

SURVEY AS A CONTEXTUAL DESIGN METHOD APPLIED TO BREASTFEEDING WEARABLES FOR MOTHERS CARING FOR INFANTS IN NICUS

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BACKGROUND

Preterm and critically ill infants are treated in neonatal intensive care units (NICUs), where human milk is increasingly recommended and prescribed to this population as a medical intervention [1]. However, due to the medical acuity and complex character of caring for preterm infants, sometimes feeding at the breast is not possible. When feeding at the breast is not possible medical devices or commercial products may influence a mothers' decision to express human milk for her NICU infant. Feeding human milk to infants cared for in NICUs reduces rates of mortality by decreasing instances of necrotizing enterocolitis (NEC) especially for extremely low birthweight infants [2] and is implicated in reducing incidence and severity of retinopathy of prematurity [3].

Since the passage of the Affordable Care Act (ACA) health insurance must cover the cost of providing a milk pump for mothers [4]. A variety of wearables such as pumping bras, breastfeeding bras and shirts aid to varying degrees the ease of breastfeeding and pumping milk. However, these wearables are not deemed medical devices nor covered by insurance and often not provided to mothers caring for infants in NICUs. In this research we ask whether and how wearables that support mothers to breastfeed or express human milk can be most impactful for the health of their infants in the NICU. This question is one component of a larger project investigating barriers to breastfeeding, milk expression, and skin-to-skin care (called kangaroo care) in NICU settings. Here we focus explicitly on wearables as a key component of medical design and NICU treatment.

Typically, only the opinions of patients and medical professionals are investigated for medical device or commercial health product design. When considering infants receiving NICU care, mothers are doing work as an essential part of the care of the infant alongside medical professionals. Contextual design stresses understanding how workers and users interact with devices and their environment in order to ideate successful

products for end users [5]. The techniques used to understand end users' behavior and motivations applied via contextual design originate from social science methods that acquire qualitative data such as interviews and participant-observation [6]. However, since the point of contextual design is to look beyond the biases of the designer and also to design for the entire market of users not just a single person, quantitative techniques from social science, such as surveys, also have a place in understanding end users and the context where medical devices are utilized. Surveys are a complementary tool that can be used to reach a large and disparate participant population.

The data reported here comes from an online survey administered from September through December 2017. The survey was distributed through state breastfeeding coalitions' social media and 148 U.S. mothers from 30 states responded regarding their NICU experiences with infant feeding at approximately 120 hospitals. The survey was developed using Qualtrics and included closed, with Likert Scale pre-coded responses, and open-ended questions. One goal of the survey was to determine the impact of wearables on the ability to breastfeed and/or express milk and use those results to inform on the design and creation of commercial health products that can better support NICU care.

Significance: The World Health Organization (WHO) and the American Academy of Pediatrics recommends human milk as the only food for infants for the first six months of life and that breastfeeding continue for two years and one year respectively [7]. However in the U.S. the exclusive breastfeeding rate for the first 6 months is just under 25% [8]. This rate is much lower than the worldwide average of 36% for 151 countries [9]. Breastfed infants have reduced incidence of diabetes, obesity, asthma, and leukemia long-term [10]. Breastfeeding preterm infants leads to improvements in motor, cognitive, and social-emotional skills [11] and higher toddler development indicator Bayley II scores [12]. Breastfeeding reduces mortality in NICUs from NEC [2] and may reduce incidence and severity of

retinopathy of prematurity [3]. Breastfeeding exclusively at least 6 months benefits baby's long-term health [10], and breastfeeding 1 year benefits mom's long-term health [13].

Women who deliver preterm infants have lower rates of breastfeeding initiation and duration than women who deliver full term infants [14], [15]. NICUs often present barriers to breastfeeding [16], [17]. A number of factors limit initiation of breastfeeding for NICU infants, including but not limited to mothers' choice, inability to create or maintain milk supply, separation of mothers and infants immediately following birth, and infants' inability to feed at the breast due to prematurity (e.g. [18]). Often mothers adjust their infant feeding plans due to their infant requiring NICU care [19], [20].

