%)	1.0
Depending on the amount of involvement the partner has had with the pregnant patient during the pregnancy?	39 (65%)	41 (68.33%)	0.60	18 (60%)	21 (70%)	0.42	23 (76.7%)	18 (60%)	0.22
Depending on the amount of involvement the partner intends to have in the child's life?	42 (70%)	45 (75%)	0.35	23 (76.7%)	19 (63.3%)	0.26	25 (83.3%)	20 (66.7%)	0.28

Parents' perspectives of decisional authority in non-heteronormative scenarios

Table 3. Parents' assignment of ultimate decisional authority in non-heteronormative family structures.

Who should have the ultimate decisional authority in the following scenarios?	Ms. H		Mr. K		Mr. & Mrs. O		Mr. & Mrs. B		Declined to answer	
	P	E	P	E	P	E	P	E	P	E
If Ms. H and Mr. K are not married, but Mr. K is planning to coparent?	58 (96.7%)	53 (88.3%)	0	5 (8.3%)		-	• 10	-	2 (3.3%)	2 (3.3%)
If Ms. H and Mr. K are not married and Mr. K is not planning to coparent?	60 (100%)	60 (100%)	0	0					0	0
If Ms. H and Mr. K are not married and Mr. K is not the biological father, but he intends to coparent?	58 (96.7%)	57 (95%)	0	2 (3.3%)					2 (3.3%)	1 (1.7%)
If Ms. H and Mr. K are the biological parents, but have selected Mr. and Mrs. O as adoptive parents?	14 (23.3%)	16 (26.7%)	0	0	46 (76.7%)	44 (73.3%)			0	0
If Ms. H is a gestational carrier (surrogate carrying their embryo) for Mr. and Mrs. B who are the biological parents?	6 (10.0%)	4 (6.7%)	0	0			53 (88.3%)	56 (93.3%)	1 (1.7%)	0
Now consider if Mrs. H and Mr. K were instead Mrs. H and MRS. K, a married same-sex couple.	Mrs. H		Mrs. K						Declined to answer	
	P	E	P	E					P	E
Mrs. K is both the pregnant patient (carrier) and biologically related mother (egg donor)?	4 (6.7%)	1 (1.7%)	56 (93.3%)	58 (96.6%)					0	1 (1.7%)
Mrs. K is the pregnant patient (carrier) and Mrs. H is the egg donor/ biologically related mother?	20 (33.3%)	18 (30%)	38 (63.3%)	40 (66.7%)					2 (3.3%)	2 (3.3%)



Surrogacy-Establishing Parentage & Decision-Making • Some state laws assume that the woman who gives birth is the

- Some state laws assume that the woman who gives birth is the legal parent of the child (along with her husband, if she's married), intended parents will need to take additional legal steps to protect their parental rights to a child born via surrogacy.
- These surrogacy laws will also affect whether or not intended parents can place their names on the baby's birth certificate right away.
- When parentage can be established will depend on the state's laws.
 - In many states, the intended parents can obtain a <u>pre-birth</u>
 order, which establishes them as the legal parents before the
 baby is born
 - Even without a pre-birth order, the intended parents are usually automatically recognized as the legal parents at birth
 - The surrogate relinquishes her parental rights after the birth, and the intended parents' names are placed on the birth certificate
- States with more restrictive surrogacy laws may require a **post-birth parentage order** to establish legal parentage

Surrogacy By State

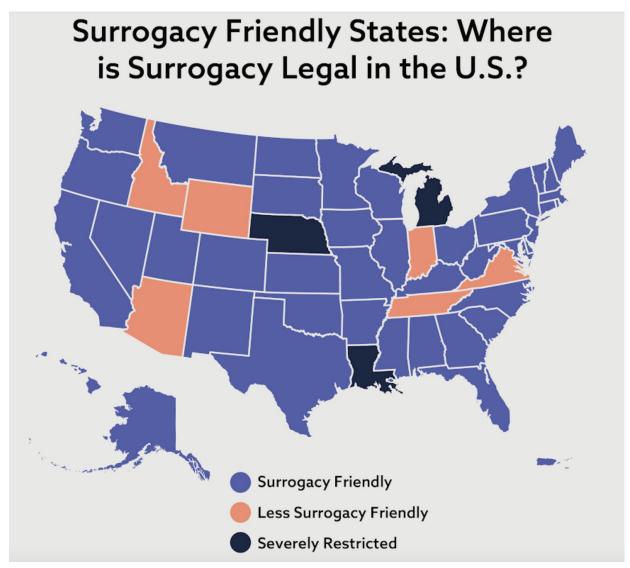


Image credit: American Surrogacy.com

Adoptive Parent Decision Making in NICU

II. DEFINITIONS

Legal Father: a male who has not surrendered or had terminated his rights to a child and who:

- (A) Has legally adopted such child;
- (B) Was married to the biological mother of such child at the time such child was born or within the usual period of gestation, unless paternity was disproved by a final order of a court of competent jurisdiction;
- (C) Married a legal mother of such child after such child was born and recognized such child as his own, unless paternity was disproved by a final order of a court of competent jurisdiction; or
- (D) Has legitimated such child by a final court order.

