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Health Literacy in the NICU: Empowering Healthcare Professionals to Enhance Parental Engagement

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Health literacy plays a pivotal role in the Neonatal Intensive Care Unit (NICU), where healthcare professionals provide specialized care to newborns requiring intensive medical attention. The topic's significance prompted the development of a National Action Plan to Improve Health Literacy, envisioning a society where individuals have equitable access to precise and actionable health information, person-centered health services are provided, and continuous learning and skills fostering good health are encouraged.¹

This article explores the concept of health literacy in the NICU setting and its significance for healthcare professionals. By understanding the impact of health literacy, healthcare professionals can better support parents and caregivers, enhance communication, and promote informed decision-making, ultimately improving outcomes for NICU infants.

Defining Health Literacy in the NICU

Health literacy encompasses the skills, knowledge, and abilities required for individuals to access, understand, evaluate, and use healthcare information and services effectively. Health literacy is a complex concept that includes reading, writing, verbal, and numeracy skills in the context of health information.^{2,3} Examples include the ability to interpret medication labels, dose medication appropriately, mix powdered formula, relay clinical information to providers, and interpret and navigate digital health information. According to the National Network of Libraries of Medicine, nine out of ten adults do not have the health literacy skills needed to navigate our current healthcare system.² It is also well-documented that health literacy is decreased when patients or caregivers are stressed, anxious, sick, or traumatized.²

According to a study by Mackley et al., upon NICU admission, 43% of parents were identified as having suspected limited health literacy (SLHL), with this figure decreasing to 32% at the time of NICU discharge.⁴ Notably, factors such as parental age, gender, location, and history of healthcare-related employment were not found to be associated with health literacy status at any time. Furthermore, it was observed that 39% of NICU parents with SLHL possessed a college education.⁴

In the context of the NICU, health literacy extends beyond the literacy skills of parents and caregivers to include their capacity to comprehend and navigate complex medical information, terminologies and procedures for their child. Examples include drawing up the appropriate amount of medication and administering it through the appropriate route at the appropriate time or following a recipe to fortify milk. Parents often need more hands-on practice opportunities to build the know-how and confidence to effectively identify and troubleshoot problems independently.

Lower health literacy in parents and caregivers is associated with worse child health outcomes.^{5,6} Healthcare professionals must recognize health literacy as crucial to their interactions with parents and caregivers. Professionals should acknowledge this population's diverse backgrounds and varying levels of health literacy and adopt a "universal health literacy precautions" approach—that is, to explain concepts in simple and straightforward terms and focus on comprehension.⁷ When designing and implementing discharge processes that adequately prepare parents to care for their child after discharge, NICU professionals must recognize that most adults do not have high levels of health literacy. We must shift our "this is how we have always done it" mentality and challenge ourselves, our institutions, and our practices to best support families and caregivers.

The Importance of Health Literacy in the NICU *Enhanced Communication and Collaboration*

Acknowledging and addressing the disconnect between professional and parental knowledge and health literacy levels enables healthcare professionals to communicate effectively with parents and caregivers in the NICU. Experts note that parents should not be screened for literacy or health literacy as this often creates shame or overestimates comprehension.⁷ Instead, best practices for communicating with parents or other caregivers include using plain language, avoiding medical jargon, employing clear explanations, discussion or hands-on-based teaching and color-coded simple pictures. Effective communication promotes collaboration, enables shared decision-making, alleviates anxiety, builds trust, and helps parents and caregivers feel informed and engaged in their baby's care. Given the frequency of interactions and other contextual factors, NICU systems and the professionals who work in them have a unique opportunity to enhance caregiver/parent health literacy and prepare parents to best care for and advocate for their infants beyond the NICU.

