

Study Measures for Translation

Demographic Background Questionnaire. Basic background information will be obtained from parents (e.g., age, education, race, ethnicity, marital status) at enrollment. (5 minutes)

Parent and Nurse Perceptions of Infant Well-Being. Because of the limited availability of infant assessment tools, the investigators used symptom inventories validated in other critically ill populations as a guide (i.e., Memorial Symptom Assessment Scale)^{44,45} to develop a new measure to assess perceptions of symptoms in the NICU. This measure was tested in a previous study and demonstrated reasonable reliability (Cronbach $\alpha_{\text{mother}}=0.74$, Cronbach $\alpha_{\text{father}}=0.90$).¹⁴ Parents will be asked about six symptoms that were identified in our previous work¹⁴ as experienced by infants and distressing to parents to create a total symptom score. Parents will be asked regarding presence, severity, frequency, treatment received, how much it bothered the infant, and how much it distressed the parent of each of the six symptoms. Infant suffering and QOL will be rated on a 5-point Likert Scale. For the present study, items assessing the impact of language fluency on care were created (e.g., “How much was your response above related to your ability or inability to understand English”) (5 minutes)

Decision-making and Goals of Care Questionnaire. This measure was developed by the investigators in a recent study and data analysis is ongoing, thus reliability scores are not yet available. Parents will be asked to report on a medical decision for their infant made in the last week. They will rate how much each of 12 factors (e.g., infant appearance, infant’s current and future QOL, cultural or spiritual beliefs) influenced their decision-making. If they felt they made no decision, they will be asked about factors that may have contributed to no decision being made, including the perception that a decision was made but the parent did not make the decision. They will also report their hopes and goals for the infant, factors that might change those goals, and how well they perceive that their goals match those of the medical team. For the present

study, items assessing the impact of language fluency on care were created (e.g., “How much do you think your responses above are related to your ability or inability to speak/read/write English”) (5 minutes)

Language Fluency and Care Experiences. A new measure was created with input from the CAB. Checklist items related to cultural differences in care and items assessing language fluency in English were included to assess how language fluency affects care experiences in the NICU.

Cognitive Interview. Parents will be asked to reflect on the questionnaires they have completed using standardized questions for each item. Standardized questions were developed by the investigator for the current study. Parents will be interviewed in person by a bilingual research assistant. (20-30 minutes)

Summary of Measure Revisions

Demographic Background Questionnaire

- Numbers that were next to survey items for the purpose of data entry were removed. The CAB indicated that this could be confusing to families, and could also convey a sense of superiority if certain categories are labelled as '1'. See below for an example of survey items before making this change.
 - Male (1), Female (2), Other (3)
- The CAB suggested excluding a question on country of origin. They explained that this question can be problematic for some families, especially those that are undocumented.
- Categories for gender were removed, and the question was converted to a write-in format.
- Race and ethnicity were combined into one question and listed in alphabetical order after translation.
- "What is your current religious preference?" was changed to "spiritual preference," and the question was converted to a write-in format.
- The question "How many pregnancies have you had (or your partner, if male)?" was changed to "How many pregnancies have you or your partner had?" to be more inclusive.
- For appropriate items, "/a" was added to the end of Spanish words to include both masculine and feminine versions.
- Likert scale and other similar answer choices were changed to sound more natural in Spanish after translation.
- Measure instructions and a few other phrases were reworded to sound more natural in Spanish after translation.
- The original survey question on education was divided into two separate questions. The CAB explained that grade levels are not the same in every country, and some countries do not have middle school. Additionally, questions about degrees needed to be more straight-forward because some families may start their degree in high school. The CAB also requested making a community college degree more present, as there are many parents that complete 2-year degrees.
 - The first question asked parents about the highest grade of school they completed. Grades were removed and replaced with three categories for each level of education: Not Completed, Some, and Completed.
 - The second question asked about the highest-level degree completed, if any. Five degree categories were offered: Associate's (2-year), Bachelor's (4-year), Vocational Degree/Certificate, Master's, and Doctorate.
- Certain words or phrases that did not translate into Spanish correctly were corrected.
- Grammatical errors were corrected after translation.

