Introduction: Why are we talking about presence?

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Background and Need

For parents, few experiences are more distressing than being apart from their newborn, yet this is often the reality when a preterm or critically ill infant requires care in the neonatal intensive care unit (NICU).

This separation is not only emotionally painful but also carries measurable clinical consequences.

Infants whose parents are more consistently present have shown improved growth and developmental outcomes, decreased time to achieve full oral feedings, and are more likely to receive their mother's own breast milk. They have also been shown to experience fewer infections and episodes of sepsis, less exposure to painful procedures, lower physiologic stress, shorter hospital stays, and reduced risk of major morbidities.

Parents of infants admitted to the NICU face far greater emotional and psychological challenges than those with healthy newborns, including higher levels of stress, anxiety, depression, and symptoms of posttraumatic stress disorder.

These burdens often interfere with parental confidence and the ability to fully step into their role at the bedside. Evidence shows, however, that when parents are able to be consistently present, these challenges are eased. Families report lower levels of psychological distress and develop stronger parent–infant relationships that foster bonding and support long-term family well-being.

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During the COVID-19 pandemic, restrictions on parental presence in NICUs intensified the challenges families already faced. Many support partners were required to leave immediately after the birth, while parents who returned home to care for other children were not allowed back. Even those permitted inside encountered rules that prevented them from being together at the bedside.

These restrictions cut families off from their usual networks of social support and disrupted bedside teaching and discharge preparation, leading to even greater parental distress. For infants, the absence of consistent parental involvement meant reduced access to their mother's breast milk, comforting touch, and the vital learning that occurs through facial interaction—all of which are essential for health and neurodevelopment.

Yet despite these well-documented consequences, parental presence policies remain inconsistent. Wide variation persists not only between provinces or states, but even among hospitals within the same city. This lack of a standardized approach undermines families' trust in the healthcare system and leaves infants vulnerable. Addressing these inconsistencies is therefore critical. As NICUs continue to recover from the pandemic, stakeholders must prioritize family- and infant-centered practices and commit to a unified, sustainable, evidence-based approach to parental presence. No parent should be forced to miss the critical first moments of their child's life, especially when their presence is proven to improve outcomes for both infant and family.

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NICU Trauma Coupled with Forced Isolation

The moment an infant is admitted to the NICU, a parent's world is forever changed. What begins as an anticipated journey into parenthood takes an unexpected turn, leaving parents in a whirlwind of fear, uncertainty, and heartache. In an instant, their infant is whisked away, and with them, the idealistic expectations of what parenting should look like. The emotional toll is profound, as parents grapple with helplessness and the stark realization that their role as a parent has shifted in ways they never imagined.

Thrust into an environment for which they had no mental, physical, or educational preparation, parents must navigate a complex and overwhelming medical landscape.

Suddenly, they are surrounded by unfamiliar terms, machines, and routines—all while battling intense distress, worry, and anxiety. Amid this storm, they are asked to absorb critical information about their infant's condition and care, often in real time. At the same time, they must juggle the demands of a life outside the hospital—a life that hasn't paused to accommodate this new reality.

Now imagine compounding all of this—the stress, the fear, the exhaustion—by removing crucial lifelines. No partner to lean on when a healthcare professional delivers news at the bedside. No mother, sister, or friend to stand beside you. No reassuring touch. No familiar voice. No one. Just you—alone—carrying the unbearable weight of it all.

> *"I was so lonely. My mental health has been in tatters for the past few years, and I believe COVID restrictions exacerbated that. I have lost friendships and relationships due to our NICU experience. More needs to be done for NICU parents after discharge, particularly for their mental health."*

This lived reality underscores how deeply restrictive policies amplify the trauma of NICU admission and highlights the urgent need for systems that protect parental presence and long-term mental health support.

