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"NICU Blues": A Novel Term for Common Parental Experiences

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"Approximately one in ten babies will spend time in a newborn intensive care unit (NICU). (1) Studies indicate that preterm birth significantly contributes to infant morbidity and mortality. Though mortality rates have been declining for preterm infants, there remains a significant percentage of infants born at the earliest gestational age who die in the NICU."

Approximately one in ten babies will spend time in a newborn intensive care unit (NICU). (1) Studies indicate that preterm birth significantly contributes to infant morbidity and mortality. Though mortality rates have been declining for preterm infants, there remains a significant percentage of infants born at the earliest gestational age who die in the NICU. (2) Regardless of gestational age or medical diagnosis, NICU parents often fear their baby's neonatal death or severe morbidity. There commonly exists some level of acute disorienting parental distress. (3)

A single definition of parental distress in the NICU does not exist. (4) A novel non-pathological term, "NICU blues," is proposed to identify common parental experiences specific to the newborn intensive care unit. Giving a name to "NICU blues" for parents provides optimal understanding, relief, and meaning for parents and caregivers moving through a unique NICU journey. Over several years, confidential comments were collected by the principal author from parents with newborns in a Level III family-centered care NICU. These condensed comments, shown in quotes, are many shared voices of pain, including reflecting parental narratives used in developing the term "NICU blues" Parents in the NICU described numerous symptoms of psychological distress not fully meeting specific pathological psychiatric diagnoses in the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5). However, the clinical reflection of these vulnerable expressions of NICU parental distress helped us formulate the proposed conceptualized term "NICU blues" to shape those collective narrative stories.

Parental "NICU blues" are defined by the intersection of four factors in figure 1: NICU trauma, baby blues, postpartum mood and anxiety disorders (5), and NICU grief. NICU blues may contain varying levels of these four factors. Both parents are included in this biopsychosocial, transitory, and non-pathological model of predicted cogent symptoms in the NICU. NICU blues normalize feelings of being out of control emotionally and behaviorally with responses and experiences for any parent in the NICU. The concept of NICU blues sets an initiative-taking stage for the healthcare professional to offer adaptive coping responses and interventions within the NICU setting. Parents were suffering from extreme emotional pain, a sense of hopelessness, and despair in response to a potential NICU death or long-term morbidity of their newborn we view as an *expected* and *understandable* transitory state of parental functioning. The proposed term "NICU blues" gives voice to the logical collective voices of "feeling like I am crazy and losing my mind." Hence, we define "NICU blues" as *a condition unique to the NICU setting that includes* ***common*** *emotional and behavioral responses to a succession of abnormal parenting events and experiences. These responses include parental guilt, specifically maternal guilt as it relates to pregnancy loss and the baby's NICU admission, father's guilt as it relates to not protecting his family from the NICU stay, negative cognition and mood, decreased interest, anger, concentration problems, sleep disturbances, and struggles to experience positive emotions.*

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NICU blues provides a paradigm for validating parental adaptation experiences within a NICU setting and is viewed similarly to the transitory phenomena of matrescence described by anthropologist Dana Raphael. (6) Maltrescence is a typical physical, emotional, hormonal, and social process of transitioning into motherhood. In this sense, NICU blues is a typical process of psychosocial adjustment into parenthood occurring within the NICU. The term NICU blues normalizes perceived "out of control and helplessness emotions," but with awareness and interventions, these emotions can transition to periods of adaptation.

Parents in the NICU need a meaningful relationship with their baby to establish a sense of parenthood, and their baby needs parental contact for optimal physiologic and psychoemotional development. Parents in the NICU often feel an additional layer of angst and guilt with physical separation from their baby. Research documents the interrelationships between NICU parents' mental health on the functioning of their infants' physical and psychological development.

Postpartum mothers in the NICU may try to numb the intense emotional pain of "not wanting to deal with the possible mortality of their precious long, imagined baby." Fathers in the NICU may experience a sense of panic and doom with potential mortality for their partner and his baby, "I'm going to lose my entire family." Parents often spend infinite initial hours in the NICU without regard for their own needs, "wanting a parent to be with the baby

