

ORIGINAL ARTICLE

Extremely long hospitalizations of newborns in the United States: Data, descriptions, dilemmas

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Problem: Neonatal and pediatric nurses and physicians care for newborn children who have been saved by technological support but who then spend extremely long periods of time in the hospital, perhaps never being able to be discharged to home. There has been little research identifying newborns who are too sick to be discharged from the health care setting and rare reports of staff or parental response to these long-term hospitalizations.

Purpose: This study provides both the numerical data and description of acutely, chronically ill newborn children whose illnesses caused hospitalizations for greater than 6-months (179 days) in the US.

Methodology: Method triangulation using a national data set (HCUP-KID 2003), a researcher created LONGTERM survey, and a qualitative question was used to identify pathologies associated with newborn length of stays greater than 6 months. Neonatal nurses and physicians provided descriptions of children spending at least 6 months in the hospital, including anecdotal reports of caring for those children.

Results: The national H-CUP data set identified 680 infants staying 6 months or longer in the hospital during 2003. Four hundred and twenty-two providers submitted LONGTERM surveys describing these infants, with 228 first hand reports on how it felt to care for children with hospital stays between 6 months and 6 years. Extreme prematurity, respiratory distress and necrotizing enterocolitis contributed to the extremely long hospital stays. Nurse and physician participants felt that extremely long hospital stays were often due to situations in which parents or colleagues were insisting upon continued futile treatment.

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($n = 55\,000$).¹ Congenital defects were found in 3% of live births ($n = 30\,000$).² In labor suites and neonatal intensive care units (NICU), it is common practice to save newborn infants who might have died in earlier times from prematurity, genetic disorders or birth trauma. In many cases, these newborns receive the highest level of care and are discharged to home to lead healthy lives. In some cases, however, the technological support has allowed children to live that remain both chronically and acutely ill. This group of newborn children may not leave the health care setting, or if they do, they may be transferred to long-term care or readmitted for continued hospitalization.

When visiting neonatal and pediatric intensive care units (PICUs) around the nation, there are often one or more infants who are 'living' on the unit. This 'living on the unit' was preceded by the HIV-infected 'boarder babies' of the 1980s.³ In these cases, because of parental death from HIV, there was nowhere for the child to go, and occasionally the child was soon to die as well. While HIV treatment for infected mothers has all but eliminated these types of deaths and abandoned newborns, the concept of children living on hospital units has returned. The new group of children have healthy parents, but some of these parents are unable to maintain the intense medical needs of their newborns. The children may be marginally conscious, on a ventilator, with a tracheostomy, on dialysis, being fed intravenously or by enteral tube, or any combination thereof. The child may move from the NICU to the PICU. Parents may try a short discharge to home, but return when it is too difficult or the child suffers a crisis. Staff members report parents who visit constantly, sometimes necessitating one parent moving away from the family in order to be available to the child residing in a tertiary center, or other situations, in which parents have 'given up', and stopped coming completely.

In the only published report found about children who could not be discharged, Smith and Uphoff⁴ wrote about children whose language skills were learned by imitating the monitor beeps and the floor polishers, and reported the dilemma of a parent having no alternative other than keeping her other small children with her at the bedside, and nurses attempts to arrange local day care for these siblings, who were also 'growing up' in the hospital. Smith

Introduction

In the year 2003, of the 4 052 000 live births in the US, 12% ($n = 480\,812$) were preterm, with 1.5% under 1500 g

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and Uphoff⁴ questioned whether technological support which resulted in children who were too sick to ever be discharged and whose parents could no longer support them was proper scientific progress. The purpose of this study was to investigate further the current picture in the US of newborns who experience extremely long hospital stays or who are unable to be discharged from the hospital, examining the causal conditions, the parental responses and physician and nurse caregiver responses to these children.

Methods

This descriptive study used method triangulation to investigate newborns with extremely long hospitalizations. The research design included three methods, (1) the use of the Healthcare Cost and Utilization Project Kid's Inpatient Discharge Data (HCUP- KID); (2) a researcher created quantitative survey (LONGTERM) and (3) a qualitative descriptive question. Institutional review board permission was obtained from the University. It was not possible to identify any individual hospitalized or discharged child or professional participant in the study.

