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Qualitative Description of Neonatal Expert Perspectives About Necrotizing Enterocolitis Risk

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ABSTRACT

The purpose of this qualitative descriptive study was to provide rich description of experts' perspectives about necrotizing enterocolitis risk. Comments from 35 NEC experts were coded by two reviewers, grouped into categories and organized into themes. From 93 category codes, 9 meta-categories, and two broad themes were derived. NEC risk was considered to arise from both individual factors of vulnerability and variation in neonatal care practices. Controversy arose about the role of patent ductus arteriosus (PDA) and its treatment, transfusions, risk differences based on gestational age, efficacy and safety of probiotics in prevention, and the role of antibiotic exposure and multiple infections. Experts indicated the need for a stronger evidence base about NEC risk yet experts cited a lack of a strong evidence base on occasion when good to high quality evidence was available.

Even after decades of concentrated study, lost infant life, and excessive national healthcare cost, the gastrointestinal complication of prematurity, necrotizing enterocolitis (NEC) remains a formidable challenge in neonatal intensive care units (NICUs) globally. As the most common cause of emergency surgery, it is also a leading cause of death and excessively long hospital stays among premature neonates.[1–5] NEC survivors frequently experience long-term neurodevelopmental impairment,[6] short gut syndrome,[5] intestinal failure, catheter-associated sepsis and are among the most likely to stay in the NICU beyond 6 months.[7] Prematurity, low birth weight and aggressive formula feeding are independent risk factors for NEC, yet cohort studies over nearly 25 years across diverse populations demonstrate contributions of additional risk factors and are described in a recent review on NEC risk by our team.[8] Expert perspectives about NEC risk have not been described but when healthcare change is planned, identifying clinician and researcher beliefs is an important preliminary step to inform the planning of broad scale change.[9,10] Understanding expert perspectives about NEC risk can be used to inform the design of unit-based and clinician-based behavioral interventions to standardize NEC risk communication and institute NEC prevention and early recognition practices broadly.

Necrotizing enterocolitis is described as an inflammatory disorder of the neonatal intestine of varying severity but when severe extends through the mucosal and submucosal layers of the bowel.[11] It most commonly affects the ileum but can occur in any segment of the gastrointestinal tract. When it extends as massive necrosis through the bowel it is referred to as *NEC Totalis* and is nearly always fatal. Overall, mortality from NEC approaches 30% with the highest mortality seen among the smallest, earliest gestation infants and those needing surgery.[3] In fact, the need for surgery is linked to the worst outcomes in both the short and long term for survivors. It is unclear if early recognition promotes survival but recent studies have shown that the mean age of NEC diagnosis is 3 days later for NEC leading to death than for NEC that is survived.[12]

The pathogenesis of NEC is multi-factorial and somewhat unclear. A unifying concept in the understanding of NEC origins is that an immature immune system over-reacts in the presence of an insult (i.e., infections, enteric feeding, response to bacterial translocation or ischemia) leading to epithelial injury, bowel necrosis, and widespread sepsis when severe. For NEC to occur, several factors coalesce including an immature or compromised intestinal barrier, an over-reactive and under-regulated immune response, a substrate (i.e., feeding), and an opportunistic infectious agent.[13] When the environment of the neonatal intestine responds to the insult, it is poorly capable of mounting a defense, epithelial injury in the bowel occurs along with bacterial translocation, and inflammatory activation from the epithelial injury perpetuates the inflammatory response and extends intestinal injury. This inflammatory overreaction has diffuse effects that is worsened in the context of an already immature intestinal barrier function, delayed peristalsis from prematurity, and prolonged exposure to feeding (i.e., from dysmotility). Even so, it is likely that the disease commonly thought of as NEC is actually the clinical presentation that derives from at least 5 different pathogenic origins. For a comprehensive discussion of variation in NEC subsets, now termed "NEC Reductionism", the reader is referred to a 2012 review by Gordon and colleagues available online.[14]

Of concern to the bedside nurse and motivating the work reported here, is the consistent communication by clinicians across transitions

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in care (i.e., change of shift) about NEC risk and to support early recognition of the disease. We propose that it is helpful to create a shared understanding of which infants are at the highest risk for NEC to tailor interventions and support heightened surveillance during times of highest risk and peak onset. To do so, it is necessary to share perspectives about NEC risk and to come to agreement about how to ascertain risk. In a review of literature in 2008, no standardized risk assessment for NEC was identified. Preliminary to the research reported here was the derivation and validation of a risk assessment for NEC called GutCheck^{NEC}.

Related Studies

The e-Delphi study published by our team in 2013 is the first report of an attempt to quantify agreement among experts about NEC risk and determine the extent to which a new neonatal risk index for NEC, GutCheck^{NEC}, was content valid.[15] Using the consensus building approach called electronic Delphi (e-Delphi), electronic surveys were conducted over three rounds and supported by email communication and a study website to report back results between rounds to experts (see Fig. 1). After 3 rounds of surveys, 43 items reflecting 33 distinct risk factors comprised GutCheck^{NEC}. An exemption from the University of Arizona Institutional Review Board (IRB) was approved for the original study and secondary analysis reported here. In the fall of 2011, upon entering the e-Delphi electronic survey for the first time, participants were presented with a disclosure informing about the risks and benefits of participating in the study. Completion of the surveys indicated their willingness to participate.