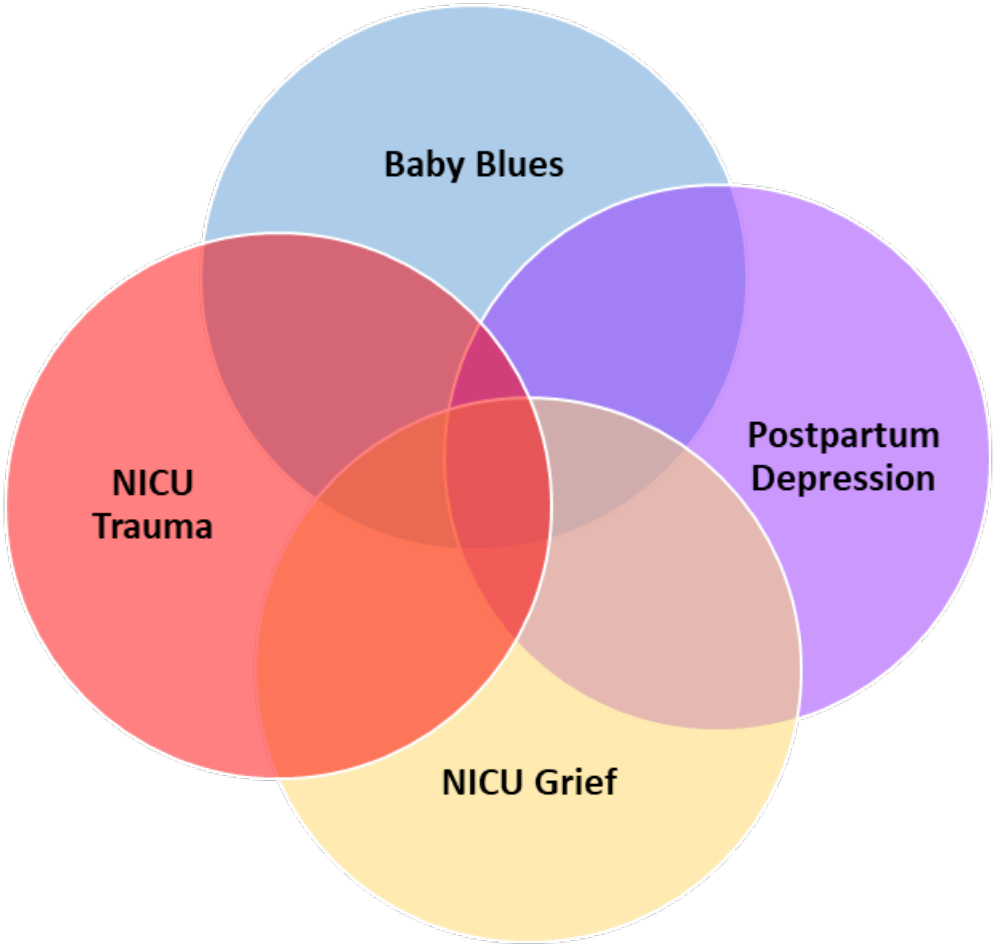

Figure 1: Conceptualization of NICU blues as a function of NICU trauma, baby blues, PMADs and NICU Grief

if they die." This perception, real or imagined, adds to the NICU blues. Often, the father may undertake to stay in the NICU as the mother cannot leave the postpartum floor until physically mobile. The father may or may not be able to express feeling alone and isolated without his partner.

"Most research on NICU parents has focused on the high prevalence rates of postpartum mood and anxiety disorders (5) and post-traumatic stress disorder (PTSD). (7-9) We strongly support the National Perinatal Association (NPA) 2015 recommendations for universal screening and treatment protocols for both parents in the NICU to identify mental health challenges."

Most research on NICU parents has focused on the high prevalence rates of postpartum mood and anxiety disorders (5) and post-traumatic stress disorder (PTSD). (7-9) We *strongly* support the National Perinatal Association (NPA) 2015 recommendations for universal screening and treatment protocols for both parents in the NICU to identify mental health challenges. Studies reveal elevated levels of depression, anxiety, and trauma symptoms shortly after their baby's birth. Without screening and identification of common parental distress, we will be unable to support the mental health needs of our parents in the NICU as partners in their newborn care.

We propose a novel term, NICU blues, for consideration by the NICU team within an ongoing supportive relationship with our parents. Identifying and treating complex emotional and mental health needs, such as NICU blues, provides parents in the NICU with additional consideration for robust universal standards of family-centered care. Figure 1 captures the interrelationship of clinical factors, including NICU trauma, baby blues, postpartum mood and anxiety disorders (5), and NICU grief, to identify a theoretical construct of a transitional, typical, and expected "NICU blues" paradigm.