A mother's breastfeeding satisfaction indicates overall success with breastfeeding her child/ren [21]. Preterm birth experience and physical and emotional separation between mothers and infants is both an obstacle and incentive for milk expression. Concerns about supply are a limiting factor for milk expression [19]. Studies show that while many mothers in the NICU express milk for their infants, the duration of milk expression is short and does not continue post-discharge [20]. However, support by NICU staff and through peer counseling for breastfeeding in the NICU encourages breastfeeding post-discharge [22], [23].

Literature demonstrates that lack of support is a main reason for non-initiation or short duration of breastfeeding in the U.S. [24]. In contrast the NICU is a site of support and advocacy for providing human milk to preterm infants as a life-saving medical intervention. For example, 5 mothers surveyed had no intention to breastfeed before birth of their children but when their children received care in the NICU 3 mothers ended up expressing milk from between 2 to just under 6 months. This finding exemplifies the advocacy and support NICU nurses provide to mothers to breastfeed their children.

However, Briere et al. (2016) found that an emphasis on attaining earlier discharge of preterm infants reduced support for direct breastfeeding in the NICU. An earlier study demonstrated that lack of support following NICU discharge made it more difficult for mothers to breastfeed [1]. A small-scale qualitative study of milk expression found that mothers' who received support from nurses and lactation consultants were more likely to express milk in the NICU [25]. In addition to support from staff, medical devices and products such as wearables may also play a role in the ease of continuing to feed human milk for mothers of infants who have been discharged from the NICU.

Existing nursing garments do not usually accommodate breastfeeding (BF), expressing milk (XM), and kangaroo care well. Kangaroo care has been shown to help mothers develop and maintain their milk supply when expressing milk especially when infants are not able to feed at the breast [26]. From other interview research carried out by the authors, NICU nurses mentioned anecdotally that mothers are also able to express larger volumes of milk when they are holding their infants in kangaroo care in the NICU. Nursing garments and kangaroo care garments available for purchase do not accommodate the leads and wires that support the health of infants in the NICU.

Additionally, space is often limited in NICUs because of the amount and size of equipment in use to support infants' health. Confined and limited space in the NICU makes using garments discreetly difficult, which many commercial garments have no accommodation for. Privacy in NICUs is lacking but remains an important factor for mothers to feel comfortable exposing their skin [26].

The aim of the larger project that this paper gleans from is to understand mothers' perspectives about breastfeeding and expressing human milk for an infant in the NICU and how wearables influence that ability. The results show that mothers' perception of milk supply has significant impacts on how long they choose to breastfeed or express milk for their children who received NICU care. The majority of mothers surveyed agreed with statements that their clothes facilitated breastfeeding or pumping milk respectively. However, mothers' opinions about wearables were not shown to result in significant differences in the duration they breastfed or expressed milk for their children in the NICU. Focusing wearable design and other efforts to improving mothers' milk supply likely will result in mothers continuing to breastfeed and express milk for their children who

Table 1. Survey Demographics, Income, and Employment

Age Range	n=
18-24	13
25-30	49
31-34	37
35-40	30
41 and up	11
Race Category	
White	131
Black or African American	4
American Indian or Alaska Native	3
Other	4
Income Range	
\$1,000-\$20,000	5
\$21,000-\$40,000	26
\$41,000-\$60,000	25
\$61,000-\$80,000	27
\$81,000-\$100,000	20
over \$100,000	39
Employment Status (at survey date)*	
Employed full time in the paid workforce	40
Employed part time in the paid workforce	25
Employed full time as a caregiver (aka stay at home parent)	57
Employed part time as a caregiver (aka stay at home parent and part time in paid workforce)	10
On paid maternity leave	3
On unpaid maternity leave	5
Using vacation time from my job in the paid workforce to be with my infant	25
Parenting Division of Labor	
Single parent, majority responsibility	5
Single parent, shared responsibility	2
Dual-parent household, shared responsibility	130
Other	4
*Respondents were invited to check all that apply	

