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Health Literacy Among Parents of Newborn Infants

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Abstract

BACKGROUND—Health Literacy is the ability to obtain, process, and understand health information to make knowledgeable health decisions.

PURPOSE—To determine baseline health literacy of NICU parents at a tertiary care hospital during periods of crucial information exchange.

METHODS—Health Literacy of English speaking NICU parents was assessed using the Newest vital Sign (NVS) on admission (n=121) and discharge (n=59). A quasi-control group of well newborn (WBN) parents (n=24) and prenatal obstetric clinic (PRE) parents (n=18) were included. A single, Likert-style question measured nurse's assessment of parental comprehension with discharge teaching. Suspected limited health literacy (SLHL) was defined as NVS score of 3.

FINDINGS / RESULTS—Forty-three percent of parents on NICU admission and 32% at NICU discharge had SLHL ($p<0.01$). SLHL for WBN parents and PRE were 25% and 58% respectively. Parental age, gender, location, and history of healthcare related employment were not

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associated with health literacy status at any time point. Thirty-nine percent of NICU parents and 25% of WBN parents with SLHL at time of admission/infant birth had a college education. Nurse subjective measurement of parental comprehension of discharge instructions was not correlated to the objective measurement of health literacy ($p=0.26$).

IMPLICATIONS FOR PRACTICE—SLHL is common during peak time periods of complex health discussion in the NICU, WBN, and PRE settings. NICU providers may not accurately gauge parent's literacy status.

IMPLICATIONS FOR RESEARCH—Methods for improving health communication are needed. Studies should evaluate SLHL in a larger NICU population and across different languages and cultures.

Keywords

Health literacy; NICU; patient education; discharge teaching; well-baby nursery; newborn; parents

Background, Significance and Literature Review

Health literacy is a major problem in the United States, affecting more than one-third of adults.¹ It is defined “as the ability to obtain, process, and understand health information to make informed decisions about health care”. Health literacy differs from standard literacy assessment since it involves numeracy in addition to prose literacy.^{1,3} It is associated with the ability to know when to take medications and how to administer them correctly; apply and understand health information and instructions; and adhere to a prescribed medical plan. Low levels of health literacy may exacerbate health outcome disparities, can lead to consumer/patient dissatisfaction with health care providers, is associated with medication administration errors, and increased health care costs.^{4,5}

Nearly half of all adult Americans lack health literacy skills needed to function adequately in the health care environment.⁶ Inability to function in the health care system can lead to inadequate health knowledge, suboptimal health behaviors, worse mental health, poor clinical outcomes, poor use of health care services, increased hospitalizations, and higher health care costs.^{1,4,6,7}

Previous research has documented the importance of parental health literacy in caring for children. In a study focusing on children with special needs, parental health literacy was not static but varied with respect to parental involvement in the child's care.⁸ Health literacy can affect parental ability to access benefits for their children and adhere to prescribed medical interventions. Mothers with poor health literacy were less likely than mothers with adequate literacy to access temporary assistance for their children.⁹ Additionally, parental health literacy is related to medication dosing accuracy.⁵ It has been suggested that medication labels should be revised in order to improve parental understanding.¹⁰

In the primary care setting, parental health literacy is linked to parental knowledge of health information necessary for basic infant care.¹¹ Infants with medical needs are dependent on their parents for adherence to a prescribed medical care health plan. Caregiver competency in delivering appropriate health care is especially important in infants being transitioned

home after a complex hospitalization in the neonatal intensive care unit (NICU). During an infant's hospitalization in the NICU, frequent complex health communication with parents is standard. Infants discharged from a NICU generally require complex post-discharge care plans beyond what a typical newborn parent would receive. Understanding parental health literacy within the NICU setting may be crucial to engaging in adequate medical communication during the NICU hospitalization, establishing appropriate discharge care plans, and ensuring parental ability to engage in their infant's care and adhere to prescribed care at discharge. One study suggested that concentrating on parental health literacy may decrease barriers to care and may increase partnership between the parent and the health care team.¹⁰ Improving communication, such as using patient-centered communication, may assist those with limited health literacy.¹²

There have not been any previous published assessments of health literacy focusing on the NICU and new parent population. The purpose and primary objective of this study was to determine baseline health literacy of NICU parents at a tertiary care hospital at two periods of crucial information exchange -- admission and discharge -- and influencing factors. We hypothesized that suspected limited health literacy (SLHL) is elevated in the NICU population and is influenced by parental education level, employment in healthcare and infant illness.

