Managing Transitions of Care: An Examination of Parents’ and Providers’ Perspectives on the Transitions of Care of Neonatal Patients from the Neonatal Intensive Care Unit

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Collaborating Across Borders VI
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Interprofessional collaboration can act as a catalyst for efficient and effective transition of care (ToC), from a high-risk neonatal unit (NICU), to care back in the community.
Questions

- What are the historic and present structures and processes in place to enable transitions between hospitals, to the community, or to the home for neonates?
- What are the enablers and challenges for ToC of neonates, from the perspective of health care professionals and the patients’ family?
Methodology

• Staged approach
  • Stage I – Document Analysis (collection of artifacts)
  • Stage II – Observation
  • Stage III – Experiential Interviews
    • Health Professional Interviews
    • Family Member Interviews (Pre & Post Discharge)
  • Stage IV – Deliberative Dialogue Workshop
Setting

• The empirical component of this research project took place in a NICU at a large teaching hospital in Ontario, Canada

• Tertiary care NICU

• 21-bed capacity

• Approximately 450 admissions/year
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Key Findings - Parents

1. Communication with HCPs
   - Comfortable with discussing with HCPs
   - Majority of communication was with RNs and not MDs

2. Felt part of the team
   - Majority indicated yes
   - “....like they were always making sure that I’m comfortable with every decision I make.”

3. Involvement in DPP
   - “Most of the time”
   - “It was me who asked all the questions.”
Key Findings - Parents

4. Overall Experience

– Rated very positive

– “Yeah, everything went as planned. There was nothing that was miscommunicated or when I got home and like something wasn’t right. No, everything was the way it was supposed to be. Everything planned happened. They took care of everything. And just right after I was discharged, my baby was discharged, they came from Montreal, like a woman for the pump. They took care of everything right away. There was no waiting or anything.”

– “It was good. Like they always had time. Even though it wasn’t about the discharge but they were always working on bringing [child] home. So that it was pretty great.”
Key Findings - Parents

1. Last-minute notification of transition/discharge
   - Parents not ready or put on the spot (e.x. car seats, time off from work, etc.)
   - More of the case with acute patients vs. chronic
   - Case I – Was told day before
     • Yeah, because we didn’t know. He tell us this week, Friday should be if he is okay, we can probably go on Friday after. But after nobody tell us whether we go or not, if the baby is okay to go. And when you asked me, I asked the nurse. She told me, “Oh, you go tomorrow.” Oh, okay.
   - Case II – Was told day of discharge
     • So it was just the day that we were leaving during rounds, they just said, “Would you like to go home?” So up until that point, it hadn’t really been discussed...... And then from there, it just went to, you know, “Bring your car seat up and have it checked.”
   - Another infant – Mom drove back home (2 hours away from hospital) without informing hospital staff when told baby was being discharged that day → not ready to take baby home
2. **Involvement in transition of care planning**
   - Only included when needed – proactive parents
   - Indicated wanting to have a say in the planning part and not after the fact
   - Frustration when certain decisions were not explained
     - *The only thing that I was kind of not happy about was the fact that it was...the feeding pump...Yeah. I wasn’t really convinced that it was, oh, not convenient.*

3. **Communication**
   - Have to seek information on their own (self-initiated)
     - Ask questions to bedside nurse
     - Made sure they were present during morning rounds
       - Eavesdrop on what was being said about their baby → they were not recognized as being present
   - Heard different stories from different HCPs about discharge
     - *He speaks with me and tell me more about what is going to happen because some nurse told me something and another nurse told me another thing.*
Key Findings – Healthcare Professionals

• Majority of HCPS indicated that IPC was occurring on the unit
  – Morning rounds
  – Discharge planning rounds (Tuesday AM)
    • Inclusive of HCPs from other floors/hospitals and the CDT members

• Main point of contact for DP
  – Social workers
  – Care Facilitators
  – Bedside Nurse
Key Findings – Healthcare Professionals

1. Complex Communication Field
   – How much information is enough?
     • E.g. transfer of information between social workers
     • Residents & trainees
       – E.g. Feeding tube size

2. Differing values
   – E.g. Including HCPs from receiving end in discharge rounds at NICU – proactive HCPs

3. Role Clarity
   – Who does what?
   – Are we including everyone that should be at the table at the table?
     • Time and availability are issues as well as differing values
4. Internally unaware of discharge plans
   - Healthcare professionals unable to answer questions of parents regarding discharge
   - Friday @ 4:30pm discharges!

5. Advise parents against fellow HCPs
   - E.g. Bedside nurse would advise parents that being more vocal would ensure they get a bed spot at a particular hospital (when in reality the discharge is on hold because there are no spots at the receiving hospital).
     - Creating problem for discharge team or care facilitator
     - Give parents the idea that healthcare team not doing their best to discharge their infant
Key Findings – Community Healthcare Professionals

1. IPC with the NICU
   - Overall positive feedback
   - “Yeah. Yeah, on the whole part. I think sometimes people...everyone is focused on their role and sometimes, you know, under-staffed and over-worked kind of a thing. There's a little bit of chasing around. But I think everybody is really good at having the client's care needs as being their main objective and working towards the discharge.”
   - Discharge Rounds ➔ Facilitator
     • “It’s been really good for me because I kind of get the whole picture before this patient goes home versus trying to collect the information later. So it's really great that they’ve kind of included me in those meetings. Yeah, it’s been very helpful.”
Key Findings – Community Healthcare Professionals

2. Communication of Team
   – Unclear communication channels
   – Not knowing what has been done increases time for discharge

3. Lack of knowledge of what’s available in the community
   – Ex. Baby who needs to feed and grow can be weighed by Family MD or Rapid Response Nurse (instead of neonatologist)

4. Uncertainty over use of resources and/or which is appropriate
   – Public Health Nurse vs. Rapid Response Pediatric Nurse (under-use)

5. Role clarity
   – Unclear understanding of role of CDT members
     • Unclear boundaries
     • Lack of knowledge of responsibilities
   – Not sure when to involve CDT
     • Late involvement or patients identified late by members of CDT (potential miss)
6. Lack of Trust Amongst HCPs
   - Hospital HCPs not trusting community HCPs with their patients (and thus tend to cling on to the child)
     • Not aware of competency of community HCPs

7. Funding
   - Not all services required are not covered by OHIP
     • Government funds can take up to 6 weeks to come through \(\rightarrow\) what to do if child is discharged prior to 6 weeks?
       - Medical Fostering
   - Referrals ask for 24-hour nursing care when in reality families can only get 5 7-hour shifts
     • Families might not need exactly what has been referred
Multi-Faceted Family Centred Care Workflow

• This model encompasses FCC principles which have been developed to facilitate ToC in order to ensure that parents/primary caregivers are completely satisfied with their participation in the care of their newborns from admission to the integration of those babies into the community following discharge from the NICU.
Thank You