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Parents often face challenges when answering questions about fundamental infant care tasks. In the study conducted by Enlow et al., it was revealed that 31% of the 137 participants demonstrated limited health literacy. Interestingly, these scores were not found to be associated with admission characteristics or complications experienced in the Neonatal Intensive Care Unit (NICU). Moreover, lower health literacy scores did not correlate with parents' self-rated readiness for discharge. These findings provide further evidence of the challenges many parents face when answering questions regarding basic infant care tasks. It emphasizes the importance of prioritizing health literacy in their communication and discharge planning processes.⁸

Empowering Parents and Caregivers

Building comprehension and enhancing health literacy equips parents and caregivers with the knowledge and skills necessary to actively participate in their baby's care. It fosters their confidence, encourages them to ask questions, and enables them to make informed decisions. By promoting health literacy, healthcare professionals empower parents and caregivers to become advocates for their baby's needs, leading to better adherence to treatment plans and improved overall outcomes. A study by Patel et al. found that during 635 home visits after NICU discharge, a comprehensive examination of 241 high-risk infants revealed 363 errors.⁹ These errors encompassed various aspects such as feeding, medication, equipment, and appointments. No significant associations were found between the presence or absence of errors and infant or maternal demographic factors.⁹ Infants' clinical outcomes improve when parents are more engaged during the NICU stay, and the length of stay decreases when parents are educated and empowered.^{10,11}

Challenges to Health Literacy in the NICU

Complex Medical Information and Terminology

The NICU environment presents parents and caregivers with an overwhelming amount of complex medical information, making it challenging to understand and process. The NICU often feels other-worldly to parents with unfamiliar terminology, equipment, people, and an environment with unfamiliar sights and sounds from the moment they enter. Each day they may face new experiences, terminology, and more that continue until the day of discharge. There is a paradigm here where families are rarely able to "catch up" to the gap in their knowledge because they are constantly bombarded with new information as their child's condition changes. If you take that coupled with the increased need for engagement, participation, and understanding required to pass the baton to them before discharge, they are set up for failure from the start. Many parents feel overwhelmed or even defeated because of this. Following NICU discharge, many parents of NICU graduates are entrusted with the responsibility of managing complex and ever-changing care routines. Healthcare professionals must recognize this challenge and employ effective communication and education strategies to bridge the gap between medical terminology, skills required to care for their child, and the parents' comprehension level.

Emotional and Cognitive Stressors

Parents and caregivers in the NICU often experience emotional distress and cognitive overload due to their baby's critical condition. These stressors can significantly impact their ability to absorb and retain information.^{2,3} Research indicates that a substantial proportion of medical information provided to

patients during office visits is promptly forgotten, ranging from 40% to 80%.¹² Furthermore, nearly half of the retained information is found to be inaccurate.

Healthcare professionals should provide support and empathy, an open-discussion style dialogue while delivering information, and allow for repeated explanations and reinforcement. NICU discharge preparation processes (which begin upon admission) must support parents' ability to learn and practice skills until they have reached an appropriate level of competency. Many NICU leaders share that the bulk of education and training is provided to families 48-72 hours before discharge. This information may include drawing up and administering medication, utilizing medical equipment such as home oxygen, or following a recipe to fortify milk properly. Not only is this not enough time for families to learn and retain the information, but it is also certainly not enough time to practice, formulate questions, and experience situations that may require troubleshooting.

Language and Cultural Barriers

Language, cultural differences, and biases can impact effective communication in the NICU. Parents and caregivers may face difficulties understanding and communicating their needs.

In their study, Harris et al. discovered that parents with limited health literacy and limited English proficiency were at the highest risk of making liquid medication dosing errors compared to parents with adequate health literacy and were proficient in English.¹³ Cultural nuances and beliefs can affect comprehension, decision-making, and reciprocal trust. Healthcare professionals should employ interpreter services, offer culturally sensitive materials, and engage in cultural humility to bridge the gaps.

Due to language and cultural barriers, families may feel embarrassed or guilty admitting they have questions or may not understand what was shared with them.³ Most NICUs do not have all the educational resources available to families in their native language. An interpreter can help communicate with the family when consulted during the NICU stay, but families need additional handouts and materials to support their training/educational needs as a reference. Many NICU nurses express guilt or anxiety after attempting to effectively educate, train, and communicate with families with language barriers. Thinking- "I wonder what happened to that family," or "I am worried about how this family will handle caring for their baby when they are home." These are the things that keep some NICU nurses up at night.

