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## Long-term outcomes and life-impacts of necrotizing enterocolitis: A survey of survivors and parents

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### ARTICLE INFO

### ABSTRACT

Necrotizing enterocolitis (NEC) is a devastating intestinal disease that primarily affects premature infants. Necrotizing enterocolitis is associated with adverse two-year outcomes, yet limited research has evaluated the impact of NEC on long-term complications and quality of life in children older than two years. We conducted a survey to characterize the long-term impact of NEC on physical and mental health, social experiences, and quality of life as self-reported by adult NEC survivors and parents of children who survived NEC. To our knowledge, this is the first study that describes the lived experience of NEC survivors and parents of children affected by NEC to understand their experience years after the original diagnosis. Our survey results describe that NEC survivors and parents of children affected by NEC experience long-term complications that impact their physical and mental health, social experiences, and quality of life.

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### Introduction

Necrotizing enterocolitis (NEC) is a devastating intestinal disease that affects approximately 3–9% of infants born prematurely (<37 weeks gestation) each year in the United States.<sup>1</sup> In a systematic literature review completed between 2010 and 2018, the overall mortality rate of known NEC (Bell Stage 2a+) was reported to be 23.5% with higher rates for infants of very low birth weight (VLBW,  $\leq 1500$  g) or

up to 30.1%, and rising to just over 50% for infants who had surgical NEC and of extremely low birth weight (ELBW,  $\leq 1000$  g).<sup>2</sup> Since many infants with NEC require surgery, there is a significant morbidity burden on survivors including, but not limited to, short bowel syndrome (SBS), inadequate digestion, and poor growth.<sup>3</sup> Interventions often include laparotomy, peritoneal drain placement, extended bowel rest with total parenteral nutrition, respiratory support, and intravenous antibiotics that often lead to prolonged hospitalization.

*Abbreviations:* ELBW, extremely low birth weight  $\leq 1000$ g; NICU, Neonatal Intensive Care Unit; GI, gastrointestinal; QOL, Quality of Life; IP, intestinal perforation; SBS, short bowel syndrome; IV, intravenous; VLBW, very low birth weight  $\leq 1500$ g; NDI, neurodevelopmental impairment; NEC, necrotizing enterocolitis

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While NEC is a life-altering diagnosis, the current literature and our understanding of the disease mostly reflect the outcomes of NEC during birth hospitalization or at follow-up that ends around 2–3 years of age, with prior studies focused on poor growth and intestinal failure<sup>4–6</sup> or neurodevelopmental outcomes between 18 months and three years.<sup>7–9</sup>

Among limited studies examining the effect of NEC on long-term complications and quality of life after two years of age, Pike et al. found an increased risk of functional impairment and bowel problems at seven years of age in children in the UK who survived known or suspected NEC ( $n = 40$ ), although there was no behavior or educational associations.<sup>10</sup>

There is an urgent need for an increased understanding of the long-term complications of NEC, with a specific focus on the outcomes that are of most importance to adult survivors and the parents of young NEC survivors. Such information has the potential to guide discussions about prognosis and treatment, as well as improve communication about the potential long-term outcomes of NEC between survivors, parents, and healthcare providers. This information is especially relevant to NEC survivors in consideration of disability support and social support in educational settings. This study seeks to examine the long-term outcomes and impact on physical and mental health, social experiences, and quality of life (QOL) as self-reported by NEC survivors and the parents of children with NEC. To our knowledge, this is the first study to survey NEC survivors and parents about long-term complications and impacts of NEC on QOL.

