

Differences Associated with Age, Transfer Status, and Insurance Coverage in End-of-Life Hospital Care for Children

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BACKGROUND: More than 40% of childhood mortality occurs while children are hospitalized. End-of-life health care utilization patterns for children have not been well characterized at the national level.

OBJECTIVE: To describe patterns of length of stay, total charges, and principal diagnoses for children who die while admitted to a hospital, versus those who survive to discharge.

METHODS: We conducted a cross-sectional analysis of 3 years spanning a decade of the Nationwide Inpatient Sample (NIS), a nationally representative dataset of hospital discharges, to analyze sociodemographic characteristics and patterns of hospital resource use associated with in-hospital mortality.

RESULTS: Inpatient mortality rate was significantly higher for non-newborn infants (<1 year old) than for all other age groups, and the overall number of deaths was greatest for newborns. Patients transferred between hospitals had significantly greater mortality rate, compared with patients admitted not on transfer. Insured children had lower mortality rates compared to uninsured, and decedents had significantly longer length of stay and higher charges compared with survivors. Uninsured decedents did not have longer lengths of stay than survivors, and hospital charges were significantly lower for uninsured children compared with insured children.

CONCLUSION: As hospital staff strive to meet the needs of ill children and their families, they must be cognizant of the high burden of mortality among the youngest children and those transferred between hospitals, and the potential for less resource use and higher mortality risk for children without insurance, because these patients may require expanded services not readily available in most hospital settings. *Journal of Hospital Medicine* 2008;3:376–383. © 2008 Society of Hospital Medicine.

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More than 53,000 children 19 years of age or younger died in 2004,¹ and more than 40% of these children died while hospitalized.^{2–5} Recently, pediatric end-of-life (EOL) issues have gained clinical and research attention, primarily focused on children with chronic conditions, ethical dilemmas surrounding childhood death and dying, and the need for interdisciplinary palliative care efforts for dying children and their families.^{2,3,6–9}

Much remains unknown about patterns of EOL hospital care at the national level for all children, both with and without complex chronic conditions. Because a large proportion of childhood mortality occurs during hospitalization, the inpatient setting is a crucial arena for patients and families facing EOL issues. However, little is known about how insurance status and interhospital transfer are associated with patterns of hospitalization and mortality for children while hospitalized, or about hospital charges and lengths of stay for children who die as inpatients versus those who survive to discharge. In addition, although spending on EOL health care in the United States has attracted considerable attention in recent years, the published literature focuses almost exclusively on adult populations.^{10–12}

Illuminating the patterns of childhood mortality in hospital settings may inform expanding institutional efforts to address death and dying for children and their families. We conducted an analysis of national patterns of hospitalization over a span of a decade (1992–2002), in order to characterize sociodemographic and health care factors associated with inpatient mortality, and to examine patterns of hospital resource use related to EOL care. We hypothesized that resource use would be higher for children who died versus those who survived, and would be higher for uninsured versus insured children.¹³ We also hypothesized that children admitted upon transfer from another hospital would have higher risk of mortality.¹⁴

METHODS

Our data source was the National Inpatient Sample (NIS), which is a component of the Healthcare Cost and Utilization Project (HCUP) sponsored by the Agency for Healthcare Research and Quality. The HCUP is a set of databases developed through partnership among health care institutions and federal and state governments.¹⁵ The NIS is the largest publicly available all-payer inpatient database in the United States, and contains de-identified, patient-level clinical data included in a typical discharge abstract. For each year, these data reflect hospital stays from between 800 and 1000 institutions sampled to approximate a 20% stratified sample of nonfederal community hospitals, including public hospitals, children's hospitals, and academic medical centers but excluding

long-term hospitals, psychiatric hospitals, and chemical dependency treatment facilities.

We chose the NIS for this analysis because we were interested in the most common diagnoses for hospitalized children. An alternative database, such as the KID (Kids Inpatient Database), is optimal for less commonly seen discharge diagnoses and did not permit a full decade of retrospective analysis.

