Family-Centered Care Taskforce November 2023 Webinar Summary

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Helping Parents Cope in the NICU with Annie Janvier, MD, PhD

Annie Janvier, MD, PhD, is a Professor of Pediatrics and Clinical Ethics at Universite de Montreal and a Neonatologist and Clinical Ethicist at CHU Sainte-Justine. She shared her experience as a NICU mom of a 24-weeker and as a Neonatologist implementing Family-Integrated Care (FICare) in her unit. Annie's presentation shed light on the complexity of implementing FICare and the ethics of FiCare, emphasizing her finding that to succeed, providers must first master the basics. This includes learning and using the infant's first name, using parent or family caregivers' preferred name, sitting eye-to-eye with parents and family caregivers to make introductions, answer questions, ask parents how they are doing, and always explain the 'why' behind your organization.

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Annie explains that the NICU experience can be traumatic and celebratory during a relatively short time; therefore, we must meet parents where they are at and keep care models flexible when putting FICare practices in place. Often, parents in the NICU do not feel they are truly parents, let alone good parents, given the highly specialized continuous medical care their infant is receiving. She offers twelve tips on ways to decrease guilt, empower and bolster confidence in parents and family caregivers, for example, by explaining skin-to-skin care in a nuanced way that includes

a caveat that parents may not feel comfortable doing it initially or addressing the guilt that many mothers feel about preterm birth. Using the sentence "some parents..... other parents" can help in these circumstances ("some parents feel anxious when they first do skin-to-skin while other parents feel this is a very positive experience. We will be with you to ensure this experience becomes positive for you").

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Lastly, Annie presented an article including the results of a FICare questionnaire administered in her unit. The survey results illustrate some barriers units may face in implementing FICare. For example, while most physicians supported the development of FICare practices, some parents expressed hesitance about doing some more medical interventions, for example, tube feedings, presenting at rounds, and being present during resuscitations. For those parents, these were not things they saw parents doing, and they preferred to have other roles. The "some parents... other parents" is a good way to ask parents about their preferences in these situations without causing harm and additional guilt. Ultimately, the survey results showed that FICare should not be felt by parents as "imposed" but instead offered in a way that helps parents based on their individual needs during their unique NICU journey.

Next Level FCC: How FICare Can Benefit US NICUs with Linda S. Franck, RN, PhD, FRCPCH, FAAN (she/her)

Linda S. Franck, RN, PhD, FRCPCH, FAAN, is a Professor and Jack & Elaine Koehn Endowed Chair in Pediatric Nursing at the University of California San Francisco Department of Family Health Care Nursing. She investigated the implementation of the Family-Integrated Care (FICare) model of NICU care delivery in US NICUs. FICare is based on Family-Centered Care (FCC) principles and includes providing a structured, parent-co-designed program of NICU care and encourages parents to become primary caregivers and full partners in care planning/caregiving for their infant. Key components of the FICare model that make it distinct from other parent support interventions include NICU staff training in working with parents (e.g., teaching, coaching, shared decision-making), parent participation in clinical rounds, peer parent mentorship, group education and psychosocial support for parents, and greater involvement of parents in caregiving for their infant. Some FICare models include parent-designed FICare app technology to increase parental access to information and support.

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Linda shared the results of a clinical trial of FICare in three different California NICUs with 253 patients 33 weeks and under. Families in the study received either routine FCC or FICare. Compared to the FCC group, the FICare group infants exhibited a lower rate of nosocomial infections and mothers who experienced higher NICU-related stress and had reduced depression and PTSD symptoms after NICU discharge. FICare components of participation in rounds, having a parent mentor, and group classes were associated with positive outcomes. Although there were no differences in outcomes specifically related to using the FICare app, it may have reinforced or increased access to other FICare content, such as education and support materials and preparation for parental participation in rounds. For more information about applying the FICare model to your NICU, check out https://familyintegratedcare.com/.

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