### Rationale and motivation for this study

The NEC Society is a 501(c)(3) non-profit organization dedicated to building a world without NEC by advancing research, advocacy, and education. Families who have been personally affected by NEC lead the NEC Society's work and drive the organization's priorities in partnership with influential NEC researchers. Through an Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI), the NEC Society provided support for adult NEC survivors to participate in the 2019 NEC Symposium. The Symposium attracted over 200 participants from eight countries, including clinicians, researchers, and patient-families. The NEC Society recognizes the power of integrating the patient-family voice in scientific conferences. Throughout the conference, participating NEC survivors shared their experiences growing up and living with complications of NEC. They described feeling doubted, disregarded, and isolated. Here is a powerful quote from a NEC survivor at the NEC Symposium: *"The long-term effects of NEC are often delegitimized, which harms my ability to access what I need for my health. Not every NEC survivor meets the SBS (short bowel syndrome) criteria, so we're left with something that is treated like it doesn't exist."* During the conference, adult NEC survivors and NICU clinicians participated in a workgroup session focused on empowering patient-families. This session offered a rare opportunity for NICU clinicians to hear directly from patients living with long-term complications of NEC. The participating NEC survivors highlighted how NEC not only continues to affect their health but also how NEC has affected their families' well-being over

the years. They disclosed how their parents often had to become fiercely vigilant and assertive to ensure basic access to care and support. Their voices compelled the NEC Society to reflect upon the scarcity of publications focused on understanding the life experiences of NEC survivors and led to the launch of this research project.

Current follow-up studies on NEC survivors are performed at young ages and thus may not fully reflect the lived experiences of patients and their families. Longitudinal follow-up studies beyond preschool age can better inform the long-term outcomes and life impacts of NEC. Therefore, we aimed to characterize how NEC affects survivors and families long-term, including their QOL, mental and physical health, and social experiences.

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## Methods

### Study design and oversight

We conducted a cross-sectional survey study involving NEC survivors and parents of children with NEC who were engaged with the NEC Society's work between September and October 2020. Our project was approved by the University of California San Francisco (UCSF) Institutional Review Board (IRB #19–28769).

### Survey development

We created two surveys designed specifically for this study, one for the parents of children diagnosed with NEC (Supplementary 1), and the second for adult survivors of NEC (Supplementary 2). The content of each survey was informed by patient-families working collaboratively with our multidisciplinary clinical and research team. The surveys were reviewed and altered in response to feedback from parents and adult survivors. The first question in each survey was a screening question asking respondents to self-identify if they were a parent of a child with NEC or an adult survivor. Each survey then explored the following topics: details of child's/self-diagnosis, type of surgical intervention, mortality, long-term morbidity/complications, social/emotional outcomes, health service utilization, access to information about NEC, suggestions for improving NEC care, and demographic information. For our survey, long-term complications from NEC were described as follows: Long-term enteral nutrition (tube feeds); Long-term intravenous (IV) nutrition (Long-term use of Total Parenteral Nutrition); Short-bowel (Diagnosis of short bowel syndrome or short gut); Digestive complications (Difficulty eating, constipation, belly pain); Cognitive (Difficulty in learning, thinking, and schoolwork); Fine motor (Difficulty working with fingers and hands); Gross motor (Difficulty walking and running); Respiratory (Trouble breathing, prone to infections). Parents were also asked whether their child's NEC diagnosis impacted their well-being and healthcare costs. Questions required a mix of closed and open-ended responses. Questions on outcomes were optional. The surveys created for parents of a child with NEC contained 33 questions, and the survey for adult survivors contained 27 questions.

### Survey dissemination

Surveys were created and disseminated using the online platform Qualtrics (Provo, UT) between September 1, 2020, through October 30, 2020. We disseminated the survey recruitment materials and survey links via the NEC Society newsletter email distribution list. This list contains over 3000 email addresses of parents, survivors, clinicians, researchers, and diverse stakeholders. We also promoted the study on the NEC Society's website and social media pages as well as on NEC Society partner charities in Brazil, the United Kingdom, and Australia. Participants were informed the survey was anonymous. All participants provided their consent before initiating the survey.

### Study participants

Participants were eligible to participate in our study if they were either the parents or caregivers of children (under 18 years old) diagnosed with NEC or adult survivors of NEC (18 years or older). Participants under the age of 18 years old were not eligible to participate.