Parent and Nurse Perceptions of Infant Well-Being

- The CAB explained that the terms “Often” and “Frequent” may have different meanings when translated into Spanish. They suggested using “Often” when referring to a specific number and using “Frequent” when referring to frequency. Thus, any questions asking “How often” were replaced with “How frequently.”
- The CAB suggested adding the question “Did you use an interpreter?” to the beginning of the questionnaire.
- The CAB explained that in Spanish, the term “Suffering” could pertain to physical suffering as well as suffering of the soul. This term was changed to “Physical suffering.”
- After translation, the CAB suggested bolding important words or phrases for better comprehension.
- Certain words or phrases that did not translate into Spanish correctly were corrected.
- Grammatical errors were corrected after translation.

Decision-making and Goals of Care Questionnaire

- The term “Goals” was changed to “Expectations” in the first question for more accurate translation into Spanish.
- To facilitate understanding, examples of an important medical decision were included.
- An extra section was added to this questionnaire, related to the impact of language fluency on care perceptions. Five questions were added with the help of the CAB.
 - How much did the health care team explain information about your baby’s care in a way you could understand?
 - How confident did you feel in making medical decisions based on how information was provided to you?
 - How much do you think that your responses above are related to your ability or inability to speak English?
 - How much do you think that your responses above are related to your ability or inability to read English?
 - How much do you think that your responses above are related to your ability or inability to write English?
- After translation, the CAB suggested adding instructions before the extra section that was added.
- Certain words or phrases that did not translate into Spanish correctly were corrected.
- Grammatical errors were corrected after translation.

Language Fluency and Care Experiences

- A new measure was created with the help of the CAB.
- Questions assessing the comfort of families in communicating in English were added.

- The CAB suggested listing NICU care experiences in a checklist format, as opposed to including a Likert scale, for ease.
- The CAB requested a space for families to write in other experiences not included in the checklist, as well as a space for families to give advice to providers in working with non-English-speaking families.
- Certain words or phrases that did not translate into Spanish correctly were corrected.
- Grammatical errors were corrected after translation.

Cognitive Interview

- The CAB advised asking families what they consider to be an important medical decision.

Supplemental Appendix 3

Study Measures – English version.

- Demographic Background Questionnaire
- Parent and Nurse Perceptions of Infant Well-Being
- Decision-making and Goals of Care Questionnaire
- Language Fluency and Care Experiences

BACKGROUND INFORMATION

We would like to ask you a few questions about yourself. Please answer all of the questions as completely as possible.

1. What is your gender? _____

2. Which of the following best describes your status when your child was born?

_____ Single

_____ Remarried

_____ Married

_____ Widowed

_____ Divorced

_____ Living with Someone

3. What was the highest grade of school you completed? (Circle one)

Not Completed | Some | Completed

Elementary	1	2	3
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High School	1	2	3
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Technical or Trade School	1	2	3
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College	1	2	3
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Graduate/Professional	1	2	3
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4. If you obtained a degree, what was the highest-level degree you completed? (Mark one)

_____ Associate's (2-year)

_____ Master's

_____ Bachelor's (4-year)

_____ Doctorate

_____ Vocational Degree/Certificate

5. What is your date of birth and age? Month _____ Day _____ Year _____ Age _____

6. Approximately what is your present annual family income?

_____	Under - \$25,000	per year
_____	\$25,001 - \$50,000	per year
_____	\$50,001 - \$75,000	per year
_____	\$75,001 - \$100,000	per year
_____	\$100,001 - or more	per year

7. What is your relationship to the child in the NICU?

_____ Biological Parent	_____ Foster Parent
_____ Step Parent	_____ Grandparent
_____ Adoptive Parent	_____ Other, please specify _____

8. How would you describe your race/ethnicity? (check all that apply)

_____ Asian	_____ Multiracial
_____ American Indian/Native Alaskan	_____ Native Hawaiian/Pacific Islander
_____ Black or African American	_____ White
_____ Hispanic or Latino/a	_____ Other, please specify _____

