# Parent Participation in Research in the NICU

**School of Nursing** 



# Understanding parental choices in determining their child's participation in NICU research

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## **Background**

- Newborn & infant time period is critical for growth & development to mitigate this negative health outcomes, there is a important need for clinical research at the NICU3
- Reasons parents decline their child's enrollment in research includes feeling they lack time/space to make the decision<sup>1</sup>

## **Objective**

The purpose of this study is to

- 1. understand parents' experience of being approached for research participation in the NICU
- understand when parents' are able to engage in research conversations
- 3. how to best support them in that decision.

### **Methods**

- Parents with current or previous lived experience of having newborn(s)/infant(s) in the NICU within the past 15 years were eligible to participate
- Parents with previous lived experience were recruited via social media and parents with current experience were contacted in person or via letter with contact information
- Semi-structured interviews completed between Sept 2018 Sept 2019
- Thematic analysis was completed as described by Nowell, et al. (2017)<sup>2</sup>

#### Conclusion

The data has illuminated that readiness is not associated with one specific point in time. Parents who have adapted to the NICU environment, have developed their caregiver role, and who's infant's health was improving, are able to listen and make informed decisions to participate in NICU research.

#### **Future Directions**

Results from this study will be used to develop a parent-centred approach to research in the NICU.

## **Demographics**

- 31 participants (23 mothers; 8 fathers)
- 11 parents had no experience with research

#### Results

Thematic analysis revealed 3 themes: 1) Adaptation to the NICU Environment 2) Confidence in Infant Wellbeing 3) Parental Role Development

- · Overarching each of these themes, parents expressed emotions that moved between an internal, natural need to protect their baby and wanting to help future families by participating in research
- · Parents expressed how they felt and what they needed during different times in the NICU and what helped them feel prepared to participate in research
- Research also helped give parents a purpose and a way to give back to the community

"I was still in defense mode. I was like hold on, this is, my baby. And you're telling me you wanna take her where?... but at the same time, I'm like it's, I know why, research is so important, cause it's probably the reason why she's here is from research..."

"Because if the baby is like, dealing with a—just found out about some sickness, or like my guys had infections at the time, and it was a very stressful time... like I don't know if I [would be] as focused on a study as much as if things were like right now where it's, he's quite stable and stead[y]..."

"I feel that the NICU is a bleak place so any rays of sunshine you can find are very welcome. Like knowing that something good could come (new research) of our NICU stay was nice..."

## **Adaptation**

**Understanding Roles and Routines** Machines and Equipment

"NICU is a roller coaster... I mean yesterday, it's like I got here in the morning and he was already being IV'd, poked and prodded and different things to get his PICC line moved so it's just a very hard day for him but, probably mainly for me, for him too but like it's a lot... something like today and he's happy and he's obviously feeling better. It's just day to day right?."

# Infant Wellbeing

Holding on to hope Preparing for home Stability

# **Parent Role Development**

Touch and hold Provide caregiving Having a purpose Feeling a sense of control

"But in general, usually, it, it took a couple of weeks but once we got into the routine [we were more comfortable with receiving information]... that's when... we touched him...[when we actually started to have the hands on], do more... cause I was only allowed to give him his vitamins and his milk and the odd bath..."

- 1, Currie, V & Jull, A. (2012), Clinical trials in new zealand--An update, New Zealand Medical Journal, 125, 22-29
- 2. Nowell, et al. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. International Journal of Qualitative Methods, 16(1). https://doi.org/10.1177/1609406917733847
- 3. Vanhelst J, Hardy L, Bert D, et al. Effect of child health status on parents' allowing children to participate in pediatric research. BMC Med Ethics. 2013;14(1). doi:10.1186/1472-6939-14-7