HCUP-KID

Sponsored by the Agency for Healthcare Research and Quality (AHRQ), the HCUP-KID uses stratified, random sampling and contains 86.5% of all pediatric discharges in the US (age 20 years or less at admission) from community, non-rehabilitation hospitals in the 36 participating states. A search program was written to examine the number of newborns during the year 2003 with a length of stay greater than 179 days, then break down the newborns by birth weight, diagnostic categories and discharge outcome.

LONGTERM survey instrument

A researcher created instrument was developed to survey health care personnel about infants that had been unable to be discharged. The LONGTERM survey questions were specifically based on the same variables collected in the national databases and the literature (diagnosis, birth weight, gestational age, maternal condition, neonatal conditions and discharge outcome). Questions were developed and validated with professional input and piloted at a major medical center. The questions were then posted on Zoomerang, an Internet-based survey tool, to allow participants to enter data on-line. Instructions were posted by the researcher on a website created and hosted by the University server to explain the study, obtain informed consent, and direct the participant to the Zoomerang survey instrument. Respondents were asked to describe an individual newborn who met the criteria of greater than 6 month hospitalization in the last 5 years by answering 14 demographic/informational questions and one open-ended qualitative question.

Qualitative question

Participants were asked to describe their thoughts, feelings or concerns about the child's hospitalization. Responses were transferred to a Microsoft Access 2003 program for category analysis in the constant comparison method⁵ and provided rich augmentation to the numerical data.

Population and sample

The population of interest was those children born alive in the US who have had extremely long hospital stays greater than 179 days and their caregivers. A sample of convenience was used to find providers who had cared for newborns with extremely long stays. Letters sent to neonatal units at children's hospitals, distributed to neonatologists at the 2005 conferences of the Society of Pediatric Research and Conference on the Fetus and Newborn, and to nurses at the 2005 meetings of the American Association of Women's Health, Obstetrics and Neonatal Nurses; American Neonatal Nurses Nurse Practitioners; and National Association of Neonatal Nurses. Two nursing journals announced the study. Responses were solicited from February to December of 2005.

After signifying informed consent, the participants were asked to complete the LONGTERM survey by describing a newborn child unable to be discharged for at least 6 months time within the last 5 years. The data were entered into the Zoomerang program, summarized and reported in real-time. Answers to the open-ended question were transferred daily from the Zoomerang survey data to a specially created Microsoft Access program. The Microsoft program allowed the researcher to categorize and cluster to create themes.

Results

The H-CUP KID data set identified 680 newborns during the year 2003 who were reported to be hospitalized for greater than 179 days. Fifty eight percentage were males and 42% were females. Of the 680 children, 44% were discharged to home normally, 27% went home with home health nursing care, 13% were transferred to long-term care facilities and 16% died in the hospital. There were 78 pathology diagnoses associated with the greater than 179 days stay. The most prevalent diagnoses were respiratory distress syndrome (56%), chronic respiratory distress (50%) sepsis (44%), jaundice with prematurity (40%), necrotizing enterocolitis (25%) and extreme prematurity under 999 g (41%). The most typical infant described spent 228 days in the hospital and weighed 1470 g (s.d. 112 g) with hospital charges of \$703 356 (s.d. \$19 846).

There were 422 completed LONGTERM surveys, describing 422 infants hospitalized for greater than 179 days. Participants were nurses (69%), physicians (10%), social workers (1%) and self-reported others (19%), with most participants coming from academic medical centers (60%) or urban hospitals (35%). Most

(91%) of the respondents worked on the unit where the child was hospitalized, and 85% of respondents worked in Level III NICUs.