In order to characterize changes in mortality and health resource utilization related to our research questions, we conducted a comparative cross-sectional analysis of 3 years of the NIS over the years 1992, 1997, and 2002. For each year of NIS data, discharge-level weights were provided to permit calculation of national estimates of hospitalization rates standardized to the concurrent national population.¹⁵ All inpatient hospital stays of children aged 17 years and younger were selected.

Discharge data were analyzed based on age, sex, payer status, and transfer status on admission. Although transfer status is not often considered in studies of mortality, we expected that it would be associated with mortality, as a potential indicator of disease severity.¹⁴ We included only interhospital transfers, and excluded patients transferred from other locations such as long-term care facilities. We categorized discharges into 5 age groups: newborns, whose hospitalization began at birth; infants up to 1 year of age who were not born during hospitalization; 1–5 years; 6–10 years; and 11–17 years. This stratification allowed us to separate infants who were admitted from home or from another hospital versus those who were born during hospitalization. Payer groups included Medicaid, private insurance, and uninsured. Medicare and other payers were analyzed, but were present in very small numbers and are not reported.

Outcomes included weighted inpatient mortality rate, weighted mean of length of stay (in days), and weighted mean total hospital charges. For nationally weighted data, lengths of stay and hospital charges are typically reported as means because weighted medians cannot be estimated.¹⁶ We compared mortality patterns for patients who were transferred between hospitals versus those who were not, using multivariable logistic regression to identify factors associated with in-hospital mortality. Of note, transfer status was evaluated from the standpoint of the receiving hospital as

children who were admitted upon transfer from another hospital. Thus, our estimates likely underestimate the effects attributed to interhospital transfer, because this evaluation is unilateral and does not include the transferring hospital. The 5 most common principal Diagnosis-Related Groups (DRGs) upon discharge were compiled for each of the study years for both survivors and decedents. In order to interpret the analyses of discharge-related hospital charges in constant dollars, we standardized all hospital charges to 2002 US dollars using the Consumer Price Index.¹⁷

Statistical analyses included bivariate comparisons of sociodemographic characteristics and the study outcomes, for each of the study years. We also conducted multivariable regression analyses of mortality, comparing effects of sociodemographic variables and transfer status. We conducted all analyses using Stata, version 8 (Stata Corp., College Station, TX), with which we incorporated sample weights to account for the complex stratified sampling of hospitals that comprise the NIS, and to generate variance estimates with which we derived 95% confidence intervals (95% CI). NIS samples included weighted data for 6.2 million discharges in 1992, 7.1 million discharges in 1997, and 7.9 million discharges in 2002. All results are presented using weighted values. The study was funded internally and all analyses were conducted by the authors. The authors had no financial interest in the outcome. The study was exempt from human subjects review as an analysis of de-identified secondary data.

RESULTS

Study Sample

NIS samples represented between 35 million and 37.8 million discharges nationally in each of the study years. Distributions of discharges across age group, gender, and payer group were similar across the study years (Table 1).

The proportions of patients admitted as transfers between hospitals are shown for each age group, as well as by payer. Non-newborn infants had the highest rate of transfer for each year studied, compared with the other age groups. Across the study years, transfer status was fairly uniform across payers.

TABLE 1
Hospitalization Discharge Data for Children by Year—United States

Characteristic	1992 N = 6,722,647‡	1997 N = 6,365,886‡	2002 N = 6,456,077‡
Age (%)			
Newborn	60.0	63.0	65.0
Admitted as transfer*	1.3	1.1	1.2
0-<1 year	8.7	8.0	8.6
Admitted as transfer*	7.6	7.2	8.8
1-5 years	11.9	11.0	9.2
Admitted as transfer*	5.1	4.5	5.6
6-10 years	5.5	5.0	5.0
Admitted as transfer*	4.9	4.7	5.3
11-17 years	13.9	13.0	12.2
Admitted as transfer*	3.1	4.2	4.8
Gender (%)			
Female	49.0	49.0	49.0
Payer (%)†			
Medicaid	37.0	36.0	39.0
Admitted as transfer*	3.3	3.0	3.4
Private	52.0	55.0	53.0
Admitted as transfer*	2.3	2.3	2.4
Uninsured	7.0	5.0	5.0
Admitted as transfer*	2.4	2.4	2.4

NOTE: Percentages in bold reflect the proportion comprised by each subgroup, using the entire year samples as denominators.