Sample Characteristics

Of the 35 expert participants, all considered themselves knowledgeable about NEC risk (37% moderately expert, 31.4% highly expert, and 31.4% very highly expert). Most (86%) worked in teaching hospitals across the United States and 4 participated internationally (Switzerland, Canada, and Australia). The panel included expert clinicians as well as researchers, with 68% having worked in their current role longer than 10 years. Experts practiced in Level III or higher NICUs (85%), as researchers (11.4%), faculty (both in nursing and medicine), and in non-surgical NICUs (20%). Experts held a variety of titles including neonatologist, pediatric surgeon, neonatal nurse practitioner, expert NICU registered nurse, and/or academic roles across all ranks in both nursing and medicine. Comprehensive sample characteristics are reported elsewhere.[15]

In the e-Delphi, 35 neonatal experts were asked to rate the relevance of 64 NEC risk factors identified in a comprehensive literature review[8] on a scale of 1–4 such that 1 = not relevant, 2 = unable to determine relevance without revision, 3 = relevant with minor revision and 4 = relevant without revision.[15] GutCheck^{NEC} items were retained, deleted or revised based on the quantitative measure of agreement (i.e., greater than 70% agreement) and stability (i.e., the mean rating for relevance did not change more than 15% between rounds). Using the consensus building approach called electronic Delphi (e-Delphi), electronic surveys were conducted over three rounds and supported by email communication and a study website to report back results between rounds to experts (see Fig. 1). After 3 rounds of surveys, 43 items reflecting 33 distinct risk factors comprised GutCheck^{NEC}. Risk items that met consensus and a full description of risk factors that were not retained are reported elsewhere.[15] Items that were retained are categorized by level of agreement in Table 1.

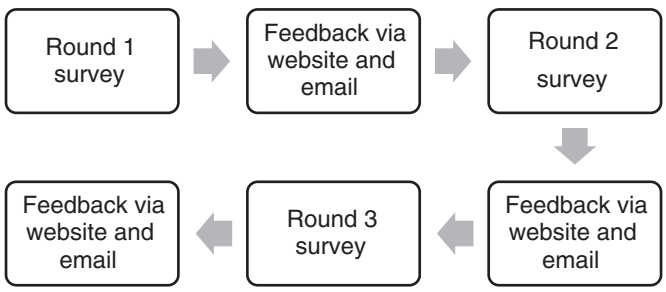

Fig. 1. E-Delphi process and explanation from related study.

To elicit recommendations from these experts regarding the revision of risk items, a comment section entitled "recommended revision" was included. Surprisingly, many experts generously added comments which reflected their willingness to engage in the process. Expert comments were shared with others anonymously at the end of each e-Delphi round but the large number of comments (i.e., 242 across 3 rounds) was well suited to a more advanced analysis. The secondary analysis of qualitative data described here goes beyond the statistical assessment of agreement and content validity we previously reported to describe in rich detail expert perspectives about NEC risk including neonatal intensive care practices and NEC risk factors that were controversial and/or uncertain.

Methods

Design

To analyze the expert's comments, we applied a qualitative descriptive approach. Qualitative description is a method which provides rich description of a phenomenon, summarizing events in everyday terms.[16] It is the preferred qualitative method when straightforward descriptions are desired, are well-suited to capture perspectives, and rely on rich description to keep the researcher close to the individuals' accounts.[17] To describe perspectives of neonatal clinical and research experts about NEC risk we asked the question: Given the opportunity, what do experts have to say about NEC risk?

Trustworthiness Criteria

To support the trustworthiness of the qualitative descriptive process, we followed recommendations by Lincoln and Guba (1985) to support the credibility, transferability, dependability and confirmability of the findings.[18] To determine trustworthiness of qualitative research, its "Truth value" (i.e., applicability, consistency and neutrality) is assessed. *Truth value* is the confidence one can have that the findings are valid; *applicability* is the ability of the work to be applied to other people and contexts; *consistency* is the confidence one can have that similar findings may be repeated in similar groups or contexts; and *neutrality* is the ability to establish that the findings are not the result of researcher bias, motivations or perspectives. Techniques that we used to support the trustworthiness of our findings included: 1) maintaining an audit trail, 2) critical review of coding and keeping records of coding decisions, and 3) sharing categorized statements with Delphi participants at the end of each round to support assessment of truth value.

In qualitative description, the burden is on the researcher to accurately convey the events, in the order in which they occurred to support descriptive validity and the meanings that participants attribute to the events, supporting interpretive validity requirements.[19] Although nearly impossible to demonstrate generalizability in qualitative research, we purposefully recruited a heterogeneous group of neonatal experts to include those from nursing, medical and academic research practice to elicit a broad and deep perspective among clinicians most likely to care for infants at risk.

Analysis

The first author initially immersed herself in the data to get a sense of the whole and to assimilate responses to share back with experts at the end of each Delphi round. The purpose of sharing responses at the end of each round was to share what the other panelists had discussed