The infants in the LONGTERM survey were 60% males and 40% females. Their dispositions were 32% discharged to home normally, 25% still hospitalized in the NICU or PICU, 13% were transferred to long-term care facilities and 30% of described infants died in the hospital. Fifty three percent weighed under 1000 g, 23% weighed between 1000 and 2499 g and 25% weighed over 2500 g. Birth weights influencing long-term stay were those born at or under 24 completed weeks (28%), followed by infants born at term (20%). The main maternal diagnosis associated with long term hospitalization was Pregnancy Induced Hypertension (21%). The infants' lengths of hospitalization ranged between 6 months and 6 years. See Table 1 below

Table 1 Survey reported length of time in hospital

Total length of time in hospital	Respondents	Response ratio (%)
6 months	88	22
7 months	60	15
8 months	52	13
9 months	33	8
10 months	25	6
11 months	26	6
12–17 months	81	19
18–24 months	32	8
Over 2 years (range 25–78 months)	18	5

Table 2 Survey reported parental involvement

Parental involvement	Respondents	Response ratio (%)
Parents involved entire hospitalization	308	78
Parents initially involved but did not continue to parent in extended hospitalization	59	15
Parents called or visited very rarely	8	2
Parents relinquished custody	17	4
Parents removed from custody	3	1
Parents never involved	4	1
Other	30	7

Table 3 Comparison between H-CUP national data and LONGTERM survey

H-CUP KIDS Data ICD-9-CM in order of occurrence for 680 infants	N	%	LONGTERM survey in order of occurrence for 422 infants	N	%
769: Respiratory distress syndrome	383	56	Respiratory Distress Syndrome	214	55
77181: Newborn sepsis	305	45	Sepsis	128	33
7775: Necrotizing enterocolitis in newborn	169	25	Necrotizing Enterocolitis	98	25
76502: Extreme immaturity 500–999 g	279	43	Extreme Prematurity 500–999 g	179	44
Intraventricular hemorrhage III–IV	64	15	Intraventricular Hemorrhage Grades III–IV	51	13
Intraventricular hemorrhage I–II	44	6	Intraventricular Hemorrhage Grades I–II	42	11

Participants reported 78% of parents remaining involved with the child throughout the entire hospitalization, with 23% not staying involved. See Table 2 below.

LONGTERM respondents were asked to describe the infant using 25 diagnostic categories. Respiratory distress (55%), severe prematurity (47%), sepsis (33%) and necrotizing enterocolitis (25%) were the highest ranked pathologies. It is of interest to note that in many areas, the researcher created LONGTERM survey data mirrored the nationally reported H-CUP data. See Table 3 below.

Qualitative question

Two hundred and eighty eight respondents (67%) answered the open-ended question on the LONGTERM survey to report their feelings and descriptions of caring for these infants. Line by line analysis found 37 initial coding categories which were then grouped into six main themes (See Table 4). The major final themes were: 'It's Not Right,' 'Pathophysiology Holds Us Back,' 'Creating a Normal Life,' 'Finding the Proper Place' and 'Who's in Charge?' Of note, the theme 'Cost of Care' was rarely mentioned.

It's Not Right. 'It's Not Right' was the prevailing theme reported. The participants wrote about the burden of providing technological support to infants who were not improving. They reported the suffering of the child, themselves, and the families. The suffering centered upon conditions in which the staff could foresee the infant's death or negative outcome but were asked to continue to provide maximal intervention. Participants talked about parents who did not understand what they were facing ahead, yet who were insisting on the provision of futile treatment. The following is a typical description:

Baby was coded in the OR, intubated, three rounds of epinephrine, seizures. An EEG was done and the baby was pronounced brain dead. Parents wanted continued support even though physicians counseled otherwise.

