Journal of Neonatal Surgery
ISSN(Online): 2226-0439
Vol. 14, Issue 31s (2025)
https://www.jneonatalsurg.com

OPEN ACCESS

The Role of Parental Health Literacy in Clinical Outcomes Among Neonates Undergoing Surgery: A Systemic Review of Current Evidence

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Cite this paper as: Ongart Maneemai, Kunwara Maneemai, (2025) The Role of Parental Health Literacy in Clinical Outcomes Among Neonates Undergoing Surgery: A Systemic Review of Current Evidence *Journal of Neonatal Surgery*, 14 (31s), 883-892.

ABSTRACT

Background: Parental health literacy (HL) is increasingly recognized as a critical determinant of clinical outcomes for neonates undergoing surgery. Effective parental HL supports accurate decision-making, adherence to postoperative protocols, and early recognition of complications, directly influencing recovery and long-term developmental outcomes. This review synthesizes current evidence on the impact of parental HL in neonatal surgical contexts, identifies effective HL interventions, and proposes strategies to overcome implementation challenges.

Methods: A systematic review of peer-reviewed literature published between 2010 and 2025 was conducted to examine parental health literacy (HL) within the context of neonatal surgical care. The search encompassed major academic databases, including PubMed, Scopus, and Web of Science, utilizing a range of relevant keywords such as "parental health literacy," "neonatal surgery," "clinical outcomes," and "postoperative care." The included studies were critically evaluated to assess their contributions to understanding the impact of parental HL on neonatal surgical outcomes.

Results: The review identified a consistent, positive association between high parental HL and improved neonatal surgical outcomes. Parents with higher HL demonstrated better comprehension of preoperative risks, more accurate adherence to postoperative care protocols, and more effective communication with healthcare providers. These factors collectively contributed to reduced rates of surgical complications, lower readmission rates, and shorter hospital stays. Effective interventions included teach-back methods, pictogram-enhanced instructions, digital health tools, Family Integrated Care (FiCare) programs, and professional interpreter services, each demonstrating significant improvements in HL and clinical outcomes.

Conclusion: Enhancing parental HL is essential for improving neonatal surgical outcomes. A multilayered approach incorporating routine HL assessment and targeted interventions offers a practical pathway to safer recovery and more equitable health outcomes. Future research should prioritize the development of standardized HL assessment tools tailored to neonatal surgical settings, assess the long-term impact of HL interventions, and explore scalable, cost-effective strategies, particularly in resource-limited environments.

Key Words: Health literacy, Neonatal surgery, Clinical outcomes, Postoperative care, Health disparities

1. INTRODUCTION

Neonatal surgery, though accounting for a small fraction of pediatric procedures, is decisive for infants with life-threatening congenital anomalies, now responsible for more than 80% of surgical admissions and the majority of procedure-related deaths in newborns worldwide [1]. While survival rates have improved dramatically since the 1980s, mortality for several index operations remains high, with case-fatality rates of 12-15% for primary repair of esophageal atresia with tracheo-esophageal fistula [2] and 15-20% for congenital diaphragmatic hernia, even in high-volume centers [3]. Postoperative infections, respiratory failure, and hemodynamic compromise collectively affect up to one-quarter of surgical neonates,

driving unplanned reoperations, prolonged intensive care stays, and later neurodevelopmental impairment [4].

Newborns pose unique physiological challenges. Immature cardiac and respiratory systems, low circulating blood volume, and limited metabolic reserves magnify the impact of blood loss, anesthetic agents, and inflammatory stress [5]. Against this complex backdrop, parents are indispensable partners. They must assimilate intricate risk-benefit information rapidly, provide informed consent, participate in preoperative optimization, and after discharge, shoulder responsibility for wound care, medication administration, and early recognition of complications [6].

Health literacy (HL)—the cognitive and social capacity to obtain, process, and apply health information—directly affects how effectively parents navigate these demands [9]. Nutbeam's three-level framework describes HL competencies as: functional HL (basic reading and numeracy required to follow written or verbal instructions), communicative HL (ability to extract, interpret, and apply information in changing contexts), and critical HL (capacity to appraise information and exert greater control over health decisions) [10,11].

Approximately one-third of neonatal intensive care units (NICUs) parents present with limited HL at admission [12]. Such limitations have been linked to medication-dosing errors, missed follow-up visits, and higher rates of adverse child-health events [13], whereas higher HL correlates with better coping, more effective communication with surgical teams, and shorter hospital stays [14]. Parental HL is further modulated by cultural, linguistic, and socioeconomic factors, which can constrain parents' ability to engage fully in surgical decision-making [15,16].