### Survey analysis

We used descriptive statistics to summarize questions with closed-ended responses using SPSS.<sup>11</sup> Our analysis considered missing data, as not all respondents answered all questions. To summarize open-ended responses we used content analysis, a systematic approach to examining open-ended qualitative data that results in a condensed understanding and description of the content.<sup>12</sup> At least two reviewers independently performed open coding using an inductive data-driven approach to identify coding categories. To ensure methodological rigor, throughout the analysis, reviewers met to refine and define coding categories, and coding disparities were discussed and resolved by negotiated consensus.<sup>13</sup>

Coding categories were then grouped into higher-order categories/themes. Microsoft Excel was used to manage the content analysis. We used the consensus-based checklist for reporting of survey studies (CROSS) to guide the reporting of our study.<sup>14</sup>

## Results

A total of 225 survey responses were received; 197 respondents were parents of NEC survivors less than 18 years of age and 28 respondents were NEC survivors  $\geq$  18 years of age. Responses to closed-ended questions are summarized in Tables 1-4 and include the percentage of the total n respondents, as well as the percentage of each question answered. Characteristics and location of the respondents are shown in Table 1 and Fig. 1, respectively, with most being white (79% parents, 71% survivors), non-Hispanic (84% parents, 87% survivors), and from North America. The average age of respondents was 31 (standard deviation 7). 81% of NEC patients were born before 37 weeks of gestational age, of which 84% experienced surgical NEC. Our mixed-methods approach integrated both quantitative and qualitative data, ensuring that results are descriptive of participants' experiences. Content analysis of open-ended questions resulted in the emergence of five overarching themes: GI/SBS symptoms, scar/self-image, social concerns, anxiety/depression, and access to care (Fig. 2).

### Long-Term complications

Seventy-two percent of parents and 89% of survivors reported long-term complications of NEC (Table 2). The most-reported long-term complication from both parents and survivors was digestive complications, 83 (42%) and 21 (75%) respectively. Eighty-six (44%) parents and 8 (29%) survivors reported a need for either long-term enteral or IV nutrition. One NEC

**Table 1 – Respondent Characteristics.**

Characteristics	Total <sup>†</sup> n = 225	Parents* n = 197	Survivors* n = 28
Race			
Black	12 (5.3%)	9/163 (5.5%)	3/24 (13%)
White	146 (65%)	129/163 (79%)	17/24 (71%)
Asian	3 (1.3%)	3/163 (1.8%)	0/24 (0%)
More than one/other	28 (12%)	22/163 (13%)	4/24 (17%)
Hispanic ethnicity	29 (2.9%)	26/162 (16%)	3/22 (13%)
Age (yrs), mean $\pm$ SD	31 $\pm$ 7		
Gestational age at birth			
22–24 weeks	25 (11%)	25/192 (13%)	0/24 (0%)
25–28 weeks	75 (33%)	68/192 (35%)	7/24 (29%)
29–33 weeks	63 (28%)	58/192 (30%)	5/24 (21%)
34–36 weeks	20 (8.9%)	15/192 (7.8%)	5/24 (21%)
37–42 weeks	33 (15%)	26/192 (14%)	7/24 (29%)
Surgery	189 (84%)	166/192 (87%)	23/26 (89%)
Laparotomy	159 (71%)	139/165 (84%)	20/23 (87%)
Drain	8 (3.6%)	8/165 (4.8%)	0/23 (0%)
Not sure	21 (9.3%)	18/165 (11%)	3/23 (1.3%)

<sup>†</sup> Values are n (%) total survey respondents.  
\* Values are n/N (%) of questions answered.