Nurses and doctors talked about being able to clearly recognize that a child was going to eventually die, and the used words such as 'torturing' or 'flogging the child to death' with interventions rather than providing comfort care at the end of life. Participants reported

This infant's short life was never comfortable. He struggled just to breath, day after day, month after month without relief unless he

Table 4 Categories to themes

Major themes	# Times coded	Initial categories
It's Not Right	435	Combined Categories of Suffering, Torturing, Was this Right?, Maximal Intervention, Parents Insisting on Futile Care, It was Hard on Us, Parents Wishes to Stop Were Overridden by Physicians, Managing a Child with No Hope, Parents Left, Families Don't Know What They Are Facing, Mother's Behavior Critiqued, Staff Wished to Stop, Support for Staff, Ethics
Pathophysiology Holds Us Back	222	Combined Categories of Nutrition Was the Issue, Could Not Wean from Vent, Tracheostomies
Creating a Normal Life	179	Combined Categories of Creating a Normal Life, Case Management, We Were a Team, Good Parental Support, Parents Came from Great Distance, Parents Supported Us, and Neurologically Intact
Who is in Charge?	116	Combined Categories of Absence of Review, Medical Experimentation, Conflict Amongst Professionals, Nurses Could See Outcome, Who is in Charge and Physicians Go Off Service
Finding the Proper Place	88	Transfer from NICU to PICU, Professional Boundaries, No Home Care, No Follow Up
Cost of Care	9	Cost of Care, Parents Here Illegally

NICU, neonatal intensive care units; PICU, pediatric intensive care unit.

was paralyzed and heavily sedated. I frequently felt we were torturing the child just doing daily care.

Physicians and nurses were upset when other staff members were not willing to stop technological support, even when the interventions were doing nothing to change the prognosis. One neonatologist wrote

We loaded him with drugs to keep him comfortable and his brain gradually deteriorated until no ventilator in existence could help him. Finally I guided his parents to let him go. I hated myself and my colleagues for putting me in this situation, a task that should have been done so many months ago. There is nothing to be proud of, just grief and tragedy all around. We did a great disservice to this child.

Another problem described were parents who were not able to care for such sick infants. Twenty three percent of the respondents reported parents who were either never involved or who gave up on the children.

The little boy never left the hospital because his mother was young and single. She had no one to help with the care of this very sick boy. He ended up being in the unit 5 months longer than necessary because we had to get medical foster care to take care of him.

Pathophysiology Holds Us Back. The most frequent anecdotal reports were descriptions of just how sick the children were. This theme regarding 'Pathophysiology' described the inability of the children to breathe or eat independently. Over 30% of all infant descriptions were about babies who had tracheostomies and were unable to be weaned off a ventilator. Thirty two percent of the anecdotal reports related to inability of the infants to eat, suck, swallow or absorb nutrition. Respondents to the survey reported nutrition categories as the most frequent reason for infants to remain hospitalized. One-third of all the children had a digestive issue, such as trachea-related malacias, fistulas, malformations,

gut related perforations, absences, short gut and liver failures. An example description was

This infant with short gut syndrome lives on total parental nutrition. His parents have been invited to live with him on our unit while waiting for a small bowel and liver transplant.

Creating a Normal Life. As the long relationships developed with the infants, participants described their difficulty of 'Creating a Normal Life' in a NICU. Respondents were concerned that children were not being taught to sit, crawl or talk as would occur outside of the intensive care unit.

We are so busy in our ICU doing our tasks that the chronic kids are left for periods of time alone in their cribs with little interaction except mobiles.

When child life personnel were available, they were described as very helpful. They would bring in developmentally appropriate toys and teach the staff how to care for 'growing, 30 pound, NICU babies.' When these children remained in the hospital for long periods, the staff often described becoming very close to the child.

This infant became ventilator dependent and trached. Despite this, he was very social. I felt an extreme bond with him and his family. His mother commented that she knew I cared for him as if he were my own. When he died suddenly just a few days from discharge, I felt depressed and hopeless.

Respondents were very grateful for families who stood by their children and wanted to help care for them. As the providers gave support to families, families also were described as supporting the staff.

Finding the Proper Place. It was difficult for the respondents to decide where the appropriate place was for these infants. Home care was often not an option due to lack of services, parental desires or the child's condition. Respondents debated whether the child

should stay in the NICU or go to the PICU or a pediatrics unit. The respondents worried about stranger anxiety of new staff members after 6–12 months. It was also difficult for the nurses and physicians to separate from the infants and families after a long period.

