Peer Reviewed

# Fragile Infant Forums for Implementation of IFCDC Standards: Pain and Stress, Families

*Joy V. Browne, Ph.D., PCNS, IMH-E*

*"Having a baby is stressful enough for any family, but it can be much worse with the unexpected complication of having their baby admitted to intensive care. Although every family is different, almost all families admitted to intensive care experience increased stress, sometimes extreme."*

Having a baby is stressful enough for any family, but it can be much worse with the unexpected complication of having their baby admitted to intensive care. Although every family is different, almost all families admitted to intensive care experience increased stress, sometimes extreme.

When referring to families, we infer that parents, siblings, grandparents, foster parents, and other relations suffer the consequences of intensive care pain and stress. However, most literature focuses on the parents, primarily mothers. Experiencing pregnancy, labor, delivery, and postpartum events, mothers, in particular, have documented pain and stress. (1, 2, 3) The result of vaginal birth and/or Cesarean section often leaves the mother with pregnancy-related physiologic changes, including pain, stress, and recovery from stressful medical procedures. (2)

*"A baby's admission to intensive care can lead to maternal and paternal mental health issues not previously experienced."*

A baby's admission to intensive care can lead to maternal and paternal mental health issues not previously experienced. Perinatal posttraumatic stress disorder, anxiety disorders, and postpartum depression have been documented in rates over and above those related to more typical births. (4, 5, 6, 7, 8, 9) Mothers who have a prior history of a mental illness like depression, anxiety, or another diagnosed mental health condition, may bring mental health complexities that are compounded by the stress of intensive care. (10, 11)

Addressing and managing stress related to intensive care experiences is essential to maximize outcomes for babies, parents, and future family functioning post-discharge. (12) Family mental health issues that develop due to an intensive care experience can impact the baby's development and outcomes. (1, 13) Additionally, the immediate and extended family also suffer the ramifications of the intensive care experience, as there is a disruption in familiar routines, support network availability, travel, and care for siblings. Cultural practices and family customs are also likely to be disrupted. As all families come to the intensive care experience with different expectations, backgrounds, and parenting practices, individualizing approaches and interventions to address stress and promote wellbeing are essential. Consideration for the entire family constellation is appropriate as all members are likely to be experiencing stress as a result of the hospitalization. (14)

The Infant and Family-Centered Developmental Care Standards, Competencies, and Best Practices (IFCDC) have articulated evidence-based practices to assess and ameliorate family pain and stress (https://nicudesign.nd.edu/nicu-care-standards/ifcdc--recommendations-for-best-practice-reducing-managing-pain-stress-in-newborns-families/). The standards, listed in the chart below, are consistent with the Psychosocial Program Standards for NICU Parents. (15) The IFCDC standards aim to recognize the prevalence of family mental health issues resulting from a baby's hospitalization and provide caregiving environments that ameliorate stress and promote wellbeing.

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**Alleviating stress and promoting wellbeing in families:**

First and foremost, ensuring families, particularly parents, have unlimited access to care for their babies is essential. Much stress results from the separation of parents and their babies. (16, 17) Family, distance, or financial issues often impede parents from being with their babies full-time (14), but assuring that when parents are available, they can be with their babies can alleviate stress. Skin-to-skin experiences (there are many ways of assuring skin-to-skin contact, not only on the parent's chest, that can be encouraged) for both mothers and fathers have been shown to reduce stress and should be encouraged regardless of the severity of the baby's medical issues. (18, 19, 20, 21, 22)

Parents are typically the most consistent and familiar caregivers for their babies. They may or may not understand the baby's behavioral communication. Providing them with information about observing and interpreting their baby's behavior and developmentally appropriate care will assist them in responding empathically and ameliorating their baby's distress. (23, 24) Psychoeducation provided individually or in group settings can

**Standard 1, Pain and Stress, Families: The interprofessional team shall document increased parental/caregiver wellbeing and decreased emotional distress (WB/D) during the intensive care hospital (ICU) stay. Distress levels of the baby's siblings and extended family should also be considered.**

**Competency 1.1**: Parents shall have unlimited opportunities to be with their baby and be encouraged to engage with their baby, including skin-to-skin interactions.

**Competency 1.2**: Education shall be provided to all parents on how to (a) recognize their baby's behavioral communications of pain and distress as well as signs of comfort and (b) support parents to use practical ways to comfort and soothe their baby safely.

**Competency 1.3**: WB/D shall be evaluated within 72 hours of admission and 48 hours before discharge (as well as other times indicated by clinical judgment).

**Competency 1.4**: Training should be provided for staff in how to screen, assess and document parent/family WB/D in accordance with ICU policies.

**Competency 1.5**: Evaluations of WB/D shall include informal and routine bedside conversations with all parent/caregivers by social workers and psychologists (one per 20 beds), who may utilize appropriate questionnaires and/or inventories to assess for postpartum depression (PPD), Posttraumatic Stress Disorders (PTSD) or other mental health concerns. This information shall be communicated to relevant members of the interprofessional team in accordance with ICU policies.