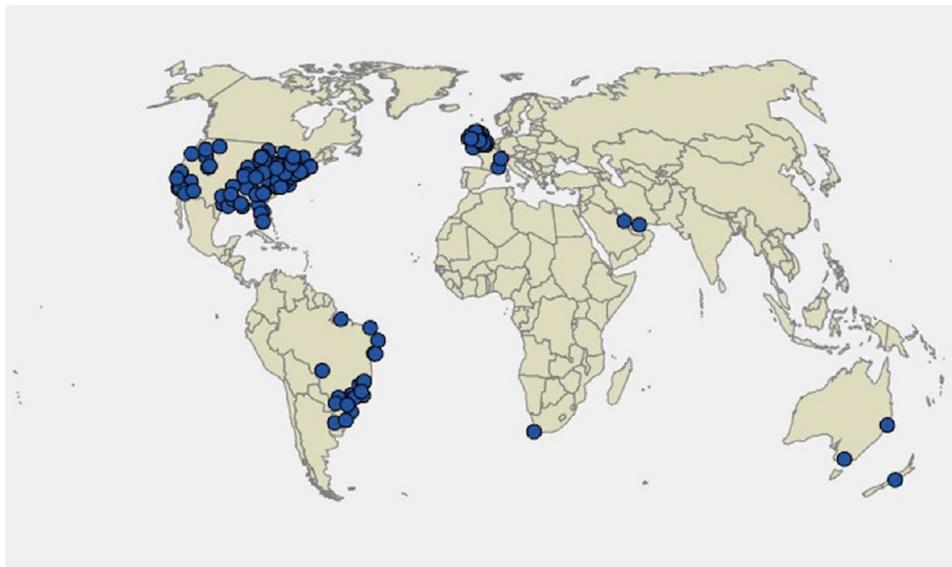


Fig. 1 – Location of Respondents.

parent shared, “The long-term effects of NEC control my son’s life. The hospital is his second home, his development is severely impacted, he has daily GI pain, he can’t eat by mouth, and he is 100% TPN dependent. And so much more.” Ninety-six (43%) respondents reported a visit to the emergency room or re-hospitalization due to complications from NEC after initial hospital discharge (54% parents, 46% survivors). Of those 96, nearly half (42%) reported visiting 6 or more times since

diagnosis. Parents shared, “My son has been hospitalized dozens of times since he was discharged from the NICU.” and “In the first 22 months, since leaving the NICU, we only spent 4 weeks at home.” When asked about social and emotional experiences, 38 (26%) parents and 20 (80%) survivors reported anxiety or worry about body image, with 73 (48%) parents and 15 (60%) survivors believing NEC has impacted their overall QOL (Table 2). Survivors shared, “I’ve always felt deformed due to the surgical