*Proportions admitted as transfer are for each subgroup independently, using each subgroup size as the denominator; ie, among all newborns, who in aggregate comprised 60.0% of all discharges in 1992, 1.3% were admitted on transfer. Among all non-newborn infants, who in aggregate comprised 8.7% of all discharges in 1992, 7.6% were admitted on transfer, etc.

†Discharges listed as Medicare and "Other" in the original datasets are not shown.

‡Weighted sample sizes are provided.

Patterns of Inpatient Mortality

During the study period, overall pediatric inpatient mortality decreased from 32,941 children (0.49% of all child discharges) in 1992 to 25,824 children (0.40%) in 2002, although this was not a statistically significant change. The inpatient mortality rate across all years studied was significantly higher for the non-newborn infants (<1 years) than for all other age groups in all study years ($P < .005$) (Table 2). The newborn age group had the second highest mortality rate in all years, and the remaining 3 groups had similar mortality rates.

However, because the majority of child hospitalizations are for newborns, the overall burden of mortality was greatest for newborns in all years studied. In 2002, 68.6% of pediatric inpatient deaths were newborns, 8.2% were non-newborn infants, 7.7% were 1–5 years old, 4.2% were 6–10 years old, and 11.3% were 11–17 years old. These findings were similarly distributed across age groups in 1992 and 1997 as well (data not shown).

TABLE 2
Annual Inpatient Mortality Rate for Children, by Age and Payer

Age Groups*	Annual Inpatient Mortality Rate		
	1992 N = 6,722,647	1997 N = 6,365,886	2002 N = 6,456,077
Overall	0.49%	0.41%	0.40%
Newborn	0.50%	0.41%	0.40%
0-<1 year	0.77%	0.64%	0.52%
1-5 years	0.43%	0.34%	0.33%
6-10 years	0.41%	0.34%	0.34%
11-17 years	0.35%	0.34%	0.36%
Payer groups†			
Medicaid	0.51%	0.44%	0.45%
Private	0.38%	0.34%	0.33%
Uninsured	0.69%	0.69%	0.58%

*P < .005 for comparison of mortality rates across age groups within each study year.

†P < .0001 for comparison of mortality rates across payer groups within each study year.

Inpatient mortality rates also differed significantly by payer in all study years (Table 2). In each year, uninsured children had the highest mortality rates followed by children with Medicaid coverage and children with private health plans. Given the proportions of discharges with coverage by Medicaid versus private plans and the differences in mortality rates, the overall burden of mortality was greatest for children with private coverage in 1992 and 1997, and was equivalent to that of Medicaid (11,292 versus 11,330, respectively) in 2002.

Table 3 presents inpatient mortality rate by age and transfer status. Patients who were admitted on transfer from another acute care hospital had a significantly greater mortality rate for all age groups, compared with patients admitted not on transfer, within the same age group. The strong association of mortality with transfer status remained in multivariable regression analyses, adjusted for age and payer status (data not shown).

DRGs were evaluated based on transfer status, mortality, and study year. The most common DRGs for survivors were generally consistent across years and transfer status: neonate, bronchitis and asthma, pneumonia, esophagitis/gastroenteritis, nutritional and metabolic disturbances, and vaginal delivery. Among decedents, the primary diagnoses also included neonate, but in contrast with survivors were more likely to include

TABLE 3
Inpatient Mortality Rate by Age and Transfer Status for Children, United States