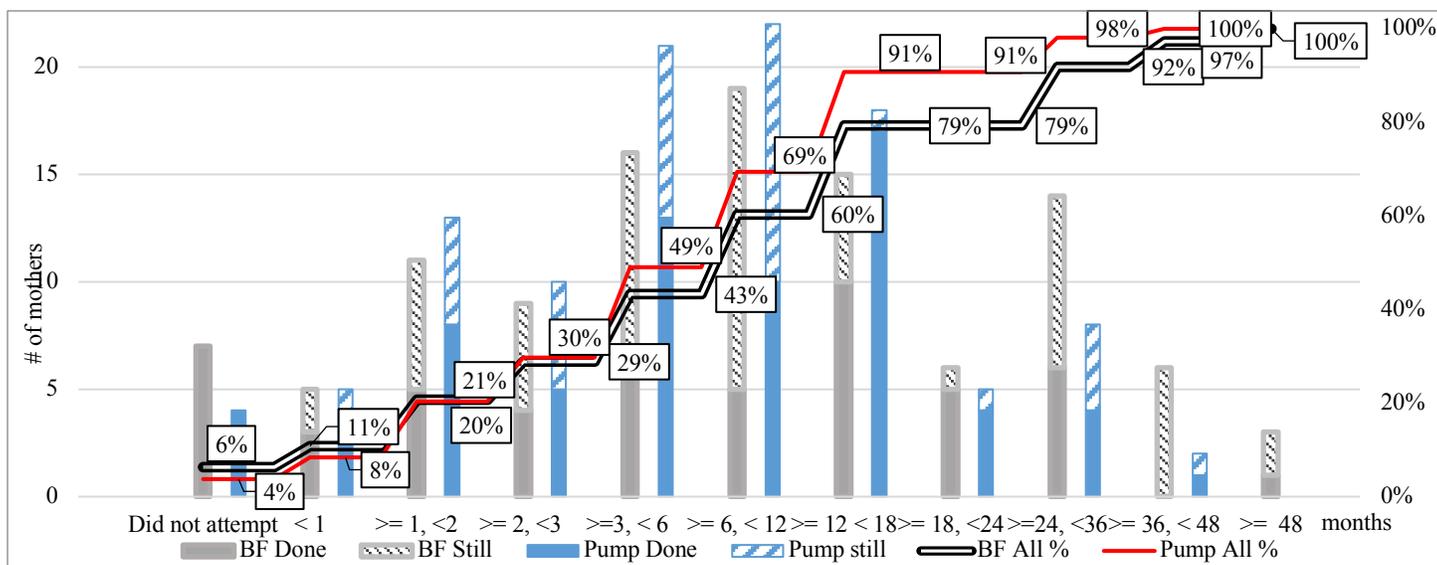


Figure 1: Duration and cumulative percentage of mother-child pairs who breastfed and/or expressed milk for children who received NICU care

received care in the NICU longer, thus improving short and long-term health outcomes for child and mother.

METHODS

148 mothers from 28 states responded to the online survey 116 mothers completed the entire survey from beginning to end and their responses form the sample for this data analysis (Table 1). U.S. State Breastfeeding Coalitions were invited via email to share the survey on social media. As a result, the participant group is made up of mothers who use social media for breastfeeding support. This factor may explain the participation of mostly White, upper-income women. The sample demographics differ from demographics of mothers in the U.S. by race with larger number of White mothers than the 52% expected from 2016 U.S. Census data of mothers by race and a smaller number of Black mothers compared to 14% across the U.S. [27]. Also a greater number of mothers from dual parent households instead of single parent households amongst respondents was found as compared to 76% and 17% of U.S. households respectively [28].