Legal Mother: a female who is the biological or adoptive mother of the child and who has not surrendered or had terminated her rights to the child.

III. PROCEDURES:

- A. Nursing will promptly refer all legal mothers and legal fathers considering release of an infant to Social Services regardless of the type of adoption that is planned (private or non-private). Social Services with gather and obtain necessary data to assist the legal mother and, if applicable, the legal father through the process.
- B. Social Services makes an entry into the medical record (of both the legal mother and the infant) stating the plan.
- C. Signed authorization by the legal mother and/or legal father for release of information to the agency is placed in the chart by Social Services.
- D. Only those visitors identified by the legal mother, legal father, and / or Social Services will be allowed to see or hold the infant.

- E. Adoptive parents are not allowed to visit during the four (4) days grace period unless accompanied by the adoption agency representative/attorney (with permission from legal mother and/or legal father), legal mother or legal father at all times. Arrangements for visitation must be coordinated at least twenty-four (24) hours in advance with Social Services.
- F. The legal mother and, if applicable, legal father are able to see and hold the infant. If for any reason there are restrictions placed on the legal mother and/or legal father regarding information or visitation, this will be noted by Social Services in the infant's medical record.
- 26. No medical information should be provided or medical decisions made by adoptive parents until surrenders are finalized. A legal mother or legal father signing a surrender of rights has the right to revoke such surrender by written notice delivered in person or mailed by registered mail or statutory overnight delivery within four (4) days of signing each surrender. The four (4) day revocation period is counted consecutively beginning with the day immediately following the date of surrender of rights is executed. If the fourth day falls on a Saturday, Sunday, or legal holiday, then the last day on which surrender may be revoked is the next day that is not one of these. Social Services will note the four (4) day time period in the medical record.
- H. Social Services acts as liaison to outside parties such as the agency, attorney, family and interested parties. To provide confidentiality to the patient, legal mother, legal father, no information is to be given out except to those specifically identified by Social Services in the medical record.
- I. Ideally the infant will be discharged between the hours of 8 AM –4PM, Monday –Friday. Exceptions to this discharge time should be previously arranged. Social Services should be present at the time of discharge.
- J. Infant is to be discharged to attorney or adoption agency, unless prior arrangements were made with Social Services.
- K. Discharge teaching is done for those individuals identified by Social Services who will be caring for the infant.
- L. At the time of discharge, the adoptive parent signs the footprint sheet as per routine discharge process.
- M. The adoptive parent is given written instructions for home care, information on follow-up appointments and discharge supplies.

Provision of Breast Milk



- Agreement prior to delivery, but what if pre-term and risks associated with being preterm may change parental bias toward availability of human milk
- Difficulties with human milk storage on mother baby units that generally do not manage this volume very well
- Most NICUs do not allow human milk obtained from "outside," only allow pasteurized donor human milk hospital obtained from a milk bank (Human Milk Banking Association of North America-HMBANA)or maternally pumped milk
 - "Caregivers are not allowed to bring informally shared mother to mother milk. Certain infections, including hepatitis, HIV, and CMV may be transmitted through breast milk obtained from an outside source. In contrast to approved donor milk, no screening for infections are done on informally shared milk. Any informally shared milk brought into the hospital must be brought home or discarded and should not be administered or stored by caregiver or Children's staff"

Summary

- NICU caregivers are at increased risk of PMADs
- US NICUs would benefit from improving family support, including universal and inclusive mental health screening and on-site resources
- The experience of non-birthing caregivers in the NICU deserves further study
- Providers and families bring stronger biases in decision making with past history of infertility
- Navigating decision making pre-birth and in the NICU is complex in "traditional" families, and legal and ethical frameworks are lacking in support of nonheteronormative families







Questions?

IVF and Prematurity Comorbidities

- Cohort study of 23–34 weeks' preterm infants from 329 US NICUs discharged from 2009 to 2016. Each IVF patient was matched to three controls
- IVF-conceived infants had no increase in non-respiratory morbidities but had significantly higher rates of bronchopulmonary dysplasia (8.4% vs 7%, p < 0.001) and significantly greater exposure to common chronic respiratory medications.
- Further research is needed to explore the influence of in vitro fertilization on the development of neonatal respiratory disease

IVF & Motherhood

- Prospective controlled study comparing 65 primiparous women with singleton IVF pregnancies and their partners, and a control group of 61 similarly aged primiparous women with no history of infertility and their partners whom completed questionnaires and interviews
- The IVF mothers tended to report lower self-esteem and less parenting competence than control mothers. Although there were no group differences on protectiveness, IVF mothers saw their children as significantly more vulnerable and "special" compared with controls. The IVF fathers reported significantly lower self-esteem and marital satisfaction, although not less competence in parenting. Both IVF mothers and fathers did not differ from control parents on other measures of general adjustment (mood) or those more specific to parenthood (e.g., attachment to the child and attitudes to child rearing).
- The IVF parents' adjustment to parenthood is similar to naturally conceiving comparison families. Nonetheless, there are minor IVF differences that reflect heightened child-focused concern and less confidence in parenting for mothers, less satisfaction with the marriage for the fathers, and vulnerable self-esteem for both parents.