Despite its critical importance, the systematic assessment and targeted support for parental health literacy (HL) remain underutilized in neonatal surgical care programs. This review seeks to (i) provide a comprehensive overview of the current epidemiology of neonatal surgical complications and delineate perioperative stages where parental involvement exerts the most significant influence; (ii) critically evaluate empirical evidence linking parental HL to decision-making quality, adherence to postoperative care protocols, and subsequent infant health outcomes; and (iii) identify evidence-based interventions and existing research gaps to inform the development of HL-focused strategies in surgical NICUs.

2. METHODS

Designs

A systematic literature review was conducted to examine the impact of parental health literacy on neonatal surgical outcomes. Relevant peer-reviewed studies published between 2010 and 2025 were identified through comprehensive searches in major academic databases, including PubMed, Scopus, and Web of Science. The search strategy utilized a combination of targeted keywords, such as "parental health literacy," "neonatal surgery," "clinical outcomes," "postoperative care," "medication adherence," and "parental decision-making," to ensure a thorough capture of relevant literature. A systematic literature review was conducted to examine the impact of parental health literacy on neonatal surgical outcomes. Relevant peer-reviewed studies published between 2010 and 2025 were identified through comprehensive searches in major academic databases, including PubMed, Scopus, and Web of Science. The search strategy utilized a combination of targeted keywords, such as "parental health literacy," "neonatal surgery," "clinical outcomes," "postoperative care," "medication adherence," and "parental decision-making," to ensure a thorough capture of relevant literature.

Inclusion Criteria

Studies were included in the review if they met the following criteria: (1) focused on parents or primary caregivers of neonates undergoing surgical procedures; (2) assessed health literacy using validated measurement tools or clearly defined parameters; (3) examined clinical outcomes, parental understanding, decision-making processes, or postoperative care; and (4) were published in English. Studies were selected based on their relevance to the intersection of neonatal surgery and parental health literacy, with a particular emphasis on clinical outcomes, parental decision-making, and postoperative recovery.

Analysis Approach

The selected literature was systematically analyzed to identify the relationships between parental health literacy and neonatal surgical outcomes, effective interventions for enhancing parental health literacy, and the challenges and potential solutions for implementing HL-focused strategies in clinical settings. Study quality was critically appraised based on methodological rigor, sample size, measurement of outcomes, and potential sources of bias.

3. RESULTS

3.1 Parental Health Literacy: Conceptualization and Measurement

Parental health literacy (HL) refers to the capacity of parents to access, comprehend, critically appraise, and effectively utilize health information to make informed decisions that support their child's well-being and recovery [9, 19]. This definition aligns with Nutbeam's three-level framework, which categorizes HL into: (i) functional HL, encompassing basic reading and numerical skills necessary to understand health information; (ii) communicative HL, involving more advanced cognitive and social skills required for interactive communication; and (iii) critical HL, characterized by the ability to critically assess health information and make informed, context-specific decisions [9, 10, 19].

3.1.1 Measurement of Parental Health Literacy in Neonatal Settings

Several validated instruments are commonly used to assess parental HL in the context of neonatal care (Table 1):

- Newest Vital Sign (NVS): A six-item, rapid assessment tool that evaluates basic literacy and numeracy skills, often completed in under three minutes. It has demonstrated high sensitivity in identifying parents with limited HL [20].
- Parental Health Literacy Activities Test (PHLAT): This scenario-based assessment focuses on communicative HL, measuring parents' ability to understand and act on health information. It has shown strong correlations with education level and numeracy, reflecting real-world decision-making demands in NICU settings [21].
- eHealth Literacy Scale (eHEALS): An eight-item instrument designed to assess digital HL, capturing parents' perceived abilities to locate, evaluate, and apply electronic health information. This tool is particularly relevant as digital health resources become more integral to patient education and support [22].