Methods

Design

A convenience sample of parents with infants in the NICU and a quasi-control group of parents with infants on the well-baby nursery unit (WBN) and parents in the prenatal obstetrical clinic (PRE) were prospectively surveyed between July 2012 and January 2014.

Sample/Setting

The study took place at Christiana Hospital, which is a tertiary care center with a Level III NICU. Parents were identified and screened for eligibility via daily census lists, appointment schedules, and discussion with the attending physicians or nurses. Mothers and fathers were screened for eligibility and subsequently approached for consent. All parents enrolled were at least 18 years old with English as their primary language. Parents of NICU infants were eligible if they had an infant in the NICU with an expected length of stay greater than or equal to seven days and were expected to be discharged to home from the NICU at Christiana Hospital. Parents of babies on the WBN unit were eligible if their infant remained on the WBN with them. Parents from the obstetrical clinic (PRE) were screened and approached for enrollment during a prenatal visit. PRE parents with a fetus with a known significant complication affecting outcomes were not included in the study. If both parents chose to participate, they were enrolled as separate independent participants.

Instrument

Health literacy was assessed using the Newest Vital Sign (NVS). The NVS is a valid and reliable, 4–6 item health literacy screening tool that assesses an individual's numeracy, prose, and document literacy¹³. Participants are asked to review a paper with health-related

information. The administrator reads questions and the participants are asked to answer them based on the information in front of them. The NVS takes approximately 3–5 minutes to complete and is validated in both English (Cronbach's $\alpha > 0.76$) and Spanish (Cronbach's $\alpha > 0.69$).¹³

Statistical Analysis

Demographic data and NVS responses were analyzed using SPSS (19.0; IBM, NY). Demographic data were analyzed using descriptive statistics. Convenience quasi-control groups from the WBN and PRE were set at 25 and 20 respectively. Five participants were excluded due to lack of race/ethnicity reporting. For the purposes of this study, literacy was divided into two categories: Adequate health literacy and Suspected Limited health literacy (SLHL). Adequate health literacy was defined by a score of 4–6 on the NVS screening tool. Suspected limited health literacy was defined by a score of less than 4 on the NVS screening tool. Nurse perception of parental understanding of discharge information was categorized into two groups: (1) parental complete or almost all understanding or (2) parental moderate or less understanding. The relationship of health literacy and nurse perception of parental understanding of discharge responses and infant and parental factors were analyzed by binary logistical regression. All data presented were weighted to reflect normal distribution of race and ethnicity for our institutional population.

Procedures

The study was approved by the Christiana Care Institutional Review Board. After obtaining consent, demographic data was collected and included: parental age, gender, self-reported race/ethnicity, highest level of education completed, history of parental health care related employment, infant's gestational age at delivery, infant's day of life at the time the survey was conducted, and gestational age in completed weeks for PRE patients.

The NVS was administered to parents of NICU infants at two points in time: Admission, defined as 1–4 days after delivery, and discharge, defined as within 5 days of infant's discharge and at least 7 days after the first NVS was administered. The quasi-control group of WBN parents and PRE patients had the NVS administered at one point in time in order to assess baseline health literacy in parents without a health-compromised infant. WBN parents were administered the NVS on admission (1–4 days after delivery). PRE patients were administered the NVS during a prenatal visit. Severity of infant illness was assessed for NICU infants using the Score for Neonatal Acute Physiology (SNAP score), a validated objective measure of neonatal infant physiologic compromise that is obtained by collecting existing data from the infant's standard medical record.¹⁴

Nurses in the NICU and WBN were asked to complete an anonymous one question perception survey at the time of discharge, once enrolled parents had received standard discharge instructions. The nurses who provided the discharge instructions were asked to answer, "What is your perception of the parental understanding of the discharge instructions for this particular infant?" on a 5-point Likert scale ("Did not understand at all"; "Minimal understanding"; "Moderate understanding"; "Understood almost all"; and "Complete

understanding”). Nurses were instructed to answer this question based on their own perception of parental understanding of the information that they reviewed with the parents.

