Gravens by Design: Words Matter: The Impact of Language on Family Presence in NICU

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Abstract

The essential nature of parental presence in the Newborn Intensive Care Unit (NICU) is irrefutable, and parental presence remains elusive. While numerous barriers to parental presence exist, not all are immovable. One modifiable factor is the microethical climate, specifically, the words used to describe their baby to the family and the words used to describe the baby or family context to fellow staff members. This brief review will provide a background in microethics, a description of how the human brain learns novel words, and the impact on family presence.

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Introduction

Families are essential to the health and well-being of their children (1). In the Newborn Intensive Care Unit (NICU), the essential nature of parental presence is irrefutable. Parent presence contributes to earlier discharge (2), greater likelihood of breastfeeding at discharge (2), and better regulation skills after discharge (3). Further, skin-to-skin care has demonstrated positive impacts that extend into young adulthood (4). Despite the known essential nature, parental presence is not universal, and multiple barriers have been identified. Parents in the NICU, similar to their preterm baby, are preterm themselves, experiencing parenthood earlier and differently than anticipated (5). Parents in the NICU are often overstimulated, unable to communicate in the NICU vernacular, and sometimes lack the tools they need to overcome major barriers (5). Barriers to parental presence include infectious concerns, transportation, financial barriers with time off of work and/or costs associated with transportation, and childcare (2, 6). In addition, there are barriers to mental health, with many parents experiencing anxiety, depression, and trauma (1, 7), which may result in a variety of behavioral responses, including hyper/hypervigilance, difficulty separating from their baby at the bedside, and unequivocal avoidance (5).

While certain aspects of the trauma of the NICU may be unavoidable, there are sources of the trauma experienced in the NICU that are modifiable. One specific aspect is the microethical environment in the NICU (8). Bioethics references the sweeping care decisions involving care systems and pivotal care decisions, such as whether to intubate. In contrast, microethics describes the everyday ethics in the minute moments of day-to-day care (8, 9). It includes the choice of words used to convey information to or about an infant or family and how these words are spoken. It includes what is said and how it is said (9).

The focus of this paper is on the choice of words healthcare professionals use and the impact of these words on family understanding of their child, as well as our understanding of families, and lastly, how all of this impacts the family presence at the bedside. While the infant may be the bedside patient, the family is now recognized as being equally patient as the infant, and it is now a major focus of NICU care. The key to this focus is first, recognizing that parents are growing as parents in this novel and frightening environment (1, 2, 5) and second, understanding the essential nature of families in caring for the infant in the NICU (2. 4). As such, the environment, the culture, and the language we use and model with families carry tremendous significance.

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Language and Culture of NICU

As with all healthcare domains, the Neonatal Intensive Care Unit (NICU) has evolved to have its vocabulary, language, and culture.

This language and culture are taught to providers as they orient to and become educated in the medicine of the infants that require care in the NICU and the existing technology and care practices. Providers transfer delicate and exquisite data and information about the infant and their family through a dialect characterized by acronyms, words, and phrases.

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Families find themselves in this unusual and often traumatic environment without warning, orientation, or education. They race to understand their newfound context, and with this comes a crash course in the vocabulary, language, and culture of the NICU. Families also come with their own culture, language, education, and context, which are often minimized for the sake of the fast-paced NICU culture. Often, there is no specific repository in the chart for this equally important and delicate data, which is transferred between providers verbally (10). As such, the choice of words can significantly impact understanding for all involved. For parents, this understanding may drive pivotal care decisions and/or shape their perception of their child and future. For staff, how the family or infant context is shared and the specific words used to do so will shape a collective understanding of the family, and it may be one based on reality, conjecture, bias, misunderstanding or a mixture of all things (10).

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Relational Frame Theory (or Why Words Matter)

The developmental theory called relational frame theory describes the significance of words and the power of words to shape understanding (8, 11). Humans learn new words through both explicit and indirect instruction. Explicit teaching of a new word is intentional. The brain, however, will also learn associations between words without explicit teaching. This bidirectional implicit and explicit instruction of words is relevant for new vocabularies (8). As vocabularies are formed, adding new combinations of words creates new associations and understandings and is equally bidirectional, playing a proposed role in psychopathology for adults (11). Relational frame theory, with its explicit and implicit creation of associations between words, is also a source of parental trauma (8). As such, it represents a modifiable source of trauma, as the choices of words by healthcare professionals can be more intentional.