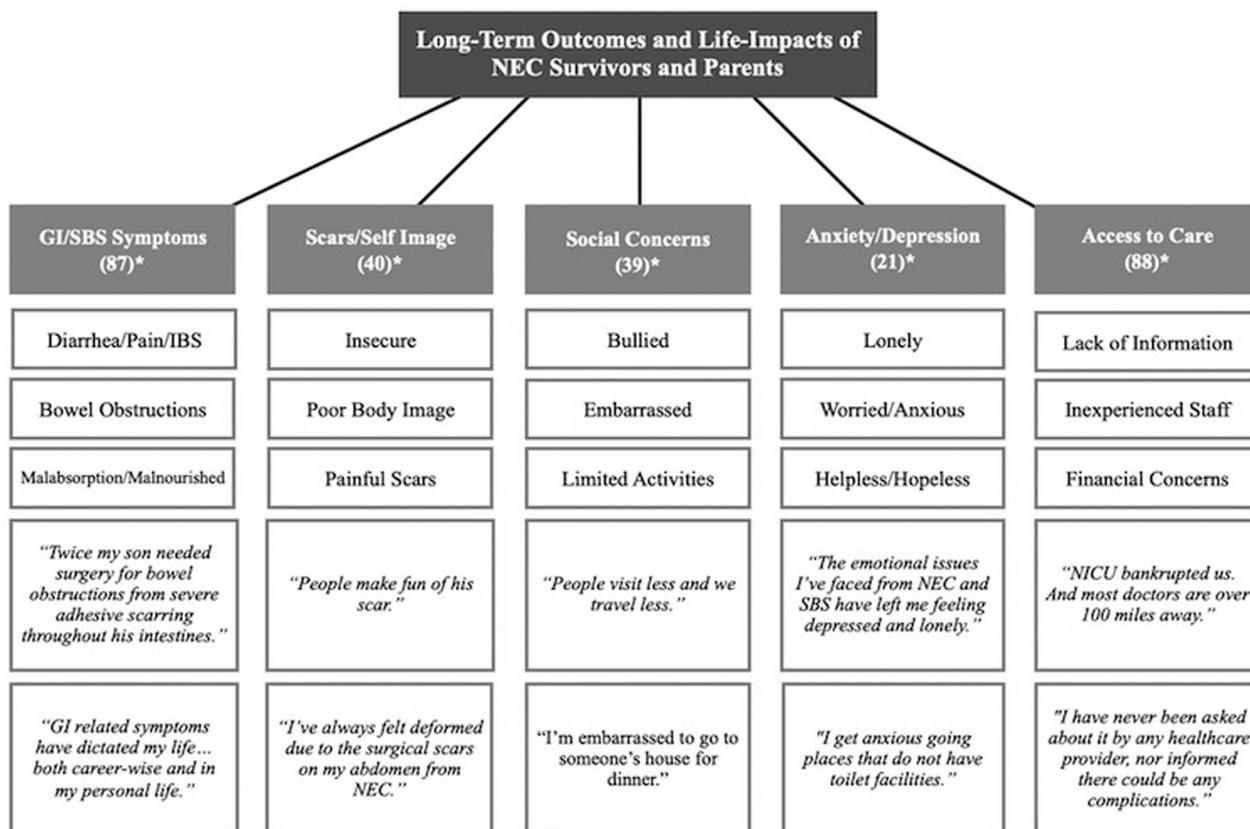


Fig. 2 – Content Analysis Exploring Self-Reported Long-Term Outcomes and Life-Impacts of NEC Survivors and Parents.

**Table 2 – Long-Term Complications.**

Characteristics	Total † n = 225	Parents* n = 197	Survivors* n = 28
Any long-term complications	136 (60%)	113/157 (72%)	23/26 (89%)
Types of long-term complications			
Digestive	104 (46%)	83/197 (42%)	21/28 (75%)
Short-bowel	71 (32%)	61/197 (31%)	10/28 (36%)
Long-term enteral nutrition	53 (24%)	50/197 (25%)	3/28 (11%)
Long-term IV nutrition	39 (17%)	36/197 (18%)	5/28 (11%)
Respiratory	42 (19%)	37/197 (19%)	5/28 (18%)
Gross motor	48 (21%)	46/197 (23%)	2/28 (7.1%)
Fine motor	43 (19%)	41/197 (21%)	2/28 (7.1%)
Cognitive	57 (25%)	53/197 (27%)	4/28 (14%)
Other	39 (17%)	31/197 (16%)	8/28 (29%)
Post-NICU hospital or ED visit	96 (43%)	84/156 (54%)	12/26 (46%)
1–2 times	27 (12%)	23/76 (30%)	4/12 (33%)
3–5 times	21 (9.3%)	18/76 (24%)	3/12 (33%)
6 or more times	40 (18%)	35/76 (46%)	5/12 (33%)
Surgery after NICU discharge	97 (43%)	85/152 (56%)	12/25 (33%)
Anxiety or worry about body			
No	70 (31%)	68/149 (46%)	2/25 (8%)
Yes	58 (26%)	38/149 (26%)	20/25 (80%)
Not sure	46 (20%)	43/149 (29%)	3/25 (12%)
Impact on relationships			
No	103 (46%)	89/151 (59%)	14/25 (56%)
Yes	37 (16%)	26/151 (17%)	11/25 (44%)
Not sure	36 (16%)	36/151 (24%)	0/25 (0%)
Impact on quality of life of NEC patient	88 (39%)	73/152 (48%)	15/25 (60%)

† Values are n (%) total survey respondents.  
\* Values are n/N (%) of questions answered.

scars from NEC.”, “The emotional issues I’ve faced from NEC and SBS have left me feeling depressed and lonely.”, and “NEC has impacted every aspect of my life, both career-wise and in my personal life.” Parents shared, “He worries that others won’t understand his medical issues or accept that he is different.”, another shared the following “In every single way, NEC has completely changed her life.”