Results

Data from 163 parents were analyzed (n=121 NICU parents, n=24 WBN parents, and n=18 PRE parents). Of the 121 NICU parents who completed the NVS on admission, 59 completed the NVS at discharge. There were no differences in parental age, gender, employment in health care, education or race/ethnicity between the NICU, WBN, and PRE groups (Table 1).

Health Literacy: all parents

Within the NICU population, 43% of parents on admission and 32% at discharge had SLHL. By comparison, fifty-eight percent of PRE patients and 25% for WBN parents were SLHL. In multiple logistical regression analysis of SLHL, using the first NVS score for the combined scores of all three groups, parental education (less than a college degree) and minority race/ethnicity status were associated with increased of SLHL. Parental age, gender, location of participant, and previous healthcare related employment were not significant variables in the model (Table 2). There was not a significant interaction between race/ethnicity and education.

Although college education was associated with greater adequate health literacy, 39.1% of NICU parents and 25% of WBN parents with SLHL at time of admission/delivery had a college education.

Health Literacy: NICU Admission

At the time of NICU admission, lower educational status, minority race/ethnicity and female parental gender were associated with increased odds of SLHL (Table 3). Parental age, previous healthcare related employment, gestational age of infant, and illness severity (defined by SNAP score), were not significant predictors of SLHL.

Health Literacy: NICU Discharge

The NVS score for NICU parents was measured at admission and discharge. The mean length of stay for this group of parents was 39 ± 34 days. Seventy-four percent of parents maintained the same health literacy status at discharge while 4.1% scored worse and 21.5% improved. At the time of discharge, education remained independently associated with SLHL (Table 4). Similarly to admission measurement, at the time of discharge from the NICU, 22.6% of parents with a college education had SLHL.

There was a trend towards an association between a low NVS score, indicating SLHL, and minority status and female gender. SLHL at NICU Admission predicted SLHL at NICU Discharge. Length of stay, parental age, previous healthcare related employment, and infant illness severity or birth gestational age were not significant variables associated with SLHL.

The positive predictive value of less than a college education and minority race/ethnicity SLHL was 49.1% and 58.4% respectively. Conversely, the positive predictive value for

White/Non-Hispanic or College education for an adequate health literacy score was 72.4% and 72.1% respectively. In multivariate modeling, the predictive ability of the models to correctly identify SLHL at time of discharge from the NICU was 65%.

The NICU nurse perception survey for parental comprehension of discharge information had a response rate of 66%. Nurse perception of parental understanding of discharge instructions was not correlated to the adequacy of health literacy for NICU or WBN parents ($p=0.26$). Nurses perceived adequate comprehension of discharge instructions in 83.3% of parents when NVS scores indicated suspected limited health literacy. There was no relationship between race/ethnicity and parent completing the NVS and the nurse perception survey score.

Discussion

To the best of our knowledge, this study provides the first report of baseline health literacy data in the neonatal population. Approximately one-in-four WBN parents and one-in-three parents of NICU infants, and over half of our obstetric clinic population have SLHL during the time period of intense healthcare communication and care-instruction concerning themselves or their dependent newborn. Our data are important in showing that SLHL is common during periods of complex health discussions such as NICU admission and discharge, as well as routine, but information intense, prenatal obstetrical checks and well newborn care interactions. We had hypothesized that SLHL would be elevated in the NICU population due to this being a vulnerable period of time with copious amounts of information being given to the families. We anticipated that this stressful experience may have an impact on parent's ability to comprehend this information.