NICU Trauma:

Considerable evidence exists that both parents in the NICU are

at risk for psychological symptoms from traumatic birth events, including acute stress disorder (ASD) and post-traumatic stress disorder (PTSD). We suggest that NICU psychological trauma symptoms may overlap with clinical symptoms in addition to and separate from NICU blues in Figure 1. There exists an intersection of NICU trauma symptoms, including actual or threatened mortality and morbidity for the baby or mother, with symptoms of NICU blues. Parents in the NICU may have the perception and experiences birth trauma events without meeting DSM-5 diagnostic criteria. In this sense, our psychological approach is expanded beyond the narrow psychiatric diagnosis focused solely on ASD or PTSD. In our clinical experience, NICU blues symptoms for parents include attributions of self-blame for their baby's NICU admission, guilt, fear/horror, feeling detached from self and others, avoidance behaviors from the NICU, decreased parental involvement with their baby, struggles to focus while in the NICU and sleep disturbance.

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A parent in the NICU needs a meaningful, loving, and nurturing relationship with their baby. In Ainsworth and colleagues' classic maternal attachment studies,(10) maternal attachment involves physical and psychological accessibility. Parents of babies in the NICU are largely limited from these crucial parental attachment behaviors. Bonding may be at risk. As mothers may be recovering from a traumatic delivery, fathers may typically be the first visitor to the NICU.

Qualitative research identifies themes for fathers in the NICU. (11-13). Fathers may believe they need to be stoic for their family, often hiding feelings of anxiety, fear, helplessness, disconnection, powerlessness, and being out of control. They encompass charting unfamiliar waters, including being the backbone of the family, shouldering heavy responsibilities alone, being torn between his partner and baby in the NICU, and the unexpected journey as an active and possibly only participant. (14) Parents may question how their involvement and participation in the NICU is important in seeing nurses and others fulfill their caregiving roles.

Trauma during a newborn's medical stay is now considered an adverse childhood experience (ACE).(15) Toxic stresses or adverse childhood experiences (15) are strongly linked to poor health outcomes. For optimal physiologic and psychoemotional development, a baby may need buffering protection from a lack of parentally connected caregiving.(15) The dearth of physical and emotional closeness between infants and their parents and parental distress can negatively affect the relationship and the infant's developmental outcomes. Research links possible long-term protective factors for parents who participate in NICU infant care.

Psychosocial education and intervention using the paradigm of the NICU blues are paramount at these initial stages for *normalization* and *validation* that these distressing thoughts and feelings are common for most parents in a NICU setting. Unique clinical themes and identification of NICU blues provide parents with alternative schemas for assimilation and adaptation.

Discussion of NICU blues normalizes parents' turmoil as understandable and *predictable* within the NICU. Early attunement and co-regulatory caregiving are the foundation for attachment and bonding. We provide a new lens of parenting in the NICU with these caregiving-bonding discussions. In highlighting NICU blues, parents are more apt to discover "what's lovely about their baby at this moment" apart from the barrage of NICU equipment and stressful environment. Normalization of NICU blues promotes parental discovery of their baby's physical and emotional nuances.

Parents often need a pause for adaptation from the many successive invasive medical procedures with their babies. With this conversation of NICU blues, parents have reported a much greater understanding of commonly shared universal NICU trauma reactions. With ongoing discussions by the staff of NICU blues, parents gain some psychological distance from their trauma symptoms, reporting greater acceptance, psychological flexibility, and adaptation for continued engagement in the NICU. In our clinical experience, identification of NICU blues sets a family-centered stage for later engagement with parents for other bedside compassionate family-centered interventions and connection between staff and parents in the NICU.

Baby Blues and Postpartum Mood and Anxiety Disorders: (5)

Baby blues, also known in the literature as postpartum blues or postnatal blues (with these latter terms excluding the father), is a mild transient disruption of mood occurring several days following delivery. It is imperative for NICU psychologists and medical and nursing staff to help parents make sense and meaning of their initial distress specific to identifiable physical changes, situational stressors, and loss (16). Parents often express relief in knowing that predictable NICU blues may be additive to or better explained to both parents than the term baby blues in addition to hormonal changes.

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Parents in the NCIU report that discussion of possible NICU blues around admission to the NICU gives them a sense of hope and being understood. Our clinical impression is that this initial connection with parents in the NICU gives clarity to an internal disruption not fully understood. Perhaps with this safe therapeutic, nourishing NICU staff-parent connection, parents may be better able to bond with their babies. In our discussion of NICU blues with parents, relationship building for parent-child bonding and meaningful parent-NICU staff communication begins another positive launch for family-centered care.

Baby blues is identified as one potential risk factor for postpartum depression. These authors posit that the risks of developing perinatal mood and anxiety disorder (PMAD) may be lessened or eliminated when identifying NICU blues or baby blues. Early parental psychological identification and intervention by the psychological, medical, and nursing staff is key. Research studies indicate that *both* parents of babies in the NICU are at risk for postpartum depression and anxiety. There currently does not exist a DSM-5 diagnosis specific to postpartum depression. (17) There is a specifier of "with peripartum onset" with symptom onset during pregnancy or in the four weeks following delivery, with the focus generally on the mother.

