“Helping Parents Cope in the NICU” with Annie Janier, MD, PhD

Q: What guidelines do you currently have in place for discharge/discharge readiness?

A: 35 weeks, a baby that no longer needs an incubator and can feed by himself and has not had apneas in 5 days, 1800g (limit for car seat). Of course some sicker babies leave with caffeine, oxygen and are tube fed.

Q: Where can we find the videos you/your unit have created?

A: https://www.youtube.com/channel/UCF9x2KBk7gjKAedVH3DH6kg

https://dranniejanvier.com/

We send parents, after the antenatal consultation, an email with the essential videos:

La vidéo de présentation de notre unité et une visite virtuelle de notre unité
https://vimeo.com/449839052/d88643480b
Le guide d’admission pour les parents de néonatologie (« Bienvenue en néonatologie »)
https://www.chusj.org/getmedia/8d373e06-b655-4c0d-85c8-d2fd38fadcea/F-2814_guide-de-vie_Neonatologie.pdf.aspx?ext=.pdf
La procédure pour exprimer le lait maternel après la naissance avec le tire-lait professionnel (qui se trouvent à la salle d’accouchement et en néonatologie)
https://vimeo.com/430113851/a3abcaa307
Une petite vidéo faite pour les parents de néonatologie (Top 10 du guide de survie, il y a d'autres vidéos sur mon site Youtube)
https://www.youtube.com/watch?v=U6fA9QNqCT4

The Hope wall is here: https://www.chusj.org/fr/soins-services/N/Neonatalogie/mur-espoir
Videos that go with it: https://www.chusj.org/fr/soins-services/N/Neonatalogie/mur-espoir/Videos

Q: 80% of our families are out of the NICU by the one-month mark; how can we be more inclusive with QI despite a shorter stay?

A: For the FiCare investigation I presented, we asked parents that were there more than one month because they were likely to know what all those interventions were (intubation, CPAP, changing oxygen levels, etc). We still offer the same thing to all parents in the NICU independent of length of stay following that QI questionnaire
The best way to do QI is to examine which population you want to improve. So we have interviewed parents of children who lost their baby to improve our palliative care and grief programs, interviewed parents of children with trisomy 13 or 18 to know how to best serve them, etc.

“Next Level FCC: How FICare Can Benefit US NICUs” with Linda Franck, RN, PhD, FRCPCH, FAAN

Q: Do you have any plans to expand your work to term and late preterm populations?

A: The mFICare content (https://familyintegratedcare.com/ficare-around-the-world/ is applicable to term and later term populations; research data were collected only on preterms. Additional content specific to term infants has subsequently been evaluated in Toronto: https://pubmed.ncbi.nlm.nih.gov/37628336/

Q: Are any of these care models or a subset of them applicable for full term babies born with disabilities like Down Syndrome or special needs like autism? Wondering if it will help build a broader support for sponsorship.

A: FICare is a model/framework for NICU Care delivery. It is agnostic to the specific conditions of the neonates cared for in the NICU. Co-design between NICU health professionals and parental to develop parental support services, staff training, parent educational content, mentorship etc to meet the unique needs of babies and families with particular needs, is encouraged. I have not seen such content for the two conditions mentioned. I'm sure it would be a great addition to NICU care should they be developed.

Q: Do you have any data on parent participation in rounds increasing the time they take? That's a concern from our staff.

A: There is a growing literature on parent participation in rounds across all of pediatrics-the benefits and how to address staff concerns. Most studies show that it can be done without increasing length of rounds. It starts with a culture change and revisioning of the purpose of rounds and then retraining/training the team in the new protocol. I suggest searching pubmed for relevant articles.

Q: Does your app share data with hospitals? Otherwise, how is the interphase done so the hospital knows if FICare processes are impactful?

A: Our We3health app was a prototype for our project and we are now in negotiations for potential commercialization. There are other apps that support parent knowledge acquisition and tracking their NICU journey. I am not aware of any that is able to share data at this time, but it is a fast evolving market. I suggest developing your own curated list of current apps that your unit feels has reputable content to recommend to families who are interested (and updating the list regularly).

Q: How do you match new parents with resource parents/parent educators/parent experts?

A: In our project, social workers played a lead role in this and then the multidisciplinary team also contributed input during weekly social rounds. As a result of the mFICare study, one site was successful in securing donated funds to support a parent liaison role (filled by a former NICU parent, who then served as a volunteer parent mentor). The position is 3 days a week. That role is still going strong and highly valued 3 years later.

Q: Are centers that participated in this research study still continuing with FICare practices?

A: Yes, to a larger or smaller degree. All of the NICUs suffered setbacks during the COVID-19 pandemic. All have restored some or all of the FICare components (except the app). Consistency and sustainability remain challenging.

Q: Can you speak to what the 'essential elements' for FICare are as compared to FCC?

A: See Table 2 of our paper (attached because not open access): https://pubmed.ncbi.nlm.nih.gov/37201991/