Although higher education was associated with increased levels of adequate health literacy, a college education did not fully discriminate between parents with adequate health literacy and those with suspected limited health literacy in our study population. Over one-third of college-educated NICU parents and one-quarter of all well baby parents did not achieve an adequate health literacy score at the time of their infant's initial hospital course. Minority race/ethnicities were associated with higher rates of suspect health literacy. There was not a significant interaction between education and race/ethnicity. Nurses' subjective measurement of parental comprehension of discharge instructions were not correlated to the objective measurement of health literacy, suggesting that nurses' subjective measurement, at a single point in time, may not be an adequate way to measure parental comprehension.

Although there were strong associations between education and race/ethnicity and suspected health literacy, using these parental demographic characteristics as a clinical tool to determine which parents may have suspected limited health literacy is not clinically useful. Using these parental demographics would lead to correctly predicting only 51% of parents at the time of infant admission correctly. Similarly less than two-thirds of parents with SLHL would be correctly identified by these demographics at the time of NICU discharge.

Limitations of this study include that this was a single-center study and results may not be generalizable to all populations. Importantly, this study did not evaluate parents with limited

English proficiency or mothers less than 18 years old, potentially even more vulnerable populations. Further investigations into limited English proficiency, non-English speaking populations, teenage mothers and various cultures need to occur in order to fully understand risks to infants after discharge and how to better communicate with parents while in the NICU. Within the NICU population, 59 of the original 121 NICU respondents remained in the study through discharge affecting the second NVS scores and assessment of health literacy change over time. Reasons for this included discharge prior to the eligibility date to complete the second NVS survey; fathers were often not present at discharge, and study staff not available to perform NVS at the time of parent's visitation around the time of discharge. The nurse perception of parental understanding was poorly correlated to parental health literacy scores; however, the study did not measure the parent's comprehension of the discharge instructions. The precise relationship between impaired health literacy and parental understanding of medical teaching during pregnancy and after delivery in the well-baby or neonatal intensive care units remains a subject for additional research.

Pregnancy, delivery of a newborn, and admission to the NICU are all stressful events for families.^{15,16} It is known that stress in both mothers and fathers is elevated on admission to the NICU and this stress persists throughout the infant's hospital stay.¹⁵⁻¹⁹ It is imperative that providers and educators be conscious that high stress times, such as hospital admission and discharge, coincide with times when copious amounts of information are communicated to parents, who are the responsible caregivers of the dependent child.

Given the high baseline frequency rates of compromised health literacy in the PRE, WBN, and NICU population, and the poor ability to predict health literacy status based upon demographic characteristics, enactment of universal methods for improving communication for all parents may be a strategy to consider. The safest approach may be to assume all parents have potential limited health literacy.

Nurse-to-parent teaching methods could be altered to focus on ways to facilitate and confirm comprehension of health-related information. Patient teaching materials could be reviewed for readability and suitability. The materials would subsequently require revision with the goal of enhancing understanding for all parents, including those with limited health literacy, in order to improve family/parental involvement in care.²⁰ Additional strategies which have been described as successful in improving education include: presentation of a small amount of information at a time, use of pictures to depict the information, decision-aids, and the teach-back method in order to confirm understanding of information presented.^{21,22}

The teach-back method is used to assess that patients understand what was explained to them. It should be viewed as a test of how well the information was explained. It involves teaching a procedure or giving information to patient and then having the patient demonstrate or "teach back" the procedure or information.¹ An example in our population would include a nurse teaching a parent how to prepare medication for their infant and then have the parent demonstrate and teach this back to the nurse.

It is reasonable to suggest that use of these methods to enhance communication and educational information has the potential to improve health communication in low or

suspected limited health literacy populations. The findings of this study warrant further research into how to effectively communicate with parents of newborns especially at times that coincide with elevated stress levels and provision of large amounts of health information.

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What this study adds

1. A description of the relationship between impaired health literacy and parental understanding of medical teaching during pregnancy and after delivery.
2. Variable levels of health literacy and comprehension of health care information especially at times of complex communications.
3. Highlights the need to enact methods for improving health communication as a universal strategy.