### Communication

Communicating about NEC has also been difficult for NEC survivors and parents. Table 3 summarizes responses related

to communication with health professionals and other adults, as well as access to information and resources about NEC after discharge. More than half (52%) of all respondents reported they were provided no information about long-term complications of NEC. Eighty-five (38%) respondents felt it was difficult to access resources, services, or specialists (52% of both groups who answered), and only 49 (22%) felt their health care providers understood the long-term complications of NEC. Only 37 (16%) respondents reported they had enough information about NEC and its associated long-term complications, with 129 (57%) having to explain NEC to other adults, including health care providers, teachers, and their

**Table 3 – Communication.**

Characteristics	Total † n = 225	Parents* n = 197	Survivors* n = 28
Provided long-term information			
No	118 (52%)	94/151 (62%)	24/25 (96%)
Yes	42 (19%)	42/151 (28%)	0/25 (0%)
Not Sure	16 (7.1%)	15/151 (10%)	1/25 (4.0%)
Problems with Resources			
No	58 (26%)	52/140 (37%)	6/23 (26%)
Yes	85 (38%)	73/140 (52%)	12/23 (52%)
Not Sure	20 (8.9%)	15/140 (11%)	5/23 (22%)
Providers understand long-term NEC complications	49 (22%)	42/139 (30%)	7/23 (30%)
Have enough information about NEC and its long-term complications	37 (16%)	35/141 (25%)	2/24 (8.3%)
Had to explain NEC to others (i.e. teachers, healthcare providers)	129 (57%)	109/140 (78%)	20/24 (83%)

† Values are n (%) total survey respondents.  
\* Values are n/N (%) of questions answered.

**Table 4 – Parent-Specific Questions\*.**

Characteristic	Parents n = 197
Year of diagnosis	
Before 2010	31/193 (16%)
2010–2015	49/193 (25%)
2016 and beyond	112/193 (57%)
Child did not survive	33/193 (17%)
Age at death	
0–6 months	29/33 (88%)
7–12 months	3/33 (9%)
1–5 years	1/33 (3.0%)
Healthcare costs made access to services difficult	
No	105/142 (74%)
Yes	27/142 (19%)
Not sure	10/142 (7.0%)
Health or mental health affected by your child's long-term complications of NEC	
Yes	106/143 (74%)
No	37/103 (26%)
Health effects experienced	
Difficulty Sleeping	63/103 (61%)
Increased anxiety	86/103 (83%)
Worry about the future	82/103 (80%)
Post-Traumatic Stress Disorder	81/103 (79%)
Financial stress	44/103 (43%)
Difficulty balancing work-life obligations	51/103 (50%)
Feelings of isolation and despair	54/103 (52%)
Constant high stress and pressure	48/103 (47%)
Depression	50/103 (49%)
High blood pressure	16/103 (16%)
Providers talked about the long-term effects of NEC	38/140 (27%)
Difference in what was told and what was experienced	
No	15/38 (39%)
Yes	22/38 (58%)
Not sure	1/38 (2.6%)

\* Values are n/N (%) of questions answered.

peers. One survivor shared “My family doctor just sort of ignores NEC. They say that was when I was a baby and has nothing to do with now.” Another survivor shared, “Every time I see a doctor, I have to educate them about NEC. Half the time, they don't believe long-term complications exist. They don't believe me, let alone understand me.” Other responses included “I have to explain NEC to every teacher, healthcare provider, anyone who serves as a gatekeeper for accessing what I need to take care of myself.” and “I need to explain NEC to whoever cares for or watches my child.”