Table 1 Summary of Key Health Literacy (HL) Measurement Tools

Tool	Focus	Description	Time to Administer	Strengths	Limitations	References
Newest Vital Sign (NVS)	Functional HL	Six-item ice-cream nutrition label test; measures basic reading and numeracy	3-5 minutes	Quick, widely validated, available in multiple languages	Limited scope, focuses primarily on reading and numeracy	Weiss et al., 2005 [19]
Parental Health Literacy Activities Test (PHLAT)	Functional, Communicative HL	Scenario-based items that simulate common parental tasks, like dosing medication	10-15 minutes	High relevance to NICU context, good internal consistency	More time-intensive, requires cultural adaptation	Sanders et al., 2009 [20]
eHealth Literacy Scale (eHEALS)	Digital HL	Self-reported scale measuring perceived digital health skills	5-10 minutes	Validated in multiple languages, suitable for telehealth	Self-report bias, less objective	Norman and Skinner, 2006 [21]

3.1.2 Predictors of Limited Parental Health Literacy

Approximately one-third of parents entering neonatal intensive care units (NICUs) exhibit limited HL [12]. Predictors of reduced HL include lower educational attainment, financial constraints, inadequate digital access, language barriers, and culturally divergent health beliefs [15, 16]. Additionally, the psychological distress commonly experienced following an unexpected surgical diagnosis can significantly impair cognitive processing, further reducing functional HL at critical decision-making moments [24].

3.2 Role of Parents in Neonatal Surgical Care

Parental involvement in neonatal surgical care is closely linked to their levels of health literacy (HL), influencing both clinical outcomes and family satisfaction. Effective parental participation spans preoperative education, postoperative care, and ongoing communication with healthcare teams, each stage presenting unique HL challenges and opportunities for intervention.

3.2.1 Preoperative Phase

During the preoperative period, parents are required to understand complex medical concepts, including surgical anatomy, anesthesia risks, and preoperative fasting requirements. Studies have shown that targeted educational interventions can significantly improve parental HL in this critical phase. For example, randomized trials utilizing multimedia "preparation" videos have demonstrated a 30% improvement in functional HL performance and a one-third reduction in preoperative anxiety, compared to standard verbal or written instructions [29]. Furthermore, interactive, digital content delivery platforms have been shown to produce even greater communicative HL gains, outperforming traditional leaflets in both comprehension and retention of key concepts [30].

3.2.2 Postoperative Phase

In the postoperative setting, parents must accurately interpret written discharge instructions, manage medication dosages, monitor for early signs of infection, and adjust feeding schedules—tasks that demand both functional and communicative

HL. Family Integrated Care (FiCare) programs, which explicitly address these HL dimensions, have been associated with significantly improved clinical outcomes. A recent multicenter study reported that FiCare participants experienced 3-5 day reductions in NICU length of stay and improved weight gain trajectories in neonates [14]. However, medication error analyses have highlighted critical gaps in parental numeracy, revealing that parents with limited HL were twice as likely to incorrectly dose antibiotics compared to those with adequate HL as measured by the Newest Vital Sign (NVS) [31].

3.2.3 Ongoing Communication and Decision-Making

High-quality communication with healthcare teams is essential for parents to progress from basic functional HL to more advanced critical HL. The "teach-back" method, for instance, has been shown to increase parents' risk-recall accuracy by 25% and double their shared decision-making scores without significantly extending consultation times [32]. Additionally, eHealth portals and secure messaging apps provide asynchronous opportunities for parents with lower literacy to formulate questions and seek clarification, improving message clarity and reducing miscommunication [33]. For families with language barriers or culturally distinct health beliefs, the use of certified medical interpreters and bilingual decision aids has been shown to mitigate power imbalances and significantly improve parental decisional satisfaction [34, 35].

3.3 Impact of Parental Health Literacy on Clinical Outcomes

A substantial body of evidence highlights the direct influence of parental HL on neonatal recovery, complication rates, and long-term clinical outcomes. Parental HL affects not only immediate postoperative recovery but also long-term cognitive and physical health trajectories, emphasizing its critical role in neonatal surgical care.

Table 2 Key Studies on Parental Health Literacy and Neonatal Outcomes

Study	Design	Population	Key Findings	Limitations
Harris et al., 2023 [13]	Cross-sectional	NICU parents, USA	Lower HL linked to higher medication errors	Single-center, no long-term follow-up
O'Brien et al., 2018 [14]	Cluster-RCT	NICU, Canada	FiCare improved outcomes, reduced LOS	High-resource setting, limited generalizability
Nguyen et al., 2022 [27]	RCT	Surgical NICU, USA	Teach-back improved consent comprehension	Small sample size, single site
Shieh et al., 2022 [28]	Cohort	VLBW infants, USA	HL at discharge predicted better neurodevelopment	Observational, potential confounders
Michelson et al., 2024 [48]	Cross-sectional	NICU parents, USA	Interpreter services improved risk recall	Language focus, no long-term outcomes