Summary of Recommendations for Practice and Research

What we know

- Health literacy is a major problem in the United States.
- Parental health literacy is an important factor in routine care of infants and young children.
- Infants discharged from a NICU generally require complex post-discharge care plans beyond what a typical newborn parent would receive.

What needs to be studied

- The relationship between impaired health literacy and parental understanding of medical teaching during pregnancy and after delivery.
- Health literacy among limited English proficiency should be assessed.
- Health literacy among various cultures should be studied
- A multi-center study might provide valuable information.
- Testing methods of assessing comprehension.

What we can do today

- Remain sensitive to variable levels of health literacy and comprehension of health care information.
- Consider use of the teach-back method when providing instruction to parents since this is an approach that would be easy for nurses to adopt
- Consider revising teaching tools and information sheets to include visual aids.

Table 1

Demographics of study population

Demographic Variable	Well-Baby Nursery (WBN) (n=24)	NICU (n=121)	Prenatal Obstetrical Clinic (n=18)	P
Parental Age	30.8 ± 7.8	30.4 ± 6.8	29.2 ± 5.8	0.613
Education: < 4 year college degree	60.0%	63.1%	85.0%	0.136
Parent completing survey	Mothers: 64% Fathers: 36%	Mothers: 66.5% Fathers: 33.5%	Mothers: 64.8% Fathers: 35.2%	0.191
Health Care Related Employment	Yes: 24% No: 44% Unknown: 32%	Yes: 24% No: 76%	Yes: 13.8% No: 84.2%	0.388
Race/Ethnicity	Non-Hispanic White: 72% Non-Hispanic Black: 12% Asian: 0% Hispanic: 12%	Non-Hispanic White 54% Non-Hispanic Black: 27.4% Asian: 5.8% Hispanic: 12.8%	Non-Hispanic White: 42% Non-Hispanic Black: 32% Asian: 5.3% Hispanic: 5.3%	0.420
Gestational Age (Completed Weeks)	n/a	32.6 ± 4.8		
Illness Severity Score (SNAP)	n/a	8.38 ± 7.1		

Table 2

Suspected Limited Health Literacy - All first NVS Responses (NICU NVS#1, WBN, Prenatal Clinic)

Suspected Limited Health Literacy for all parents (n=163)				
		P	OR	95% CI
Education < 4-year College		0.005	3.13	1.40–6.96
Race / Ethnicity	White / Non-Hispanic	-	1	-
	Black / Non-Hispanic	0.001	3.48	1.613–7.49
	Asian	0.022	5.84	1.30–26.29
	Hispanic	0.001	7.35	2.33–23.17

* Controlled for Education, Race/Ethnicity

Table 3

Suspected Limited Health Literacy – NVS NICU Admission

Suspected Limited Health Literacy at NICU Admission (n=121)				
		P	OR	95% CI
Education < 4-year College		0.005	3.58	1.35–9.53
Parent completing survey = Mother		0.09	2.19	0.89–5.43
Race / Ethnicity	White / Non-Hispanic	-	1	-
	Black / Non-Hispanic	0.007	3.41	1.39–8.36
	Asian	0.029	6.79	1.22–37.82
	Hispanic	0.06	3.57	0.95–13.42

* Controlled for Education, Race/Ethnicity, parent completing survey

Table 4

Suspected Limited Health Literacy – NVS NICU Discharge

Suspected Limited Health Literacy at NICU Discharge (n=59)				
		P	OR	95% CI
Education < 4-year College		0.015	12.15	1.62–91.02
Parent completing survey = Mother		.057	0.934	0.93–87.44
Race / Ethnicity	White / Non-Hispanic	-	1	-
	Black / Non-Hispanic	0.093	5.1	0.76–34.14
	Asian	0.048	23.9	1.03–556.25
	Hispanic	0.156	6.16	0.501–75.89

* Controlled for Education, Race/Ethnicity, parent completing survey