9. How would you describe your infant's race/ethnicity? (check all that apply)

_____ Asian	_____ Multiracial
_____ American Indian/Native Alaskan	_____ Native Hawaiian/Pacific Islander
_____ Black or African American	_____ White
_____ Hispanic or Latino/a	_____ Other, please specify _____

10. What is your current spiritual preference?

11. How spiritual do you consider yourself to be?

_____ Not spiritual at all	_____ Fairly spiritual
_____ Not very spiritual	_____ Very spiritual

12. About how often did you attend religious services in the past year?

_____ Several times per week	_____ Once a month or less
_____ About once a week	_____ Never
_____ 2-3 times per month	

13. How many pregnancies have you or your partner had? _____

14. How many biological children do you currently have? _____

15. How many other children do you currently have? (e.g., step, adoptive) _____

Parent Perceptions of Infant Well-being

Did you use an interpreter? (Circle one) YES NO

INSTRUCTIONS: We have listed 6 symptoms below. Using YES or NO, please indicate if your infant experienced the symptom **IN THE PAST WEEK**. If he/she had a symptom, please indicate how **FREQUENTLY**, how **SEVERE**, and how much it **BOTHERED** him/her using the scales listed.

DURING THE PAST WEEK DID YOUR INFANT HAVE ANY:

1. PAIN?	___NO	___YES	If yes, see below		
How <i>frequently</i> did he/she have it?	___Almost never ___Sometimes ___A lot ___Almost Always				
How <i>severe</i> was it usually?	___Slight ___Moderately ___Severe ___Very Severe				
How much did it <i>bother</i> him/her?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much				
How much did it <i>bother</i> you?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much				
Was there an attempt to relieve the symptom?	___NO ___YES				
How well did it work?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much				
How much was your child's pain explained to you in a way you could understand?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much				
How much is your response above related to your ability or inability to understand English?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much ___N/A				

2. IRRITABILITY/AGITATION?		___NO	___YES	If yes, see below
How <i>frequently</i> did he/she have it?	___Almost never ___Sometimes ___A lot ___Almost Always			
How <i>severe</i> was it usually?	___Slight ___Moderately ___Severe ___Very Severe			
How much did it <i>bother</i> him/her?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much			
How much did it <i>bother</i> you?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much			
Was there an attempt to relieve the symptom?	___NO ___YES			
How well did it work?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much			
How much was your child's irritability/agitation explained to you in a way you could understand?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much			
How much is your response above related to your ability or inability to understand English?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much ___N/A			

3. TROUBLE BREATHING ON THEIR OWN?		___NO	___YES	If yes, see below
How <i>frequently</i> did he/she have it?	___Almost never ___Sometimes ___A lot ___Almost Always			
How <i>severe</i> was it usually?	___Slight ___Moderately ___Severe ___Very Severe			
How much did it <i>bother</i> him/her?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much			
How much did it <i>bother</i> you?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much			
Was there an attempt to relieve the symptom?	___NO ___YES			
How well did it work?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much			
How much was your child's trouble breathing on their own explained to you in a way you could understand?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much			
How much is your response above related to your ability or inability to understand English?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much ___N/A			

4. SWELLING/SKIN BREAKDOWN?		___NO	___YES	If yes, see below
How <i>frequently</i> did he/she have it?	___Almost never	___Sometimes	___A lot	___Almost Always
How <i>severe</i> was it usually?	___Slight	___Moderately	___Severe	___Very Severe
How much did it <i>bother</i> him/her?	___Not at all	___A little bit	___Somewhat	___Quite a bit ___Very much
How much did it <i>bother</i> you?	___Not at all	___A little bit	___Somewhat	___Quite a bit ___Very much
Was there an attempt to relieve the symptom?	___NO	___YES		
How well did it work?	___Not at all	___A little bit	___Somewhat	___Quite a bit ___Very much
How much was your child's swelling/skin breakdown explained to you in a way you could understand?	___Not at all	___A little bit	___Somewhat	___Quite a bit ___Very much
How much is your response above related to your ability or inability to understand English?	___Not at all	___A little bit	___Somewhat	___Quite a bit ___Very much ___N/A