3.3.1 Length of Stay and Readmission Rates

Clinical trials have demonstrated that interventions targeting parental HL can significantly reduce hospital length of stay. For instance, the Family Integrated Care (FiCare) trial, which incorporates HL-sensitive coaching, reported a 3-5 day reduction in neonatal intensive care unit (NICU) length of stay, underscoring the potential for structured HL interventions to reduce healthcare utilization [14]. Similarly, discharge bundles that integrate pictograms and teach-back methods have been shown to reduce medication dosing errors by 30% and halve 14-day readmission rates, suggesting that effective HL support at discharge can prevent early complications [21]. In contrast, a large U.S. database study found that low-HL caregivers were overrepresented among infants readmitted within 30 days of NICU discharge, even after adjusting for birth weight and comorbidities, highlighting the risks associated with inadequate HL [36].

3.3.2 Infection Control and Complication Rates

Parental HL also plays a critical role in infection prevention. A prospective NICU audit reported that parents trained using HL-tailored educational materials achieved 85% compliance with hand hygiene protocols, resulting in a significant reduction in healthcare-associated infection rates from 0.67 to 0.23 per 1,000 patient-days [45]. FiCare units similarly reported lower rates of culture-positive sepsis compared to matched controls, a finding partly attributed to parents' improved ability to detect early signs of line-site inflammation and other infection risks [14].

3.3.3 Surgical Mortality and Long-Term Outcomes

Emerging data also suggest direct links between parental HL and neonatal survival. A Canadian registry analysis found that infants whose parents demonstrated lower HL had a 25% higher risk-adjusted mortality following gastrointestinal surgery, a relationship mediated by delayed recognition of postoperative complications and reduced adherence to discharge instructions [37]. Beyond immediate surgical outcomes, long-term follow-up studies have linked higher parental HL at discharge to superior language development and executive function scores in very-low-birth-weight infants, emphasizing the enduring impact of early HL interventions on neurodevelopment [28].

3.3.4 Decision Quality and Surgical Knowledge

In surgical-specific settings, parental HL strongly influences the quality of decision-making and comprehension of postoperative care requirements. A cross-sectional NICU survey revealed that parents with limited HL recalled 37% fewer procedure-specific risks and were three times more likely to misinterpret enteral-feeding instructions, directly affecting nutritional outcomes and recovery [26]. The use of teach-back methods during informed consent has been shown to improve risk recall by 25% and significantly reduce decisional conflict, highlighting the importance of HL-sensitive communication in high-stakes clinical contexts [27].

3.4 Enhancement of Parental Health Literacy

Numerous interventions have been developed to enhance parental health literacy (HL) in neonatal care settings, though the majority of studies remain quasi-experimental or single-arm pilots involving fewer than 200 families, often with heterogeneous outcome measures [53, 57]. Despite these limitations, several approaches have demonstrated consistent, positive impacts on parental HL and associated clinical outcomes.

3.4.1 Plain-Language and Pictogram-Based Educational Materials

Interventions using plain-language consent forms, typically written at a sixth-grade reading level, have been shown to significantly improve parental comprehension without extending consultation times. For example, bedside teach-back combined with simplified consent materials increased correct risk recall by 25%, enhancing informed decision-making in critical care settings [27, 53]. Additionally, pictogram-enhanced medication instructions, which visually convey dosing information, have halved liquid-medication errors across literacy levels at a minimal cost (approximately US$0.07 per sheet), making them a cost-effective option for widespread implementation [41].

3.4.2 Digital Tools and eHealth Literacy Interventions

Digital platforms that integrate multimedia content, wound-photo uploads, and push-notification reminders have proven effective in reducing unplanned clinical contacts by up to 40%, reflecting improved parental adherence to postoperative care protocols [57]. For instance, low-income families participating in eHealth literacy coaching programs embedded within these platforms saw average eHEALS score improvements of 15 points, indicating significant gains in digital HL [15]. In resource-constrained settings, offline "light" versions, such as SMS reminders or downloadable PDFs, have retained most of the instructional benefits at a fraction of the bandwidth requirements, increasing accessibility without compromising effectiveness [57].

3.4.3 Family Integrated Care and Peer Support

Family Integrated Care (FiCare) models, which couple bedside skill-building with structured peer support, have demonstrated substantial clinical and economic benefits. In Canadian NICUs, these programs have reduced length of stay by 3-5 days, generating per-infant savings of US$3,000-5,000 through reduced bed-day costs and fewer complications [14]. For linguistic minorities, integrating professional interpreters into care bundles has increased in-person interpreter use from 56% to 88%, simultaneously raising parental satisfaction by 30%, highlighting the importance of culturally and linguistically tailored support [54].