Statistical analysis was performed in MS Excel for descriptive statistics, and JMP 14.0 for other statistical tests. Normality of distributions were tested before analysis using graphical inspection with a Normal Quantile plot and with the Shapiro-Wilk test to evaluate goodness-of-fit. Some statisticians endorse the Shapiro-Wilk test as most appropriate for evaluating data normality [29]. None of the data were found to be normal.

The comparison of means between two groups was analyzed using a nonparametric approach. The Wilcoxon test does not require normal data, however it does require that the two groups compared are independent and have equivalent variance [30]. All durations of breastfeeding and pumping are independent by representing different mother-infant dyads or pairs. Whether the group variances were equivalent was tested with Brown and Forsythe's test for not normal data [31]. The data of

breastfeeding and pumping duration is characteristically skewed since the mothers who did not breastfeed or pump would have a duration of zero. Brown and Forsythe's test is most effective in not creating a type 1 error, i.e. finding a false difference, for skewed distributions [31]. All groups but one were confirmed to

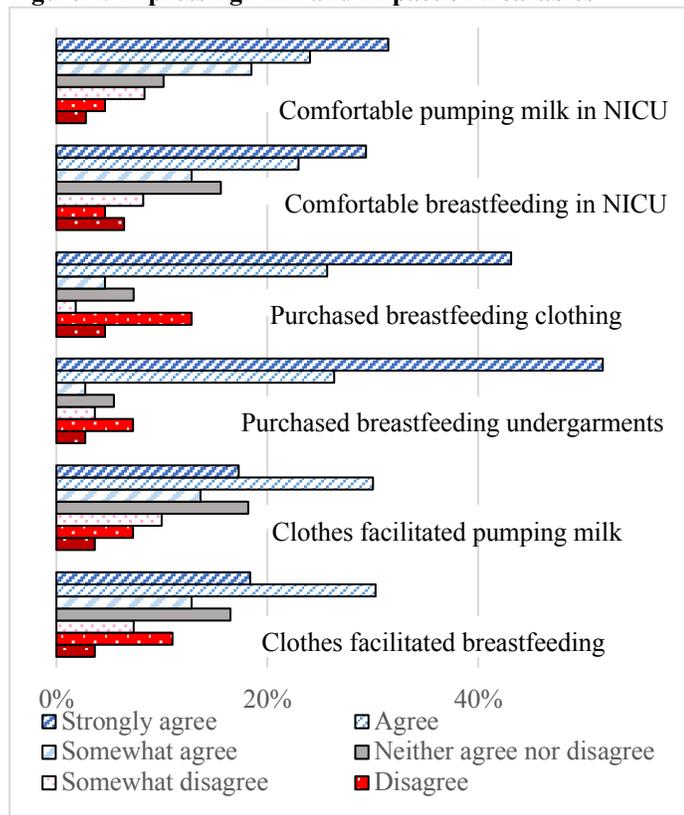
have equal variance. Welch's Anova is used to compare means for heteroscedastic data, i.e. groups with unequal variances [32], and was used in this case.

The comparison of means between groups for more than two groups was analyzed using the Kruskal-Wallis test, a nonparametric test. In order to use the Kruskal-Wallis test all samples must be random, independent, and an ordinal scale must be used for comparison of samples. A Kruskal-Wallis is used when there are means from more than two cohorts to compare with each other with regards to a single dependent variable [33]. The Steel-Dwass post hoc test that compares the means of each pair was used to eliminate Type 1 error, i.e. any false positives, or false differences found between the means of different groups. The significance level was taken as $p < 0.05$ for all tests.

RESULTS

Figure 1 shows the duration in months and years that survey respondent moms ($n=116$) breastfed and pumped milk ($n=111$) for their children in the NICU. The striped columns in Figure 1 indicate mothers who were actively breastfeeding or expressing milk at survey response time whereas the solid columns indicate mothers who finished. The lines in Figure 1 indicate the cumulative percentage of mothers who breastfed (double line) and/or expressed milk (single). Two moms reported that more than one set of siblings born had been in the NICU. Thus, a total of 118 unique Mom-infant dyads or pairs are reported on in this paper. Also note that infants in the NICU who were born at different dates are considered separately, infants born as multiples (e.g. triplets) are considered as a single data point.