#### Parent-Specific responses

The parent survey included an additional set of questions relating to their child's year of diagnosis and/or death, healthcare costs affecting access to care, and the impact of NEC on their own physical and mental health. Over half of parent respondents (57%) reported their child was diagnosed with NEC after 2016, 25% between 2010 and 2015, and 16% before 2010 (Table 4). Thirty-three parents (17%) reported their child did not survive. Of those 33, most (88%) reported the age of death was before 6 months of age. Of the parents whose child survived, 27 (19%) reported healthcare costs made it difficult to access care for their child. One parent shared, “Copays,

deductibles, and exclusions cost us nearly everything.” Another shared, “Most doctors are over 100 miles away.” Nearly three-fourths of NEC parents reported that their own mental and/or physical health has been affected as a result of their child's long-term NEC complications, with the most common effects being increased anxiety (83%), worry about the future (80%), post-traumatic stress disorder (79%) and difficulty sleeping (61%). Only 27% of parents reported receiving information from providers about the long-term effects of NEC.

#### Discussion

In this study, we show that NEC affects survivors and families years or even decades after they have left the NICU. NEC complicates families and survivors' mental and physical health, social experiences, and overall QOL. The open-ended responses gave parents and survivors the ability to reveal their authentic life experiences in their own words. The complications and life-impact of NEC are persistent throughout childhood, adolescence, and adulthood.

Our results highlight that parents and survivors need more information about NEC and its long-term outcomes beyond 2 years after discharge. Resources and effective tools need to be developed and utilized by health care providers to help patients and families cope with and manage the physical, social, and emotional life impacts of NEC. Moreover, healthcare providers should be aware of those long-term complications so NEC patients can receive proper follow-up care from infancy through adulthood. By illuminating how NEC affects survivors and their parents years after the original NEC diagnosis, the NEC community will be better equipped to facilitate and deliver quality care to patient-families with complex and poorly understood medical needs due to NEC.

Our study has limitations. Convenience sampling was used to invite eligible individuals subscribed to the NEC Society's e-mail list to participate. We do not know how many of these individuals meet our study's eligibility criteria therefore we are unable to provide an exact survey response rate. Based on the higher proportion of respondents with surgical intervention for NEC, it is likely that our survey reflects the experiences of families and adults with more severe cases of NEC. Nevertheless, our survey was circulated to the international NEC community, and our results provide novel, critical insights as they represent the reality of families and adults living with the complications of NEC, using their voices. We also acknowledge our sampling approach has its limitations and may not be representative of every family or survivor affected by NEC. Our respondent group was overwhelmingly non-Hispanic, white, impeding our ability to better understand how responses are reflective of populations based on race and ethnicity. Moreover, many patient-families affected by NEC during their time in the NICU may not realize the potential to experience complications of the disease years later. Many respondents report being disregarded by clinicians who say their health problems are unrelated to NEC because years have passed since their original NEC diagnosis. Therefore, patients and families may not know to seek information about NEC. Finally, we also acknowledge that all

responses are self-reported, thus the possibility of response bias.

This study serves as a crucial platform to foster an improved understanding of long-term NEC complications and to initiate strategies aimed at better serving the patient community. It is important to recognize that consistent, attentive follow-up and serial assessments can help to improve long-term outcomes.<sup>15</sup> We aim to build a broad, inclusive NEC community and collaborate with healthcare providers who are committed to engaging NEC patient-families. To build upon this work, the NEC Society is launching a NEC patient registry and will continue to partner with investigators focused on improving NEC outcomes. Future research should consider identifying strategies to quantify the costs of long-term NEC complications and improve disability resources to more appropriately capture the financial and other burdens of the disease on survivors and families. Finally, racial disparities exist in the rates of preterm birth and infant mortality.<sup>16-18</sup> Because black and brown infants are disproportionately affected by NEC, even when controlling for socio-demographic factors,<sup>19</sup> it is critical for further research to consider how systemic racism contributes to NEC pathogenesis and for quality improvement initiatives to focus on equity in NEC prevention and treatment, as well as more broadly in neonatal and perinatal care.

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### Declaration of Competing Interest

Ravi Mangal Patel, MD, MSc Financial Interest; Infant Bacterial Therapeutics/Premier Research (Currently Ongoing) (Products/Services: Consultant) All other authors report no proprietary or commercial interest in any product mentioned or concept discussed in this article.

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### Supplementary materials

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