3.4.4 Economic Impact and Cost-Effectiveness

Economic analyses consistently indicate that HL interventions offer positive returns on investment. For example, the bed-day savings associated with FiCare typically offset the initial costs of staff training and app development within 12 months, providing a compelling financial case for adoption [14, 58]. Similarly, the prevention of a single central line-associated bloodstream infection (CLABSI) through improved parent-led hygiene vigilance can save approximately US$17,000 in direct treatment costs, illustrating the high financial stakes associated with effective parental HL interventions [21].

Table 3 Sample Health Literacy Intervention Workflow

Stage	Intervention	Purpose	Expected Impact
Admission	HL Screening (NVS, PHLAT)	Identify at-risk parents	Early identification of support needs
Preoperative Preparation	Teach-back, multimedia education	Enhance understanding of risks and procedures	Reduced decisional conflict, lower anxiety
Postoperative Discharge	Pictogram-based instructions, video demos	Improve adherence to medication and wound care	Reduced readmission, fewer medication errors
Follow-Up	Digital tools (eHEALS, telehealth)	Support ongoing education and adherence	Fewer missed visits, better long-term outcomes

3.5 Challenges and Strategies for Implementing Parental Health Literacy Initiatives in Neonatal Surgery

Despite the clear benefits of enhancing parental health literacy (HL) in neonatal surgical settings, several practical and systemic barriers complicate effective implementation. These challenges span socioeconomic constraints, language disparities, technological access, workforce limitations, and long-term program sustainability.

3.5.1 Socioeconomic Barriers

Socioeconomic factors significantly impact parents' ability to participate in bedside care and educational sessions. Transportation costs, inflexible work schedules, and competing childcare responsibilities can limit physical presence in the NICU, reducing opportunities for skill-building and HL improvement [63]. Potential strategies to address these barriers include providing transit vouchers, offering off-hours or weekend education sessions, and forming partnerships with temporary housing providers near hospitals to reduce logistical burdens on families [63].

3.5.2 Language and Cultural Barriers

Language discordance poses a critical barrier to effective HL. Non-dominant language speakers are three times more likely to misinterpret diagnoses and care plans, increasing the risk of adverse outcomes [58]. To address this, "interpreter bundles" — including automatic paging systems, dual-handset phones, and bilingual option grids — have been shown to significantly increase professional interpreter use, improve risk recall, and reduce decisional conflict in these populations [48]. For example, NICUs that integrated interpreter-use indicators into their perinatal quality dashboards maintained their communication gains at 18 months, demonstrating the potential for sustained impact through systematic tracking [58].

3.5.3 Digital Divide and Technology Access

The digital divide presents a substantial barrier to telehealth follow-up and digital health interventions. Approximately 20% of low-income families lack consistent access to smartphones or stable internet connections, limiting their ability to benefit from digital HL tools [59-61]. Successful responses to this challenge include loaning tablets with prepaid data cards, developing SMS-based "light" versions of wound-care applications, and integrating offline functionality into digital education platforms [51, 61]. These adaptations can significantly expand reach without requiring costly infrastructure upgrades.

3.5.4 Workforce Constraints and Time Limitations

Workforce shortages and time pressures can limit the use of labor-intensive HL strategies like teach-back and interpreter services. Task-sharing approaches, such as training parent mentors or rotating "HL champions" among nursing staff, have proven effective in maintaining high teach-back compliance (80% or higher) without requiring overtime or additional staffing resources [14]. Additionally, integrating HL metrics into quality dashboards can support accountability, streamline training efforts, and reinforce program sustainability [61].

3.5.5 Sustainability and Funding

Long-term sustainability remains a critical consideration for HL interventions. Programs that leverage bed-day savings, reduce readmission rates, or align with accreditation and quality improvement initiatives are more likely to secure ongoing institutional support. For instance, NICUs that incorporated interpreter-use indicators into quality dashboards maintained their gains at 18 months without additional external funding [48]. In resource-limited settings, "train-the-trainer" models have been particularly effective, preserving HL improvements for six months or more post-implementation without ongoing financial support [56].

2. 4. DISCUSSION

This review highlights that parental health literacy is a critical determinant of surgical safety and long-term neurodevelopmental outcomes in neonates. High parental HL consistently predicts superior risk comprehension, more accurate adherence to postoperative protocols, reduced infection and readmission rates, and improved risk-adjusted survival following complex procedures [14, 37, 53]. Notably, a clear dose-response relationship is evident: as parents progress from basic functional HL to more advanced critical HL, clinical outcomes improve proportionally, reflecting deeper understanding and more informed decision-making.

