

Perspectives from parents of infants impacted by NEC: NEC communication in the NICU
NEC Society, Ann Arbor, MI

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Aim: To characterize parent perceptions of the practices and events related to their child's development of necrotizing enterocolitis (NEC).

Setting: An online international survey administered using Qualtrics Survey Software to parent members of the NEC Society, a non-profit dedicated to empowering parents and preventing NEC.

Methods: A quantitative survey with 64 items was developed and assessed for face validity by a panel of NEC experts. Parent members of the NEC Society were invited to take the survey (N=258). Demographic information regarding the parents, infants and hospital course was collected.

Measures: Data was collected using demographic, open-ended, multiple choice, sliding scale and close-ended questions. All questions, except respondent's year of birth, were optional.

Data/Results: Of 258 invited to complete the survey, 115 (45%) parents participated. Parents were, on average, female (87.2%), Caucasian (91%), college educated (80%), with children born in 2010 or more recently (87%). The average gestational age of their children was 28.5 +/- 4.0 weeks at birth and 32.1 +/- 5.5 weeks at time of NEC diagnosis, with 71% of NEC leading to surgery. There was a 64% survival rate and most deaths (60%) occurred within one month of diagnosis. Of the survivors, 44% developed short bowel syndrome.

63% of the parents never heard about NEC until the child was being treated while 33% were unaware that surgery may be needed, and 52% were unaware of long-term consequences. 65% parents were unsatisfied with NEC information they were given. Gaps were identified in the timing of lactation consultation and sharing of information related to the importance of human milk. Only 42% of the babies received human milk throughout their NEC hospitalization with 41% receiving human milk for less than four weeks. Only 34% of the parents felt that it was possible for their baby to receive donor milk. Of the 56% of parents who suspected something was wrong before their baby's NEC diagnosis, 98% notified the medical team; in only half of these instances was anything done. 40% were unsatisfied with the education they got while 23% and 22% did not feel like partners or decision makers in their child's care. Over half of the parents felt that their baby's NEC could have been prevented with suggestions including earlier diagnosis and treatment of NEC, less bovine products, slower feeds and more human milk.

Discussion: Partnering with parents for NEC prevention and early recognition is not commonplace. Areas for further quality improvement include better communication/teamwork through early education and engagement of families in NEC prevention and recognition, advocacy for standardization of human milk practices and universal access to donor milk.