Figure 4: Expressing Milk and Impact of Wearables



For moms of infants cared for in the NICU, breastfeeding duration recommendations were not followed by a significant percentage. 35% of moms breastfed and 40% of moms pumped milk, considering only mothers who were finished breastfeeding or pumping at the time of the survey, for less than the 6 months recommended for improving infants' short-term and long-term health as represented by the double line or single line respectively in Figure 1. Nearly half of moms breastfed and 56% of moms pumped less than one year, when benefits for moms' long-term health accrue.

NICU infants are often treated for extended periods of time in the NICU from weeks to months. Since human milk is the preferential food for preterm infants who often are treated in NICUs, some of the barriers to moms of NICU infants not breastfeeding or pumping milk deserve exploration. The durations of breastfeeding and pumping milk were compared by moms' answers for other survey questions.

Moms were also asked questions on a 7 point Likert scale about whether they felt comfortable breastfeeding (n=107) or pumping milk (n=106) in the NICU. Figure 4 shows that the majority of mothers agreed with these statements. However over 20% of mothers disagreed that they felt comfortable in either case, which might contribute to ceasing breastfeeding and pumping milk especially if their infant was hospitalized for longer periods of time in the NICU.

Previous research explored whether areas that lack privacy have an influence on clothing choice. The small sample of

Table 2: Statistical Analysis of Survey Wearable Questions

V 1	Variable (V) 2	n	Test	chi squared	p	No significant differences
BF	Clothes facilitated BF	48	Kruskal-Wallis	7.093	0.312	
XM	Clothes facilitated XM	63	Kruskal-Wallis	2.634	0.853	
XM	Comfortable XM	41	Kruskal-Wallis	4.996	0.661	
BF	Comfortable BF	46	Kruskal-Wallis	12.421	0.053	
BF	Purchased BF clothes	48	Kruskal-Wallis	4.180	0.652	
BF	Purchased BF undergarments	49	Kruskal-Wallis	7.619	0.267	
XM	Purchased BF clothes	62	Kruskal-Wallis	7.615	0.268	
XM	Purchased BF undergarments	63	Kruskal-Wallis	6.749	0.345	

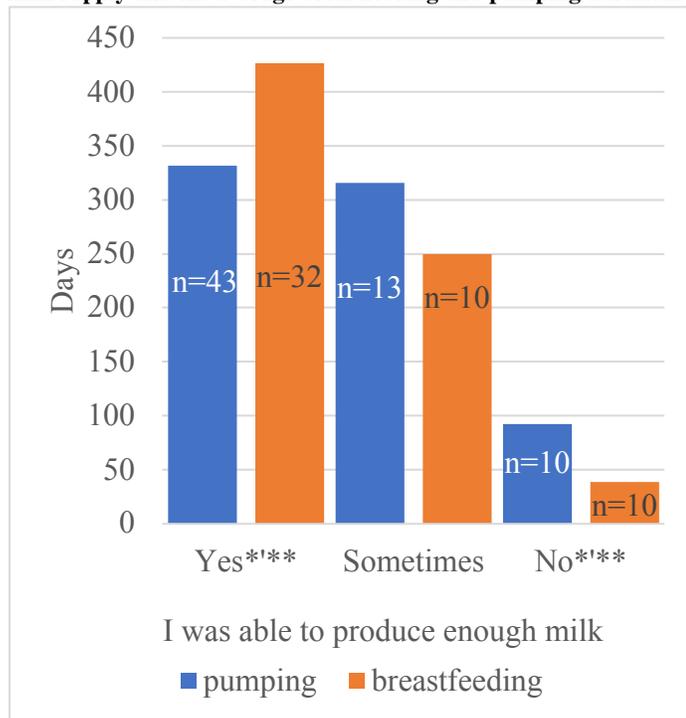
interviewed moms (n=13) were found to select specific clothing to improve comfort and ease of kangaroo care in NICUs. Similar to breastfeeding and pumping milk, kangaroo care involves skin exposure in the semi-public space of the NICU [34]. Participants in the online survey were asked if they purchased specific clothing for breastfeeding and whether their clothing facilitated breastfeeding or pumping. 81% and 72% of moms surveyed purchased breastfeeding undergarments (n=108) and clothing (n=107) respectively. Thus, the majority of moms decided that specially designed wearables were necessary to aid their breastfeeding and pumping experience in a NICU setting.