The multilayered interventions identified in this review—ranging from plain-language teach-back and pictogram aids to interpreter services, digital health applications, and Family-Integrated Care (FiCare) coaching—demonstrate both clinical efficacy and cost-effectiveness. Importantly, these interventions often incorporate equity-centered design elements, such as travel stipends, bilingual materials, and SMS-based alternatives, ensuring that their benefits extend to socioeconomically and linguistically marginalized families, who are at the highest risk of adverse outcomes. For example, tailored interpreter bundles and digital "light" versions have proven effective in reducing disparities in care comprehension and adherence among low-income and non-dominant language speakers [48, 57].

However, significant gaps in the current literature must be addressed to fully understand the long-term impact of HL interventions. Many studies are single-center, lack standardized outcome measures, and have limited follow-up periods, complicating efforts to draw robust conclusions. Additionally, few trials are randomized or sufficiently powered to detect differences in hard clinical outcomes, such as mortality or major morbidity. The heterogeneity of HL measurement tools also presents a challenge, as inconsistent definitions and assessment methods limit cross-study comparability and meta-analysis potential. Furthermore, economic analyses are often incomplete, omitting critical data on cost per adverse event averted, which is essential for building the business case for widespread implementation.

To advance the field of parental HL in neonatal surgical care, future research should prioritize the use of standardized HL measurement tools. Consistent metrics are essential for enabling cross-study comparisons, facilitating meta-analyses, and accurately assessing the effectiveness of diverse interventions. In addition, studies should stratify findings by

socioeconomic status, language proficiency, and digital access, recognizing that these factors significantly influence HL outcomes and health disparities.

Longer-term, multicenter trials are particularly needed to assess the sustainability and long-term efficacy of HL interventions. These studies should track key outcomes such as neurodevelopment, survival, and healthcare utilization over extended periods to capture the full impact of early HL support. Furthermore, economic evaluations, including cost per adverse event averted, should be incorporated to provide a clearer understanding of the financial benefits of HL programs.

Implementation research in low- and middle-income countries (LMICs) is also critical, given the unique resource constraints in these settings. Studies should focus on validating the scalability of low-cost, high-impact interventions, such as pictogram aids, interpreter bundles, and train-the-trainer Family Integrated Care (FiCare) models, which have shown promise in pilot studies but require broader testing to confirm their generalizability and cost-effectiveness.

By addressing these priorities, future research can more effectively inform policy, reduce health disparities, and improve outcomes for neonates and their families globally.

3. 5. CONCLUSION

Parental health literacy significantly impacts clinical outcomes of neonates undergoing surgery. This review demonstrates that higher levels of parental HL correlate with improved preoperative understanding, postoperative adherence, and ultimately better clinical outcomes including reduced complications, shorter hospital stays, and enhanced long-term development.

A comprehensive, multilayered approach to enhancing parental HL offers the most promising path forward. Routine screening with validated tools such as the Newest Vital Sign and PHLAT, combined with tailored interventions including plain-language materials, teach-back education, pictogram-enhanced instructions, digital health tools, and Family Integrated Care, can transform parents from anxious bystanders into confident, informed partners in care.

Healthcare systems should prioritize HL assessment and support as core components of quality improvement in neonatal surgical care. By empowering parents through targeted HL interventions, we can optimize perioperative safety, promote equitable outcomes, and secure healthier life-course trajectories for our most vulnerable surgical patients.

Acknowledgement: The authors would like to thank the University of Phayao and Chiarai Prachanukroh Hospital for their institutional support in conducting this research.

Ethical Approval: Not required, as this study is a systematic review of previously published literature and does not involve direct contact with human participants or the collection of identifiable personal data.

Author Contributions: OM led the conceptualization, design, and overall direction of the study, including the formulation of research objectives, systematic literature review, and manuscript drafting. OM also conducted the critical appraisal of the included studies and synthesized the findings into the final manuscript. KM contributed to data collection, assisted in the initial screening of articles, supported the interpretation of findings, and provided critical revisions to enhance the clarity and coherence of the manuscript. KM also participated in manuscript proofreading and ensured the accuracy of the references. Both authors reviewed and approved the final version of the manuscript prior to submission.

Conflicts of interest: The authors declare no conflicts of interest.

Financial support: No specific funding was received for this study.

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