**Competency 1.6**: Standardized education programs on the reduction of distress and anxiety in families shall be provided for all professionals and include topics: (a) provision of Infant and Family-Centered Developmental Care; (b) recognition of symptoms of anxiety, PPD, and PTSD; (c) use of reflective listening skills and non-judgmental feedback; (d) understanding of implicit cultural biases; and (e) utilization of emotional and physical self-care.

**Competency 1.7**: All parents/caregivers shall be provided with psychoeducational groups emphasizing developmental care as well as the opportunity for individual peer-to-peer support by trained volunteers in the ICU.

**Competency 1.8**: Selected ICU staff should be appointed to provide targeted levels of support (e.g., listening visits) for parents/caregivers deemed at risk for emotional distress.

**Competency 1.9**: Appropriate emotional interventions and support shall be provided by social workers, psychologists, and psychiatrists within the ICU to parents/caregivers with debilitating levels of symptoms or acute distress.

**Competency 1.10**: Referrals of ICU family members for psychotherapy outside the ICU shall be provided using established hospital resources and referral strategies.

**Competency 1.11**: Discharge planning should include information about parent WB/D and related interventions. This information should be communicated to follow-up providers to promote optimal IFCDC at home.

also benefit parents so that they understand the cause and impact of stress in intensive care. (25) Often peer to peer conversations can effectively provide support and promote wellbeing. (26) Talking with someone who has gone through a similar experience can help alleviate stress.

**Mental health screening, assessment, and supportive interventions:**

An intensive caregiving environment provides appropriate assessment and interventions individualized to the baby and family's needs. It ensures the availability of well-trained professionals who provide supportive interventions to alleviate parental stress. (27)

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Appropriate, timely mental health screening and assessment should be expected practice, normalized in supporting the parents to care for their baby appropriately. (4, 28) IFCDC competencies related to this standard include that wellbeing and/or distress be evaluated within 72 hours of admission and 48 hours before discharge (as well as other times indicated by clinical judgment). Training in how to screen for and document wellbeing and/or distress should be provided to all intensive care professionals.

***"Psychoeducation provided individually or in group settings can also benefit parents so that they understand the cause and impact of stress in intensive care."***

Various professionals can do screening and assessment, but it would be best provided by those trained to determine the best strategies to provide supportive intervention both in the NICU and referrals for when the family is discharged into their community. Perinatal Social Workers (https://www.napsw.org) have been at the forefront of providing support to families and are typically available to ensure that appropriate referrals are made to various resources, including mental health. They are now joined by increasingly available Neonatal Psychologists trained to address mental health concerns in intensive care https://www.nationalperinatal.org/psychologists. Many intensive care units also have access to Psychiatrists for mental health consultations. Current recommendations for mental health staff to address mental health needs include at least one per 20 beds. (29)

All professionals need education about recognizing and responding to mental health concerns in family members. Approaches may include active listening and reflective questioning, typically not taught in professional education, so they must be included in educational sessions. (29, 30) Often, family and/or staff mental health crises reveal the need for access to professionals who can appropriately respond to these emerging challenges, provide emotional/psychological intervention and take necessary steps to address the issue. (31) Appropriately trained staff and policies targeted to address crisis episodes and provide referrals to resources outside the hospital setting are essential. (32) Another competency for alleviating stress in family members is to, with permission, assure appropriate referrals upon discharge to community mental health resources.

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**Conclusion:**

The stress of intensive care impacts the parents and the baby's extended family. The literature is replete with documentation of parents' mental health concerns that should be assessed and appropriately addressed during the intensive care experience and as the family transitions to the community. As parental mental health issues can subsequently affect the baby's developmental outcomes, *prevention* measures to avoid adverse baby and family outcomes and *intervention* measures to address immediate concerns are necessary.

The IFCDC standards provide an evidence-based rationale for developing significant educational, procedural, and systems change strategies to alleviate stress and promote wellbeing in family members. First and foremost, parents and babies with unrestricted physical, social, and emotionally supported access to each other can reduce stress, enhance wellbeing and result

in more optimal outcomes. Awareness of stress-related behavior, communication, and provision of screening procedures by all intensive care professionals will help determine family mental health needs. Adequately staffed mental health providers should provide focused assessment, crisis intervention and referral to appropriate resources. Awareness of the importance of addressing optimal family wellbeing, developing policies prioritizing reducing stress in families, and strong leadership is foundational to implementing the IFCDC evidence-based standards on Pain and Stress in Families.

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*Corresponding Author*

*Joy Browne, Ph.D., PCNS, IMH-E(IV)*
*Clinical Professor of Pediatrics and Psychiatry*
*University of Colorado School of Medicine*
*Aurora, Colorado*
*Telephone: 303-875-0585*
*Email:* Joy.browne@childrenscolorado.org