

Megan Trout, MS, SLP-CF
Northern Arizona University

Chelsey L. Tarazi, BS
Northern Arizona University

Laura M. Rodriguez, MA
Northern Arizona University

Introduction

Parents experience many social, systemic, and psychological stressors as their infants receive care in the Neonatal Intensive Care Unit (NICU) (Guyer, McDorman, Martin, Peters, & Strobino, 1997; Doucette & Pinelli, 2014). For rural families specifically, these stressors are further confounded by issues such as geographical isolation and limited access to resources (Doucette & Pinelli, 2014; Discenza, 2016; Laadt, Woodward, & Papile, 2007). Given this, medical service providers employ a family-centered care approach, which includes providing informal/formal levels of support, and can improve infant health outcomes and collaborative efforts between family, infant, and provider (Doucette & Pinelli, 2014; Hung, Henning-Smith, Casey, & Kozhimannil, 2017).

After observing the Flagstaff Medical Center (FMC) Special Care Nursery, investigators were interested in learning how to support these families. Based on the investigators' collaborative efforts to partner with the FMC staff, ArizonaLEND, and Northern Arizona University's Institute for Human Development (IHD), they determined a webpage resource tool was needed as an informal method of support for families in rural Northern Arizona.

Objectives

In this pilot study, the investigators created a centralized bilingual webpage resource with information to support families during and after their infant's NICU stay including:

- Local lodging discounts, transportation, and childcare.
- Kangaroo care (skin-to-skin), perinatal mood disorders, counseling resources, and medical glossary terms.
- Developmental norms, transitioning home, and parenting education.

The investigators developed a bilingual survey to collect data regarding the webpage's usefulness and accessibility and to gather information to further improve the resource.

For the study, it is hypothesized that:

- This webpage resource tool is both accessible and useful for users in rural Northern Arizona.
- Users and practitioners will provide information regarding areas of need within the resource.

Methods

Investigators interviewed Flagstaff Medical Center Special Care Nursery staff members and obtained copies of a paper resource packet provided to families during their infant's NICU stay. A bilingual webpage resource was created based on the information: <https://nau.edu/ihd/special-care-nursery/> The investigators released a survey regarding the usefulness and accessibility of the webpage.

Participants

With a total sample size of 17, ($N=17$), participants included Hispanic/Latino ($N=3$) and Non-Hispanic White ($N=14$) respondents. 77% of respondents were from Northern Arizona while 28% were from Central Arizona. Majority of respondents had a 4-year degree, followed by professional degree and doctorate degree. See Table 1 below for further participant demographics.

	N
Total	17
Relationship with infant	
Parent	1
Family member	1
Provider	4
Friend of family	0
Other	1
No relationship with infant	10
Ethnic status	
Black	0
Hispanic/Latino	3
Non-Hispanic White	14
Asian	0
American Indian/Alaska Native	0
Native Hawaiian/Pacific Islander	0
Level of Education	
Less than high school	0
High school graduate	2
Some college	0
2-year degree	0
4-year degree	8
Professional degree	3
Doctorate	4

Q6: Age of Infant in Months
Q7: Level of Care for Infant
Q8: How helpful is the special care nursery webpage?
Q9: How often have you accessed the webpage?
Q10: Did the webpage have information you needed?
Q11: What was the most helpful about the webpage?
Q12: What was the least helpful about the webpage?
Q13: Was the information presented in a way that was easy to understand?
Q14: What other information would you like on the webpage?

Measurement

The investigators developed a survey that included both Likert scale questions and open-ended questions. The survey questions included demographics information, information regarding the infant, and general questions about the usefulness and accessibility of the webpage resource. In the table above, basic demographic information is listed.

Analysis

Frequency statistics were utilized for all Likert scale questions on the survey, while open-ended questions were analyzed qualitatively. Investigators looked for all responses addressing webpage usefulness and accessibility from the participants within the open-ended questions.

Results

In regards to how helpful the participants found the webpage resources, 100% of respondents found the webpage extremely helpful, very helpful, or helpful. 14 of the respondents had accessed the webpage for the first time when they took the survey. 70% of respondents indicated the webpage had more information than expected. One respondent indicated it had some information but they needed more, and another respondent indicated the webpage did not have the information they needed at all. 100% of respondents indicated the webpage was presented in a way that was easy to understand.

Qualitative Responses

What was the most helpful about the webpage?

- glossary of terms
- local hotels and resources
- Bilingual options
- quality of information

What was the least helpful?

- Information a parent may still feel uncertain about
- Hard to know what level of care the infant may need

Discussion and Limitations

When visiting the FMC Special Care Nursery, the investigators noted the majority of resources were given in paper form, which can be lost or damaged. The investigators hope that an online resource can provide accessible resources for families dealing with taking their infant home after a NICU stay. The sample size was quite small, which lowered statistical power overall and generalizability. The investigators hope this online resource can be used as a model for other rural NICUs, as well as provide a safe and culturally appropriate space for families to seek out resources and information. In the coming months, the investigators will seek Navajo translation for the material to make the resource trilingual.

References

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