The move was traumatic for the staff. When death occurred after an unanticipated code event, in a place that was not familiar to him, to his family, and with a team that did not know and 'love' him, it was extremely difficult for the neonatal staff.

Cost of Care. Although respondents frequently discussed the emotional toll to all concerned, the monetary cost of long-term stays was very rarely (<1%) mentioned.

Mother here illegally. She had no home, no money, no food. The mother and child live in the unit and no organization or insurance carrier is willing to help provide a home. In rescuing this child the medical team did not evaluate that she could not be discharged on dialysis and in such a fragile state to Mexico.

Who's In Charge? The final theme from the respondents was the questioning of 'Who's In Charge?' Conflict was described between the providers and parents, physicians with physicians or the physicians and nurses. Respondents described an absence of review or oversight of infants with extremely long hospitalizations. Just who was supposed to make decisions about children who were extremely and chronically ill? Was there ever an end point? What was the end point? Can interventions once started ever to be stopped? Who was to determine that the burden on the child was now greater than the benefit? Some respondents critiqued physician colleagues who would not halt the treatment:

Child in the hospital since birth. Suffered numerous setbacks including line sepsis, feeding disturbances, skin rashes, infections, developmental delay, respiratory failure. Died in ICU after several resuscitation attempts. I thought this was unnecessary as everyone knew he would ultimately die and the resuscitation was painful and traumatic.

Other respondents critiqued the parents who insisted on continuing technological support

Parents never accepted the diagnosis of a lethal condition. Despite several neonatologists, cardiologists and an ethics committee referral, no one had the courage to discontinue respiratory support. In the last two months has had several cardiopulmonary arrests and was resuscitated because 'everyone is scared of the parents'.

Discussion and conclusion

The data collected in this study provide a contemporary picture of newborn infants hospitalized for extremely long periods in the US. In both HCUP KID data and the LONGTERM researcher survey, the

most frequent sufferers of long-term hospitalizations were premature infants with respiratory disease, necrotizing enterocolitis and sepsis. Cotton *et al.*⁶ found similar results in their multicenter study of 685 premature infants with hospital stays ranging from 99 to 734 days: the associated morbidities were necrotizing enterocolitis, chronic lung disease and sepsis. The seriousness of necrotizing colitis and the need for ongoing research to prevent and treat this condition is essential. Participants reported children with limited bowel, living on total parental nutrition, then needing liver transplants and not able to leave the hospital.

Davison *et al.*⁷ also found extended hospitalization associated with male gender, prematurity with respiratory syndrome and necrotizing enterocolitis. Extended length of stay has been reported in infant heart surgery (71 days);⁸ necrotizing enterocolitis (204 days);⁹ nosocomial sepsis (additional 100 days);¹⁰ mechanical ventilation (120 days).¹¹ In comparing NICU data between 1991 and 2001, Meadow *et al.*¹² found no change in the percentage of extremely low birth weight infants who died, but a significant increase in the number of days until they died.

Transfers from the NICU to the PICU were discussed. Davison *et al.*⁷ found that when infants were transferred to the PICU after extended stays in the NICU, 20% died in the PICU, with other infants remaining there up to another year. Marcin *et al.*¹³ in a study of 32 PICUs with over 11 000 admissions, reported infants under 12 months of age having the longest stays, with a large percentage having tracheostomies and feeding tubes, many of whom had come to the PICU after living in the NICU. Evans and Madsen¹⁴ mirror the respondents in this study by describing the emotion trauma of transferring infants from the NICU to the PICU.

Parental responses to their children's long stays were mostly supportive. Survey participants reported 77% of parents were remained involved with their children through the entire hospitalization. Thus, approximately 100 children (23%) described in the study had parents who no longer related to them in their long-term stays.

Only one maternal condition was reported to contribute to long-term stays, and this was pregnancy induced hypertension (21%). In a factor analysis of 59 861 pregnant women,¹⁵ multiple gestation related to long-term stay was the prevailing factor 19% of the time, with pregnancy induced hypertension, diabetes and premature rupture of membranes also independent contributors. In the LONGTERM study multiple gestation was not a maternal variable, although 24 participants (7%) wrote in 'multiple gestation' in the 'other' category.