Outcomes of prematurity

Words matter as they describe to parents their future should their child survive. Critical to understanding outcomes in development is how the outcome is described, which varies amongst fields of medicine. In neonatology, outcomes are often distilled into a binary phenomenon. In developmental pediatrics, however, outcomes are often reported along a spectrum, focusing on function rather than 'impairment' (12). With this in mind, much of what is reported in the literature, and then to parents, reflects the presence or absence of a disorder, resulting in impacts on function in two or more environments (13). Less reported and less understood in neonatology is the concept of the spectrum, with behavior presenting in the expected or typical manner, variant with skills demonstrated within a window of expected but at the margins of expectations, and then problem behavior, reflecting undesirable behavior that is mediated by the environment (13). While this is often used for how children present, it describes all behavior in many ways.

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The words used to describe the outcomes of children hospitalized in the NICU have been characterized in a binary manner by what the child will not/cannot do rather than what they can do (12). Historical and ongoing outcomes of prematurity have included the presence or absence of cerebral palsy, cognitive impairment (defined as a demonstration of learning skills that falls below 1 or 2 standard deviations on formal developmental testing), and neurosensory impairment (vision or hearing) (13). Collectively, these have been referred to as the presence or absence of neurodevelopmental impairment (13). The likelihood of these outcomes is relatively rare, depending on the gestation reported and specific outcome reported (13). Parents, however, report more pressing early import outcomes, such as feeding, sleeping, and respiratory concerns (12). Further, outcomes that emerge later in childhood with challenges in school have been identified as common, including attentional weakness, executive dysfunction, subtle language processing challenges, motor challenges such as developmental coordination disorder, mental health issues with increased anxiety and depression, and socioemotional immaturity (13). Equally important, however, is an understanding that these children also demonstrate tremendous strengths, not captured in the literature but reported by parents (14).

Less recognized as an 'outcome' of preterm birth is that of the parents. They are also preterm, becoming parents before expected dates (5). The trauma experienced is shared across the family, and 45% of parents have reported clinically significant depression, anxiety, and trauma while in the NICU (7). These noxious experiences have been reported to pose a barrier to parental presence in the NICU, further exacerbating an already strenuous attachment process. Parental mood, anxiety, and trauma persist beyond discharge and pose a challenge to bonding, attachment, and parenting (7, 13).

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This combination of the preterm neurodevelopmental strengths and challenges and characteristic pattern of development has been referred to as the behavioral phenotype of prematurity (15). It has been used to describe the preterm survivor specifically, but in actuality, it also describes the family unit, with their strengths and trauma (13). Each family's individual patterns of the emergence of strength and challenge are variable. Some experience trauma in the NICU and recover as they leave and transition to home. Others experience trauma from the NICU later with flashbacks and intrusive memories consistent with post-traumatic stress disorder (13). Others still experience some pattern prior and then new trauma as they transition to home, navigating a different version of the healthcare system for their infant.

Family Presence in the NICU and the Impact of '-Ism'

While the infant has historically been the focus of NICU care, the family is increasingly recognized as an equally important focus (1, 2). The essential role of parents in the care of the infant has been demonstrated with breast milk provision (16), skin-to-skin care (4, 16), auditory exposure (17), and greater behavioral regulation after NICU with parental presence in day-to-day care (16). Despite this essential role, parental presence is hindered by barriers such as transportation, traffic, financial burdens with parking and time off work, work requirements and lack of parental leave, concern for infection, and parents' mental health (1, 2, 5–7). Experiential avoidance is a stress-behavioral response to conditions that are difficult, painful, or traumatizing (18). This experiential avoidance related to traumatic exposure is modifiable, to a degree, and one key aspect is through our unit language and culture.

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Historically, discussions about the infant and outcome have centered on survival and the absence of neurodevelopmental impairment (12–14). Neonatologists and pediatricians specializing in NICU care have led many of these discussions. As such, the experience and exposure to the care of children across a lifespan, particularly children who may be neurodiverse, is limited (19). The result is reliance upon the neonatal outcome literature for data on outcomes, and this literature, as noted above, is riddled with impairment-focused outcomes rather than function or parent-designated important outcomes (12–14).

> ***"This association created for parents as they learn about cerebral palsy (or any other outcome) is now forever linked to a negative or subpar outcome when, in fact, parents may report that other outcomes are more or less desirable. Once linked, however, the association is formed and cannot be undone. The associations assigned by medicine assign value, and it may not align with the values of the families, thus being a source of trauma."***

Further, the presence of ableism in medical culture and training is undeniable (20). Ableism refers to the perpetuation of a belief that there is a 'normal' when it comes to the standard for a body type and function, and anything less than this normative standard is inferior (21). This bias exists both explicitly as demonstrated in health care allocation or articulated by providers as that those with a disability experience a lower quality of life (20, 22). It also exists implicitly with the unconscious choice to use value-based language such as 'risk' and cerebral palsy together, thereby conveying an ableist bias to the condition of cerebral palsy (8). This association created for parents as they learn about cerebral palsy (or any other outcome) is now forever linked to a negative or subpar outcome when, in fact, parents may report that other outcomes are more or less desirable. Once linked, however, the association is formed and cannot be undone. The associations assigned by medicine assign value, and it may not align with the values of the families, thus being a source of trauma (8).