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Moments Stolen by Isolation

A mother cradles her infant against her chest, experiencing the warmth of skin-to-skin contact for the first time. Her infant's tiny body nestled close brings a fleeting moment of peace in the storm of the NICU—a moment she has longed for since the chaos began. Her face glows with pure joy and relief. Tears stream down her cheeks as she looks up, desperate to lock eyes with her partner, to share this indescribable moment of connection and hope. *But no one is there.* The chair beside her is empty. The one person who should be here is not allowed in. They're outside, waiting—missing this once-in-a-lifetime moment. And in an instant, the joy is swallowed by a hollow ache. A reminder of how alone she truly is. A feeling she will never forget—or ever get over.

"I had to go through one of the most traumatic experiences of my life entirely alone. I've truly never been so lonely and depressed in my life. I was in a town I didn't live in, surrounded by people I didn't know, and told to come alone from day one. It had a huge impact on my mental health, which affected my milk supply—one of the only ways I could help my baby at this stage."

Her story was not unique. Fathers, too, were left to shoulder terrifying moments alone. A father sits beside his fragile infant, watching her tiny chest rise and fall with each labored breath. Suddenly, alarms pierce the air. Her condition deteriorates in an instant. Nurses scramble, machines blare, and a team of healthcare professionals rushes to her bedside.

Panic sets in. His heart pounds. He stands frozen, helpless, as the room erupts into controlled chaos. Instinctively, he reaches out, searching for the comfort and strength of his partner's presence. *But his arm falls into empty air. She's not there.* She can't be there—not at the same time as he is. He is alone, watching their daughter fight for her life. No one to lean on. No hand to hold. Just the crushing weight of fear and isolation. A moment no parent should ever have to face alone. A moment that will haunt him forever.

"There were several occasions where my daughter would start coding or her sats were all over the place, and I was forced to the side to watch without any support. I was extremely alone and had to deal with the scary situations by myself."

These are not just fleeting memories. They are lifelong scars—moments of joy stolen, moments of fear endured alone, and moments no parent should ever be forced to carry without support.

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An Impossible Choice

New parents. Twin boys. Two different NICUs. They have just learned that their more critical son needs emergency surgery to save his life. The weight of this devastating news hasn't even fully settled when a nurse hands them a piece of paper that states: "From this moment forward, only one parent is allowed back into the NICU." They stare at the words in disbelief. She looks at her partner, searching his face, hoping—praying—that she will wake from this nightmare. But his expression mirrors her own: shock, fear, helplessness. This can't be real. *This has to be a mistake. But it is real.* And now, they are being asked to make an impossible choice. To decide which one of them will stay, and which one of them will go. To decide who will be with their critically ill son as he fights for his life, and who will stay with their other twin. How does a mother walk away, knowing she may never see her son alive again? And how does she ever move past the gravity of a decision she was forced to make?

"The two days leading up to my son's death, I wasn't able to visit him because I was the main visitor for my other son. The guilt I feel will never leave me. My husband and I have both suffered tremendously."

Their story is not unique. Parents across the country recount similar experiences of pain, isolation, and trauma:

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"There was no support for parents with sick children in the NICU. It 100% added to the trauma. My husband wasn't allowed in with me. I watched my son being resuscitated three times in one afternoon—all alone. My husband had to sit in the car and wait for me to call with an update."

"My twins were born at 29 weeks when there were no visitors allowed at all in the NICU. One of my daughters became septic and was put on the oscillator. They called us to the bedside for an hour. This was the first time my husband met our daughters. Since I couldn't visit, I put up a wall from the beginning so I wouldn't be sad that I couldn't see them. I still have PTSD about it."

"My nurse told me to think about how my baby smells while I pump in my room alone. I bawled my eyes out and told her, 'I have no idea what she smells like since I've always had a mask on in the NICU.'"

"My husband and I couldn't be in the room together, so we couldn't make decisions together. It was horrible and isolating."

These are not isolated accounts—they are a collective testimony to the harm caused when families were forced apart at the very moment their infants needed them most. No parent should ever be put in the position of choosing which child, which moment, or which memory they are allowed to keep.