Mothers in NICUs who cannot breastfeed often pump milk every 3-4 hours, upwards of 7 times per day for 15-45 minutes each time. Pump flanges require support to stay on the breasts in an optimal position for expressing milk by the hands or a wearable such as a pumping bra. Wearables such as pumping bras allow moms the use of their hands while pumping milk which can even improve milk production and fat content by allowing massage of the breasts while pumping [35].

By and large pumping bras are not provided in NICUs, but the majority of moms, 81%, purchased some type of breastfeeding undergarments – showing the majority of moms surveyed saw breastfeeding undergarments as necessary. The majority of mothers agreed with the statement that their clothes facilitated breastfeeding or pumping milk (62%, 60% respectively), see Figure 4. However, no significant differences were found in BF or XM duration between moms who had different opinions about BF clothing.

Milk supply issues also influence duration of breastfeeding [19]. Figure 5 shows the significant difference in breastfeeding and pumping duration between mothers who said that yes they were or no they were not able to produce enough milk for their babies in the NICU. How moms perceived their milk supply, as being enough for their infants or not, seems to have a clear connection with the number of days that mothers continued to breastfeed or pump milk for their children who received NICU care.

Figure 5: The impact of Moms' opinion on whether they had enough milk supply and the average breastfeeding and pumping durations



*p=0.0279, p<0.05 denotes significance difference between groups
 **p=0.002, p<0.05 denotes significance difference between groups

INTERPRETATION

Infants treated in the NICU are often not able to breastfeed due to prematurity even though consuming human milk is recommended as part of their medical care. Thus, mothers become an essential part of medical care for their children in the NICU by expressing milk. The majority of mothers surveyed purchased breastfeeding clothing or undergarments. Because of the Affordable Care Act breast milk pumps must be covered by health insurance plans for mothers but wearables such as pump bras are not provided or covered by insurance. Although the majority of mothers surveyed agreed that clothing facilitated breastfeeding and pumping milk, no statistically significant differences between durations spent breastfeeding or pumping milk by their opinions about wearables was found. The design of commercially available pump bras and breastfeeding garments may not be providing all the support needed for developing and maintaining milk supply for mothers to persist in these important activities for their children who have received NICU care. Qualitative statements from mothers for this research suggest that other factors of concern for wearables may include privacy, support by NICU staff and the infant and mother’s extended family, and support when returning to work.

In agreement with other findings, mothers who selected that they had enough milk supply had statistically significant longer durations of breastfeeding and pumping milk than mothers who selected that they did not have enough milk supply. Kangaroo care is known to increase milk supply and duration of breastfeeding after infants are discharged from the NICU [36].

Wearables that support kangaroo care, breastfeeding, and pumping milk with a focus on developing and maintaining milk supply may support mothers of infants in the NICU to increase the length of time they continue these important caregiver behaviors. In the future a focus for the design of wearables on supporting mothers of children in the NICU to develop and maintain supply during challenging circumstances is warranted. Confirmation of whether or not the provision of wearables to mothers of infants in the NICU impact the duration of breastfeeding and pumping breastmilk as well as other desired health outcomes is also needed since the majority of mothers chose to purchase wearables and agreed that wearable facilitate these behaviors.

Many wearables are commercially available to aid breastfeeding and pumping milk. NICU nurses and the NICU environment especially encourage mothers to provide human milk for their children. Existing wearables may not meet the needs of all mothers in the NICU and may require redesign.

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