Strategies to Enhance Health Literacy in the NICU

Effective Communication Techniques

Healthcare professionals should use plain language, visual aids, and simplified explanations to convey complex medical information.² Clear, concise, and visual communication helps parents and caregivers better understand their baby's condition, treatments, and expected outcomes. It is recommended that professionals ensure the family understands what is being communicated before moving on to the next topic.¹ The Joint Commission highlights the "Teach Back" method as an easy and effective communication tool to assess understanding and assist with decision-making.^{12,14} Another example of open-ended dialogue includes phrases such as "What questions do you have?" instead of "Do you have any questions?" —signals to families

that questions are a routine and an expected part of medical communication.¹⁵

Universal Health Literacy Precautions

While limited health literacy is widespread, medical professionals are notoriously inaccurate in predicting who has limited health literacy.¹⁶ For example, a study by Mackley et al. determined no correlation between nurses' subjective assessment of parental comprehension of discharge instructions and the objective measurement of health literacy. Given this, experts recommend that healthcare professionals communicate information utilizing "Universal Health Literacy Precautions."¹⁷ According to the Agency for Healthcare Research and Quality Toolkit, these universal precautions simplify communication, ensure comprehension, and make the healthcare environment easy to navigate and empower parents.⁷ This universal practice may be even more critical in the NICU given the high prevalence of stress, feeling overwhelmed, trauma, anxiety, depression, and physical health issues among parents.

Creating a Supportive Environment

Healthcare professionals should foster a supportive environment encouraging questions, active participation, and collaboration. This may include taking the time to sit down with the family at the bedside or even scheduling a care conference with the multidisciplinary team to ensure the family has all of the information they need to make educated and informed decisions regarding their child's care. Professionals can alleviate stress and enhance engagement by addressing emotional and psychological needs, improving outcomes.

Utilizing Health Literacy Resources

Healthcare professionals should provide parents and caregivers with reliable health literacy resources in print and online formats.⁶ These resources may include brochures, videos, and websites that offer understandable and evidence-based information about NICU care, developmental milestones, and follow-up support. It is best practice if these materials are created by a multidisciplinary team that includes designers and parents.

Collaborating with Interdisciplinary Teams

Interdisciplinary collaboration is vital in addressing health literacy challenges in the NICU. Social workers, interpreters, and other healthcare team members can provide valuable insights and support in overcoming language and cultural barriers and addressing social determinants of health that may impact health literacy.

Staff Training and Education

Most medical professionals erroneously make assumptions about a parent's health literacy level, and few receive formal training in health literacy.¹⁶ A recent study of pediatric residents by Griffeth et al. found that only 19% of pediatric residents and 26% of pediatric residency faculty were familiar with universal health literacy precautions. Additionally, 37% of residents and 38% of faculty reported not receiving any health literacy training.¹⁶ Continuous professional development programs should include effective communication strategies, health literacy awareness, and cultural competence, motivational interviewing training. By equipping healthcare professionals with the knowledge and skills necessary to navigate health literacy challenges, they can better support parents and caregivers in the NICU. Training for professionals should emphasize parental comprehension as the

primary goal and measure of effective communication, no matter the parent's health literacy level.

Health literacy plays a critical role in the NICU, enabling healthcare professionals to enhance parental engagement and improve outcomes for infants in their care. By recognizing the importance of health literacy, healthcare professionals can employ effective communication strategies, address challenges, and provide the necessary support and resources to empower parents and caregivers. With a focus on health literacy, healthcare professionals can promote informed decision-making, strengthen collaboration, and foster a supportive environment in the NICU. Ultimately, by enhancing health literacy, healthcare professionals contribute to the overall well-being and success of NICU infants and their families in the hospital and at home.

AngelEye Health has spent much of this year researching and understanding the need to improve education and discharge processes in the NICU to facilitate a successful transition to home for NICU babies and their families. As we formally sponsor the National Perinatal Association (NPA) to ensure wide distribution and implementation of their recent publication, "*NICU Discharge Preparation and Transition Planning: Guidelines and Recommendations*," AngelEye is also actively developing solutions to help hospitals effectively implement the guidelines.¹⁷ Its newest solution, Empower, includes automated, relevant, and timely education and resources delivered to families both during the NICU stay and for six months post-discharge. The goal of this new turnkey solution is to address a significant unmet need to help mitigate the issue of health literacy and the challenges faced by staff in empowering families to be their child's best advocate. Empower further amplifies AngelEye Health's mission to equip care teams and empower families of neonatal and pediatric patients to improve outcomes.

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