The Devastating Impact of Isolation

Being physically separated from their infant—or from the only other person who truly understands their pain—deepens the wounds.

Parents of NICU infants endure one of the most emotionally and physically draining experiences of their lives. The trauma of watching their fragile infant fight for survival is compounded by isolation, fear, and the lack of support when they need it most. Being physically separated from their infant—or from the only other person who truly understands their pain—deepens the wounds.

While medical advancements continue to improve outcomes for premature and critically ill infants, the emotional and psychological well-being of

their parents is often overlooked. The long-term impact of isolation in the NICU doesn't end at discharge—it lingers for months, even years, affecting mental health, relationships, and the ability to heal from the experience.

No parent should ever have to face the NICU alone. And yet, too many have.

This collective reality, combined with the foundation of the Presence Study, led to the formation of a collaboration focused on protecting and prioritizing parental presence in the NICU.

PRESENCE Study Summary

Aim

We brought together a diverse team of families, multidisciplinary neonatal healthcare professionals, researchers, and decision makers to investigate the impact of parent-infant separation on neonatal health outcomes and parent well-being and mental health, and to create consensus recommendations regarding parental presence.

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Methods

To accomplish our goal, we collected information from parents, healthcare professionals, and leaders regarding the impact of parent restrictions across Canadian NICUs via online surveys. Using this data and existing evidence, we identified a list of 50 items of interest related to parent restrictions.

Two rounds of Delphi surveys were circulated to Canadian parents of an infant requiring a NICU admission during the pandemic, neonatal healthcare professionals, and decision makers to rank and prioritize the top list of items.

We identified a list of 50 items of interest related to parent restrictions

A diverse consensus group consisting of 25 individuals with expertise related to the project through lived experience, career, education, health policy, community engagement, and public health decision-making was created. This group reviewed rapid synthesis evidence-based summaries of known benefits and potential harms related to parental presence and involvement on infant and parent outcomes. Thirteen priority recommendations were identified.

Recommendations for each item were either 'strong' or 'conditional' based upon the certainty of evidence for the outcomes.

- **Strong:** the consensus panel was confident that the desirable effects of adherence to a recommendation outweighed the undesirable effects and that given the certainty of the evidence and consistency of values and preference, it would be unlikely that the recommendation would change with new evidence.

- **Conditional:** there was a small margin between favorable and unfavorable outcomes, and the consensus panel concluded that the desirable effects of adherence to the recommendation probably outweighed the undesirable effects or the evidence was of lower quality, there was greater variability in individual values and preferences, and there was a possibility that the recommendation may change with new evidence.

Conclusions

Consensus recommendations included six strong recommendations and seven conditional recommendations. **The strong recommendations** are *parents as essential caregivers*, *providing skin-to-skin contact*, *direct or mother's own expressed milk feeding*, *attending medical rounds*, *mental health and psychosocial services access*, and *inclusion of parent partners in pandemic response planning*. **The conditional recommendations** are *providing hands-on care tasks*, *providing touch*, *two parents present at the same time*, *food and drink access*, *use of communication devices*, and *in-person access to medical rounds* and *mental health and psychosocial services*. See manuscript below for further details.

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Significance

Variations of parental presence restrictions remain in effect around the world. Implementation of consensus recommendations are essential to support the health and well-being of infants and their parents, actively prepare for future infection control crises, and ensure equitable promotion and maintenance of consistent parent presence NICU policies, resources, and advocacy.

Variations of parental presence restrictions remain in effect around the world

Resources

Practice recommendations regarding parental presence in NICUs during pandemics caused by respiratory pathogens like COVID-19. Front Pediatr. 2024
https://doi.org/10.3389/fped.2024.1390209

Understanding and addressing mental health challenges of families admitted to the neonatal intensive care unit. J Perinatol (2025)
https://doi.org/10.1038/s41372-024-02187-9

NICU Hospitalization: Long-Term Implications on Parenting and Child Behaviors. Curr Treat Options Pediatr.2018
https://doi.org/10.1007/s40746-018-0112-5

The spark:

The negative impact of restrictive parental presence policies in NICUs during the COVID–19 pandemic.