In both the HCUP KID data set and the LONGTERM survey reported here, children went home on home health when it was available. Participants reported the lack of available home health nursing care contributed to long hospitalizations. Ray¹⁶ reported the barriers to obtaining home health care, such as failure to inform parents about available services, cyclical funding and non-availability of technological machinery for home use. Hummel

and Cronin¹⁷ delineate the comprehensive planning requirements for home discharge of a technologically supported infant. Increased funding for home health care and recruitment of nurses into the home health field will be essential if complexly ill newborns are discharged to home.¹⁸

The HCUP KID data tell a story in numbers; 680 long-term stay infants were reported. Those numbers are made real by the LONGTERM 288 qualitative descriptors. 'Who's in Charge?' and 'It's Not Right' were the main themes found in this and other similar studies. Nurses frequently described their moral distress. Badger¹⁹ also describes nurses' moral distress over end of life care, quoting one participant who was 'praying for them (the patient) to die while the family is praying for them to live.' Stutts and Schloemann²⁰ described a staff and family in gridlock while the infant seized, was septic and began to necrose from inside out. Beckstrand *et al.*²¹ reported moral distress in 861 critical care nurses who were trying to convince both physicians and families to accept 'when enough was enough'. Elpern *et al.*²² reported nurses' moral distress occurring when they were 'providing aggressive interventions for patients who could not benefit from the care'. One of their participant's said: 'I often equate my job with keeping dead people alive'.

It was not only nurses who described their moral distress in the LONGTERM study. The 46 physicians also described their burden over these children's hospitalizations. This burden has been reported elsewhere. Hefferman and Heilig²³ reported the moral distress of physicians in their ability to 'inflict harm rather than do good with technology.' Neonatologists Muraskas *et al.*²⁴ reported neonatologists 'held hostage by technology.' Researchers in a study of 781 physicians and nurses²⁵ reported 54% of the providers had acted against their consciences; with five times as many saying 'We are saving children who should not be saved;' and 20 times as many saying 'The treatments I offer are overly burdensome' than those who felt they were undertreating.

Although a protocol for palliative care for marginally viable infants has been written about since 2002^{26–29} and put into practice in select US hospitals,^{30–31} nurses and physicians in this study described lack of agreement on the implementation of end of life palliative care. Nurses described physicians or parents insisting upon treatments that nurses could see were futile. Physicians described colleagues and parents who could not come to agreement on changing the model of care from attempts at cure to dignified end of life care. Thus many of the children in this study spent long periods of time in the hospital before either discharge to home with or without home health care or dying in the hospital.

This study and all those mentioned above depict provider suffering in the care of patients with long-term hospital stays without improvement. In this study, providers discussed inappropriate treatments that caused harm to infants. Rushton³² addresses the provider suffering caused by being asked to provide treatments that do not offer improvement. She suggests caregivers

ask themselves if they can live with the type of treatment they are being asked to deliver. 'Integrity', per Rushton, 'demands that professionals... raise a conscientious voice and make a conscientious refusal'. Catlin *et al.*³³ are studying nursing conscientious objection to treatments which cause harm or inflict suffering. This work may assist in influencing the focus of treatment from long-term technological NICU or PICU support that does not change the underlying condition to dignified and loving palliative care. In good palliative care, the quality of life, rather than the length of life, remains the essential focus.

Suggestions for further research

Results from this study show that more is needed to be known on activities that will keep parents actively involved in their ill child's care both in and out of the hospital. Increased dissemination and study of the palliative care protocol for newborns would be helpful. Creation of forum beyond the ethics committee, such as hospital policy for requests of unwarranted treatments³⁴ or use of a futility policy³⁵ is essential. Members of the National Association of Neonatal Nurses and the American Academy of Pediatrics Perinatal Subsection will continue to work together and with families on defining and implementing appropriate forms of care for each infant.

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