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PMAD symptoms fail to voice the entire story of NICU parents. Underlying parental NICU distress reveals clinical themes. Using a 4-stage model by Beck, research authors identify maternal loss of control as the underlying problem with a NICU postpartum depressive experience. (18) Beck identified a 4-stage process termed "teetering on the edge" between sanity and insanity with stages of (1) encountering terror, (2) dying of self, (3) struggling to survive, and (4) regaining control. (19) The author described stages with four identifying themes: incongruity between expectations and the reality of new motherhood, a spiraling downward process, pervasive loss, and making gains. Like Beck's proposed process of "teetering on the edge of insanity," parents in the NICU express "a sigh of relief knowing sanity exits and feelings expected within the term NICU blues."

A Father's expectations of ideal fatherhood may, too, be affected by the fears and challenges of parenting a medically fragile baby in the NICU and supporting a mother who is not coping well. (20) Themes of loss fill the NICU room with both parents experiencing the loss of the "perfect" birth to the shocking experiences of seeing their fragile baby for the first time, often with tubes that may affect parental identity and self-esteem. (21) Paternal feelings of helplessness may be incredibly overwhelming.

Parental suffering is often silent. NICU parents may encounter various symptoms, including NICU blues, baby blues, or PMADs. In our clinical experience, parents present with some level of emotional and behavioral NICU distress. They commonly experience an intrusive cognitive disruption to their expected and perceived positive parental role.

Parents often experience elevated levels of negative self-blaming and misattributions for the baby's NICU admission exacerbating parental guilt. Dreams of completing a term pregnancy, of expecting a typical delivery complete with physically holding your baby in the delivery room, are abruptly crushed. Multiple losses for any NICU parent are monumental. Parents do not dream of finding themselves as a family in a NICU. As staff present to parents the clinical term NICU blues as a *common* reaction to their loss of a normal newborn experience, they often feel understood and comforted. In ruling out psychiatric pathology, NICU blues provides an intersecting paradigm of composite reactions, including baby blues and postpartum mood disorder, guilt, sadness, and feelings of parental worthlessness.

NICU Grief:

Parents in the NICU may experience an avalanche of immense losses accompanied by grief associated with those losses. Significant losses for parents may include sudden pregnancy termination, medical complications, loss of anticipated motherhood and fatherhood roles, and loss of hopes and dreams of a highly anticipated future with a healthy full-term baby coming home shortly after delivery.

Symptoms of NICU blues for parents may be further conceptualized within Kubler-Ross's model of grief and loss.(22) Those stages include shock/denial, anger, bargaining and self-blaming, depression, and acceptance with the recent inclusion of an additional newly defined stage, meaning. Overlap of NICU blues symptoms with stages of Kubler-Ross's model of grief exists, as shown in Figure 1. As Kubler-Ross's model reflects, these symptoms of grief are experienced in stages without the nuance of diagnostic pathology. Considerations for different cultural, ethnic, and races may also affect expressions of grief and stressors within the NICU setting.(3)

These disorienting grief responses may disrupt parental NICU involvement in baby care bonding behaviors. Parents may further isolate themselves from family and peers, intensifying experiences of NICU blues. This withdrawal from meaningful social support fuels feelings of helplessness and shame with possible stigma adding to their secret "of being different" from other parents leaving the hospital with healthy newborn babies.

"Life in the NICU does not make sense. Many parents express negative self-blaming attributions for "causing" their baby's NICU admission and stay. These parental experiences seem to coincide with feelings and thoughts of NICU blues. We suggest that parental expressions of grief, loss, and shame are strong predictive variables contributing to NICU blues."

Discussion:

Life in the NICU does not make sense. Many parents express negative self-blaming attributions for "causing" their baby's NICU admission and stay. These parental experiences seem to coincide with feelings and thoughts of NICU blues. We suggest that parental expressions of grief, loss, and shame are strong predictive variables contributing to NICU blues. There is no clear clinical definition for the array of parental psychological distress unique to the NICU. Identifying the NICU blues seeks to add to the understanding of psychological distress as a *common* contextual response. Thus, parental adaptation to the NICU is viewed as adaptive versus non-adaptive. Awareness of these parental responses by NICU staff and early intervention can ease the experi-

ence of NICU blues, foster increased bonding between parent and baby, increase interactions among NICU staff and between staff and parents, and promote an overall more positive parental NICU experience. However, this new paradigm and theoretical concept "NICU blues" for parental distress, needs further empirical qualitative and quantitative evaluation to determine its efficacy and effectiveness for NICU family-centered clinical standards of care.

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