NICU to Home Transition Training

Maryam Attai
Suhui Chen
Stephen Jacobson
Design Thinking

- Empathize
- Define
- Ideate
- Prototype
- Test
EMPATHIZE

Immerse, Observe, and Engage

- “We felt rushed out of the NICU” *(parent)*
- “We had 24x7 nursing care when the baby was in the hospital. When we got home it really took a toll on us. We didn’t sleep and didn’t eat. Everything went on hold.” *(parent)*
- “We lacked experience, which is normal with preemie parents. We would have liked to have a little more medical training in case there was an episode.” *(parent)*
- “Discharge teaching starts at admission.” *(nurse LPCH)*
Discovering insightful nuggets

- “There was little to no instruction on the use of the equipment, and the medications were not easily administered due to my daughter’s condition. While we were referred to specialists and a pediatrician upon discharge there was no real ‘warning’ that my daughter would have 2 or 3 appointments per week.” (parent)

- “Because the schedule in the NICU was so strict and looking for cues from baby were hard to find so I always felt stressed about what my baby needed. I felt I had to keep the same strict schedule which stresses me out.” (parent)

- “A 5 minute training with a med tech is nothing like keeping a squirmy infant hooked up to equip meant for adults.” (parent)
Making sense of the user insights by building point of view statements

- **We met** Grace.

- **We were amazed to realize** Grace needs a way to prepare for her daughter’s transition from the NICU to home. Grace is worried about taking her baby away from constant medical supervision and wants to feel more confident as a parent and primary caregiver.

- **It would be groundbreaking if** Grace had the opportunity to practice caring for her baby as she would at home while still in the comfort of the NICU.
We explored How Might We statements in order to generate ideas

- **How might we** provide the educational information parents want and feel they need to effectively care for their baby?

- **How might we** involve parents in *even more* hands on care with the nursing staff till they feel confident they know how to care for their baby when they go home?

- **How might we** simulate common transition scenarios so parents can practice resolving them with guidance from the baby’s medical team?
Example of Open Ended Questions

- Thinking back to the first few weeks when your baby was home, what did you wish you had done differently to ease the transition from the NICU to home (i.e., ask friends or family to care for other children, or hire a babysitter occasionally)?

Example of Yes/No Questions

- Did your baby have a medical condition upon being discharged from the hospital?
  - 60% of parents responded yes

Example of Scale Questions

- If your baby was transferred to a nursery-like setting, please rate your experience. If not, please share how helpful the transition to a nursery-like room would have been for you as a parent.
  - Not at helpful: 8%, Slightly helpful: 18%, Somewhat helpful: 28%, Very helpful: 27%, Extremely helpful: 18%
Please select any of the following situations which you felt underprepared to handle upon your baby’s arrival home?

- **Baby’s feeding schedule**: 26%
- **Baby’s sleep schedule**: 33%
- **Spending time away from baby**: 33%
- **Understanding baby’s cries**: 28%
- **I felt completely prepared**: 29%
### Prototype 1 - Bathing

#### Excerpt from initial script

| Mom            | “Do I just submerge her in the water?” |
| Nurse          | “No. You want to start with only sponge baths. When the umbilical cord falls off, you know it’s the time to submerge your baby.” |
| Mom            | “Okay. Where should I start?” |
| Nurse          | “You want to start with the cleanest part of the body with a wet soft cloth on the face without any soap (do not put any soap on the face). Using baby soap, start washing with the hair, then the arms and legs.” |

#### Feedback from parents and NICU nurse

- “We were only allowed to stay with him one night and never given an opportunity to bathe him before he came home” (parent)
- “As a nurse I can bathe them in 30 seconds but the parents go so slowly” (nurse)
- “There are so many bathing products out there and prior to having the baby you don’t know which feature is most important. My child hated baths at first but slowly came around” (parent)
 Prototype 2 - Feeding

Excerpt from initial script

Mom: “I’m so confused... I am not sure how to make the formula. I have no idea how to mix the correct recipe with this new bottle.”
Nurse: “Don’t worry, let’s mix it together. The formula recipe states “three level scoops per six ounces of water.”
Mom: “Yes. But this bottle is only 2.5 oz. so I don’t know how many scoops I need.”
Nurse: “Let’s do a little calculation. How about remember this - for every ounce of water, half of a scoop is needed.”
Mom: “Yes. Now I have 2.5 oz of water, so half of that is ... one and a quarter of scoop.”
Nurse: “That’s correct!”