Additional exacerbations include sources of bias and discrimination, including a lack of understanding or respect for other cultures, languages, gender identity and expressions, health literacy, and racism. As they struggle to learn about their baby, parents in the NICU are also tasked with sharing their family context (10). There is no formalized structure for this process, and family preference for what is shared, how it is shared, and with whom may be captured in fragments in the chart, but more often is shared by verbal report (10), offering further opportunities for miscommunications, personal insertions, and misunderstanding due to bias, confusion, and exhaustion. Words like 'difficult' are both assigned to and used to describe parents, providing a negative association of this family. The use of 'difficult' as a descriptor is not problematic in itself; it is the context in which it is used. 'Difficult' more accurately describes a situation; it reflects parental stress and trauma due to their current circumstance (5) and their attempts at coping with limited tools, support, or guidance. Phrases like 'Parent is absent' provide additional opportunities for inaccurate and harmful associations to be made, i.e., somehow linking that the parental absence is negligent/negligence rather than reflective of one of the many barriers to being in the NICU or perhaps a need for self-care or self-preservation. The vernacular of the NICU seems benign, but it shapes team understanding, separates and often excludes parents from the team, and provides additional sources of trauma. The ideal would be a central family context in the medical chart described by Dahan et al. (19), providing the family context as told by the family to the team, minimizing opportunities for misperceptions.

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Lastly, for families, the words we use to describe the infant daily have an impact. Through the NICU binary lens, the infant is either sick or well. Instead, the infant develops in an artificial and stressful environment (23, 24), which results in permutations in developmental trajectories (13, 23, 24). An example of this is the NICU reference of 'respiratory distress syndrome (RDS)' to refer to premature infants and the associated lung immaturity and surfactant deficiency. Developmentally, preterm infants at 24 or 28 weeks should not yet have mature surfactant, and yet, the absence of it becomes a disease state. Parents are then led to perceive their infants as fragile, sick, and unwell when, in reality, they are growing in an alternative environment and will experience illness for certain, but the infant receiving developmental support as they grow and mature characterizes many days. Choices of words, such as 'failure to extubate,' drive home this narrative of the child as a failure, being at fault for a treatment course success or lack thereof, or being unwell.

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Conclusion

Families are essential in the NICU to care for their babies (1, 2, 4, 16). Parents of preterm infants are preterm themselves in navigating this environment (5). Both the infant and their parents are developing in the NICU, which is unnatural and often stressful and traumatizing. The culture and the language of the NICU have deep roots in medical care and, with that, ableism, bias, and elitism. With greater awareness of factors associated with health equity, the NICU can modify its language to create an environment that would be more welcoming and less traumatizing—creating an essential aspect of all charts to include a 'Family Snapshot' (10) as told by the family for the team offers a tool to facilitate steps to change and greater awareness. Explicitly referring to infants as developing and, as such, as having strengths and challenges as they grow in the unnatural NICU environment empowers parents to see the children as they are rather than as diseased, feeble infants. Shifts in neonatal research to focus on important functional outcomes identified by parents, including feeding, sleeping, and behavioral regulation, would then offer more salient, less ableist data to be reported to families as they learn about their infant (12, 14, 19). Descriptions of neurodevelopmental diversity in value-neutral ways allow parents to determine the value of this outcome and make decisions reflective of the family values rather than medical bias. In doing so, parents can mature in a safer environment, be more present for their infant whilst in the NICU, and be more effective as parents for their child's future.

References:

1. Urbina T, Balasundaram M, Coughlin M, Sorrells K, Toney-Noland C, Day C. The Why and How of Family-Centered Care. Neoreviews 2024;25(7):e393–400.

2. Franck LS, O'Brien K. The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. Birth Defects Res 2019;111:1044–59. Doi:10.1002/bdr2.1521.

3. Church PT, Grunau RE, Mirea L et al. Family Integrated Care (FICare): Positive impact on behavioural outcomes at 18 months. EHD 2020;151:105196. https://doi.org/10.1016/j.earlhumadev .2020.105196.

4. Charpak N, Tessier R, Ruiz JG et al. Twenty-year Follow-up of Kangaroo Mother Care Versus Traditional Care. Pediatrics 2017;139(1):e20162063. Doi:10.1542/peds.2016-2063.