5. LACK OF ENERGY/FATIGUE?		___NO	___YES	If yes, see below
How <i>frequently</i> did he/she have it?	___Almost never	___Sometimes	___A lot	___Almost Always
How <i>severe</i> was it usually?	___Slight	___Moderately	___Severe	___Very Severe
How much did it <i>bother</i> him/her?	___Not at all	___A little bit	___Somewhat	___Quite a bit ___Very much
How much did it <i>bother</i> you?	___Not at all	___A little bit	___Somewhat	___Quite a bit ___Very much
Was there an attempt to relieve the symptom?	___NO	___YES		
How well did it work?	___Not at all	___A little bit	___Somewhat	___Quite a bit ___Very much
How much was your child's lack of energy/fatigue explained to you in a way you could understand?	___Not at all	___A little bit	___Somewhat	___Quite a bit ___Very much
How much is your response above related to your ability or inability to understand English?	___Not at all	___A little bit	___Somewhat	___Quite a bit ___Very much ___N/A

6. VOMITING OR FEEDING DIFFICULTIES?		___NO	___YES	If yes, see below	
How <i>frequently</i> did he/she have it?	___Almost never ___Sometimes ___A lot ___Almost Always				
How <i>severe</i> was it usually?	___Slight ___Moderately ___Severe ___Very Severe				
How much did it <i>bother</i> him/her?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much				
How much did it <i>bother</i> you?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much				
Was there an attempt to relieve the symptom?	___NO ___YES				
How well did it work?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much				
How much was your child's vomiting or feeding difficulties explained to you in a way you could understand?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much				
How much is your response above related to your ability or inability to understand English?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much ___N/A				

INSTRUCTIONS: Did your child have any other symptom not listed on the previous pages? If yes, mark yes and write that symptom in the space below and complete the rest of the survey. If no, mark no and proceed to questions #8-10.

7. OTHER: _____	___NO	___YES	If yes, see below
How <i>frequently</i> did he/she have it?	___Almost never ___Sometimes ___A lot ___Almost Always		
How <i>severe</i> was it usually?	___Slight ___Moderately ___Severe ___Very Severe		
How much did it <i>bother</i> him/her?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much		
How much did it <i>bother</i> you?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much		
Was there an attempt to relieve the symptom?	___NO ___YES		
How well did it work?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much		
How much was your child's symptom explained to you in a way you could understand?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much		
How much is your response above related to your ability or inability to understand English?	___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much ___N/A		

8. During the PAST WEEK, which symptom do you think was the WORST?

___Pain	___Irritability/Agitation	___Trouble breathing on their own
___Swelling/Skin Breakdown	___Lack of Energy/Fatigue	___Vomiting or Feeding Difficulties
___Other, listed above	___Other, not previously listed: _____.	

9. During the PAST WEEK, how much do you feel your child suffered?

___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much

How much was your child's **physical suffering** explained to you in a way you could understand?

___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much

How much is your response above related to your ability or inability to understand English?

___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much ___N/A

10. Overall, how would you rate your child's current quality of life?

___Very poor ___Poor ___Good ___Very good ___Excellent

How much was your child's **quality of life** explained to you in a way you could understand?

___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much

How much is your response above related to your ability or inability to understand English?

___Not at all ___A little bit ___Somewhat ___Quite a bit ___Very much ___N/A

Decision-Making and Goals of Care Questionnaire**PART A.****1. What are your expectations of current medical treatment for your baby?**

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
2.	How much do you and your partner agree on these expectations?	1	2	3	4	5
3.	How much do you and your child's health care team agree on these expectations?	1	2	3	4	5

PART B.**1. Has an important medical decision been made for your baby? (i.e., this is any decision you consider important, ranging from feeding decisions to surgery)**_____ Yes (*Complete the rest of this survey*)_____ No (*Do not complete Part C*)**2. Who made this important medical decision?**

_____ Me

_____ The Medical Team

_____ Both

3. What was that important medical decision?

PART C: Do not complete if you marked "No" for PART B.

During the LAST WEEK I considered the following when making a decision for my baby's medical care:						
		Not at all	A little	Somewhat	Quite a Bit	A Lot
1.	Symptoms my baby was having (e.g. pain, fussiness, trouble breathing)	0	1	2	3	4

PART C (continued): Do not complete if you marked “No” for PART B.