Feedback from parents via survey

- “The nutritional guidelines were complex and confusing and with the other things I hadn't done or been there 24/7 like the NICU staff had so I had to still learn a lot when baby came home”

- “Feeding teaching was rushed. It was much different to do in home vs hospital. Would've helped to have someone at home first day to watch over us.”
Mother: He’s starting to gasp for air, what should I do?
Father: I’m not sure, is his breathing device properly inserted?
Mother: I think so, I don’t know what to do.
Father: Let me get the nurse.
Nurse: Let’s see here, you said he’s not breathing normally?
Mother: Yes he keeps gasping.
Nurse: Hmm, yes sometimes that happens, it’s nothing to be worried about but what you can do is gently massage him to help stimulate his breathing.
Mother: “Like this?”
Nurse: “Yes, and if it’s just a few gasps it’s completely fine. Notice he’s dozing off, it’s likely that he was forgetting to breath.
Mother: How do I know when I should be worried about his breathing?
Nurse: Yes that’s a great question, let’s go over the various breathing patterns to look out for so you can recognize them on your own.
Prototype 3 - Breathing

Feedback from parents via survey

- “My daughter had apnea and I was always terrified she might stop breathing”
- “No one really explained to us the different types of breathing”
- “It took some time to learn the meaning of his cries. They were different in the quiet house than in the loud NICU, where more often we just watched the monitors or the schedule to tell what was needed.”

Feedback from NICU nurses at LPCH

- “It’s important to emphasize having parents be as hands-on as possible, from day one.”
**Primary Nurse:** Let’s see here, you said she’s not breathing normally?

**Mother:** Yes she sounds like she’s gasping.

**Primary Nurse:** Hmm, yes sometimes that happens but it’s nothing to be worried. When that happens you can gently massage her like this to help stimulate her breathing.

**Father:** So it’s nothing to worry about? Should we page the Nurse Practitioner or Dr. Rhine?

**Primary Nurse:** I think she’s going to be just fine, if it’s only a few gasps it’s probably because she’s in a deep sleep. Notice how she’s sleeping, it’s likely that she was just forgetting to breath. She’s so comfortable in her mom’s arms. I will however be sure to let the NP know.

**Father:** How will we know when we should be worried about her breathing?

**Primary Nurse:** Great question! Here let me finish feeding one of the baby’s and then I’ll come back and we can go over the various breathing patterns to look out for.

**Father:** That would be great thank you.
Social and Emotional Support

Feedback from parents via interviews and survey

• “Parent mentors a must”
• “I think a mentor program would be great. I could have used the support when transitioning home.”
Physical Layout

- Warm colors to simulate home environment
- Fewer chairs – not a conference room
- Wallpaper, carpet, and natural lighting if possible
Next Steps

- Further refine physical environment
- Incorporate alumni parents into transition training for parents' benefit and to reduce burden on nursing staff
- Examine the potential for a formal, regularly scheduled (weekly) class for parents prior to discharge
  - Example, John Muir discharge class for parents
Other ideas we came across

- More collaboration between NICU and PICN
- Redesign pumping room
- Alumni parent volunteers for care assistance and emotional support
- A volunteer home visit program
Special Thanks

Madeline Doron
Brittany Lothe

Kate Teague
Nick Hall

As well as...
Heather Keller
Elizabeth Pavlov
Jules Sherman
Dr. Rhine