5. Dixon SD, Vaucher YE. Neonatal Intensive Care Unit: Special Issues for the at'Risk Infant and Families. Dixon SD, Stein MT et. Encounters with Children, 4th Ed. Mosby Elsevier 2006;171–97.

6. Haward MF, Lantos J, Janvier A. Helping Parents Cope in the NICU. Pediatrics 2020;145(6):e20193567. https://doi.org/10.1542/peds2019-3567.
7. Malouf R, Harrison S, Burton HAL et al. Prevalence of anxiety and post-traumatic stress (PTS) among the parents of babies admitted to neonatal units: A systematic review and meta-analysis. Lancet 2022;43(Jan):1-32. https://doi.org/10.1016/j.eclinm2021.101233.
8. Church PT, Dahan M, Rule A et al. NICU Language, Everyday Ethics, and Giving Better News: Optimizing Discussions about Disability with Families. Children 2024;11:242. https://doi.org/10.3390/children11020242.
9. Sisk BA, Baker JN. Microethics of Communication—Hidden Roles of Bias and Heuristics in the Words We Choose. JAMA Pediatr 2018;epub. Doi:10.1001/jamapediatrics2018.3111.
10. Dahan M, Rotteau L, Higazi S et al. Understanding the Family Context: A Qualitative Descriptive Study of Parent and NICU Clinician Experiences and Perspectives. Children 2023;10,896. https://doi.org/10.3390/children10050896.
11. Blackledge JT. An Introduction to Relational Frame Theory: Basics and Applications. Behav Anal Today 2003;3(4):421–433.
12. Synnes A, Lam MM, Ricci MF et al. How to measure patient and family important outcomes in extremely preterm infants: A scoping review. Acta Paediatr 2024;113:1228–35. DOI:10.1111/apa.17228.
13. Church PT, Banihani R, Litt JS, Msall M. Reimagining Neonatal Follow Up: An Equitable Model of Care Emphasizing Family and Child Function. Pediatr Clin N Am 2024
14. Jaworski M, Janvier A, Lefebvre F, Luu TM. Parental Perspectives Regarding Outcomes of Very Preterm Infants: Toward a Balanced Approach. J Pediatr 2018;200:58–63. https://doi.org10.1016;j.jpeds.2018.03.006.
15. Church P, Banihani R, Luther M, Maddalena P, Asztalos EV. Premature Infants: The Behavioral Phenotype of Premature Survivor. In Needleman H, Jackson BJ, ed. Follow-Up for NICU Graduates: Promoting Positive Developmental and Behavioral Outcomes for At-Risk Infants. Cham, Switzerland, Springer;2018.
16. O'Brien K, Robson K, Bracht M et al. Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicenter, multinational, cluster-randomized controlled trial. Lancet Child Adolesc Health 2018;2(4):245–54. https://doi.org/10.1016/S2352-4642(18)230039-7.
17. Pineda RG, Neil J, Dierker D et al. Alterations in Brain Structure and Neurodevelopmental Outcome in Preterm Infants Hospitalized in Different Neonatal intensive Care Unit Environments. J Pediatr 2014;164(1):52–60. http://dx.doi.org/10.1016/j.jpeds.2013.08.047.
18. Hayes-Skelton SA, Eustis EH. Experiential avoidance. In Abramowitz JS & Blakey SM (Eds) Clinical handbook of fear and anxiety: Maintenance processes and treatment mechanisms. 2020; American Psychological Association:115–131. https://doi.org/10.1037/0000150-007.
19. Dahan M, Banihani R, Church PT. Neonatal research outcomes: the ethical imperative to change attitudes. Lancet Child Adolesc Health 2022; https://doi.org/10.1016/S2352-4642(22)00127-4.
20. VanPuymbrouck L, Friedman C. Explicit and Implicit Disability Attitudes of Healthcare Providers. Rehab Psychol 2020;65(2):101–12. http://dx.doi.org/10.1037/rep0000317.
21. Campbell FK. Inciting legal fictions: disability's date with ontology and the ableist body of the law. Griffith Law Rev 2001;10:42–62.
22. Iezzoni LI, Rao SR, Ressalam J et al. Physicians' Perceptions of People with Disability and Their Health Care. Health Affairs 2021;40(2):297–306. Doi:10.1377/hlthaff.2020.01452.
23. Inder TE, Volpe JJ, Anderson PJ. Defining the Neurological Consequences of Preterm Birth. NEJM 2023;389(5):441-53. Doi:10.1056/NEJMra2303347.
24. Back SA, Miller SP. Brain Injury in the Preterm Neonates: A Primary Cerebral Dysmaturation Disorder? Ann Neurol 2014;45:469–86. Doi:10.1002/ana.24132.

Disclosure: *There are no conflicts of interests to disclose.*

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