During the LAST WEEK, I considered the following when making decisions for my baby’s medical care:						
		Not at all	A little	Somewhat	Quite a Bit	A Lot
2.	The appearance of my baby, such as his/her color, presence of tubes or wires	0	1	2	3	4
3.	Feeling that my baby was suffering	0	1	2	3	4
4.	My baby’s current well-being	0	1	2	3	4
5.	My baby’s future quality of life	0	1	2	3	4
6.	Continued hope for a cure	0	1	2	3	4
7.	Chance of medical benefit	0	1	2	3	4
8.	Chance of medical burden	0	1	2	3	4
9.	Doing what I thought was best for my baby	0	1	2	3	4
10.	My cultural, spiritual, or moral beliefs	0	1	2	3	4
11.	Being a good parent	0	1	2	3	4
12.	The stress on our family	0	1	2	3	4
13.	The financial impact on our family	0	1	2	3	4
14.	What my partner thinks	0	1	2	3	4
15.	What my family thinks	0	1	2	3	4
16.	What my friends think	0	1	2	3	4

PART C (continued): Do not complete if you marked “No” for PART B.

During the LAST WEEK I considered the following when making a decision for my baby’s medical care:						
		Not at all	A little	Somewhat	Quite a Bit	A Lot
17.	What my baby’s healthcare team thinks or says	0	1	2	3	4
18.	Other: _____	0	1	2	3	4

PART D.

During the **LAST WEEK**, I considered the following when making decisions for my baby’s medical care:

	Not at All	A Little	Somewhat	Very	Completely	Not Applic.
1. How much did the health care team explain information about your baby’s care in a way you could understand?	0	1	2	3	4	N/A
2. How confident did you feel in making medical decisions based on how information was provided to you?	0	1	2	3	4	N/A
3. How much do you think that your responses above are related to your ability or inability to speak English?	0	1	2	3	4	N/A
4. How much do you think that your responses above are related to your ability or inability to read English?	0	1	2	3	4	N/A
5. How much do you think that your responses above are related to your ability or inability to write English?	0	1	2	3	4	N/A

The following questions ask about how comfortable you are with the English language...

	Not at All	A Little	Some-what	Very	Completely	Not Applic
1. How comfortable are you speaking English?	0	1	2	3	4	N/A
2. How comfortable are you reading English?	0	1	2	3	4	N/A
3. How comfortable are you writing English?	0	1	2	3	4	N/A
4. How comfortable are you understanding spoken English?	0	1	2	3	4	N/A

NICU Experiences Checklist

Please mark all items that you feel are representative of your experience in the NICU:

- | | |
|---|--|
| <input type="checkbox"/> I was not offered an interpreter, but one would have been helpful. | <input type="checkbox"/> I was not asked to make medical decisions for my baby's care. |
| <input type="checkbox"/> The interpreter I had was not useful. | <input type="checkbox"/> I felt my decisions were not understood by staff, and therefore not carried out how I wanted. |
| <input type="checkbox"/> I felt embarrassed asking for an interpreter. | <input type="checkbox"/> I felt uncomfortable in the NICU. |
| <input type="checkbox"/> I had an interpreter, but medical information was not explained in a way I could understand. | <input type="checkbox"/> I felt unwelcome in the NICU. |
| <input type="checkbox"/> I had trouble filling out forms in English. | <input type="checkbox"/> I was not given detailed written information in my primary language. |
| <input type="checkbox"/> I had trouble talking to staff in English. | <input type="checkbox"/> I felt the staff was unapproachable. |
| <input type="checkbox"/> It was difficult to communicate with the staff about my child's care. | <input type="checkbox"/> I felt the staff avoided talking with me. |
| <input type="checkbox"/> I felt like I could not ask the staff questions. | <input type="checkbox"/> It seemed like explaining medical information to me was a burden to staff. |
| <input type="checkbox"/> My questions were not understood or poorly answered. | <input type="checkbox"/> I was afraid of medical errors due to the difficulty in communicating with staff. |

Other experiences:

What recommendations do you have for the staff and medical professionals that work with families whose native language is not English?

[illegible]