Rationale

- Hospitals restricted parental access leaving babies without a parent or a support person, even during extreme illness or death.
- Significant variations existed in parental access policies, even in the same city.
- Parents reported higher negative mental health outcomes during the restrictions.

The response:

Co–created best evidence practice recommendations regarding parental presence in NICUs during pandemics caused by respiratory pathogens such as COVID–19.

How we got there:

Consensus Panel: A diverse group of individuals with expertise related to the project.

Values, preferences, and evidence guided our recommendations

Step 1: Gathered impact data (via national surveys) from parent/caregivers, healthcare providers, and NICU leadership

Step 2: Completed literature review

Step 3: Identified 50 potential recommendation items

Step 4: Conducted two rounds of Delphi surveys. Participants *(n=59)* rated and ranked each item on importance:

- ***Round 1:*** *Rated 50 items (on scale of 1 – 5)*
- ***Round 2:*** *Ranked the top 20 items of Round 1 (from 1 – 20)*

Step 5: Presented rapid **evidence synthesis** of the benefits and potential harms for the top rated items to the consensus panel. Categorized each item as a ***Strong*** or ***Conditional recommendation***, based on strength of evidence and value.

Step 7: Asked panel members: **Do you agree with including this item as a national recommendation?**

Consensus was reached if at least 80% of the panel agreed to add the item

PRESENCE STUDY
Keeping Families Together in NICU

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Visit the Canadian Premature Babies Foundation at canadianpreemies.org for more information.

Read the full study here.

Consensus practice recommendations regarding parental presence in NICUs

Parent/Caregiver(s) should have:

Strong recommendation*

Conditional recommendation*

1. **Status for parent/caregiver(s) as essential caregivers**
2. **Unrestricted access to provide skin-to-skin contact** for their infant in the NICU.
3. **Unrestricted access to breastfeed and to receive breastfeeding supports** (including early hand expression, pumping and pumps, encouragement, and lactation support) for their infant in the NICU.
4. **Uninterrupted access to mental health and psychosocial support services** while their infant is admitted to the NICU.
5. **Uninterrupted access to attend medical rounds** while their infant is admitted to the NICU.
6. **Inclusion in co-designing/decision-making** for parent-related NICU policies (e.g., infection control, response planning), including NICU parent partners and advocates.
7. **Unrestricted access to provide hands-on care tasks** for their infant in the NICU.
8. **Unrestricted access to provide healing touch** for their infant in the NICU.
9. **Unrestricted, in-person access to attend medical rounds** while their infant is admitted to the NICU. **Virtual care services may be preferred**, based on the local context or if parent need/parent preference warrants it.
10. **Unrestricted, in-person access to mental health and psychosocial support services** while their infant is admitted to the NICU. **Virtual care services may be preferred**, based on the local context or if parent need/parent preference warrants it.
11. **Uninterrupted access for two parents/caregivers to be present while their infant is admitted** to the NICU.
12. **Unrestricted access to food and allocated spaces to eat/drink** while their infant is admitted to the NICU.
13. **Unrestricted access to use communication devices** (their own or hospital devices) for remote connectedness and support (with partners, family, peers, etc.) while they are in the NICU with their infant.

**'Strong': the consensus panel was confident that the benefit outweighed the undesirable effects. 'Conditional': the consensus panel concluded that the benefits probably outweighed the undesirable effects, and should be implemented, but new evidence might change the recommendation.*

Call to Action: Consistent nationwide evidence-based recommendations must be implemented and maintained at all times to support the health and well-being of infants and their families, ensuring equitable care, promoting the sustainability of best practices for optimal outcomes.

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