Age Group and Transfer Status	Mortality Rate (% of Discharges)		
	1992 (95% CI)	1997 (95% CI)	2002 (95% CI)
Newborn			
Admitted as transfer	4.57 (3.56, 5.59)	4.22 (3.44, 5.00)	4.75 (3.80, 5.93)
Admitted not on transfer	0.45 (0.40, 0.51)	0.37 (0.33, 0.40)	0.36 (0.32, 0.40)
0-<1 year			
Admitted as transfer	5.05 (3.83, 6.28)	4.38 (3.59, 5.17)	2.86 (2.32, 3.53)
Admitted not on transfer	0.43 (0.34, 0.50)	0.35 (0.28, 0.43)	0.30 (0.23, 0.40)
1-5 years			
Admitted as transfer	2.26 (1.61, 2.19)	1.59 (1.20, 1.98)	1.33 (0.97, 1.83)
Admitted not on transfer	0.33 (0.25, 0.40)	0.27 (0.22, 0.33)	0.27 (0.22, 0.33)
6-10 years			
Admitted as transfer	2.01 (1.23, 2.96)	1.48 (0.92, 2.03)	1.11 (0.83, 1.49)
Admitted not on transfer	0.32 (0.26, 0.39)	0.28 (0.22, 0.34)	0.29 (0.24, 0.36)
11-17 years			
Admitted as transfer	1.87 (1.42, 2.33)	1.09 (0.81, 1.38)	1.33 (1.02, 1.73)
Admitted not on transfer	0.30 (0.25, 0.35)	0.30 (0.25, 0.34)	0.32 (0.27, 0.37)

traumatic injury, cardiothoracic surgery/medical care (ie, for congenital cardiac/valve disease), respiratory diagnosis with ventilatory support, and craniotomy. DRGs for decedents were consistent across years and transfer status (data available upon request to the authors).

DRGs were also evaluated based by payer status across all 3 study years (data not shown). The most common DRGs showed no meaningful differences in the types of conditions for children who were transferred versus not, across all payer types (including uninsured children).

Length of Stay and Hospital Charges, by Survival, Payer, and Transfer Status

Table 4 illustrates the national patterns of mean length of stay by age, survival, and transfer status. Data for 2002 are shown; the other study years had very similar findings and are available from the authors.

Length of stay differed significantly by transfer and survival status, and also varied significantly by insurance coverage. In 2002, among children who were admitted not on transfer, those who died had significantly longer mean length stay than those who survived. Among children admitted as a transfer, for all but non-newborn infants and those 1–5 years of age, length of stay did not differ significantly by survival status.

For children covered by Medicaid and private insurance, decedents had significantly longer length of stay compared to survivors, regardless of transfer status. However, this was not the case for uninsured children, for whom those who died and those who survived had statistically indistinguishable lengths of stay, within the transfer/non-transfer groups. Findings for 1997 and 1992 were similar (data not shown).

Mean hospital charges are presented in Table 5. For children covered by Medicaid and private insurance, among patients who were admitted not on transfer, those who died had more than 8-fold greater charges than those who survived. A similar trend was seen for patients admitted on transfer who were covered by Medicaid and private insurance, with more than 3-fold greater charges for those who died versus those who survived. In contrast, for uninsured children, those who were admitted not on transfer and died had only 3.5-fold greater charges compared to survivors, and those who were admitted on transfer and died had only 2-fold greater charges compared to survivors.

TABLE 4
Length of Hospital Stay (Days) by Child Age, Payer, Survival, and Transfer Status—United States, 2002

	Admitted on Transfer (95% CI)		Admitted Not on Transfer (95% CI)	
	Alive	Died	Alive	Died
Age				
Newborn	16.9 (14.7-19.0)	19.6 (15.1-24.0)	3.2 (3.0-3.3)	8.3 (6.9-9.7)
0-<1year	11.3 (9.1-13.0)	24.8 (18.8-30.8)	3.5 (3.2-3.8)	20.1 (12.8-27.5)
1-5 years	4.8 (4.2-5.6)	16.0 (8.5-23.4)	3.0 (3.4-4.0)	12.7 (7.2-18.2)
6-10 years	6.4 (4.7-8.2)	12.9 (4.9-20.8)	3.7 (3.4-4.0)	13.8 (9.7-17.8)
11-17 years	8.0 (6.0-10.0)	8.8 (5.8-11.7)	4.0 (3.7-4.3)	10.2 (6.4-14.0)
Payer				
Medicaid	11.4 (9.7-13.1)	21.8 (16.2-27.4)	3.5 (3.4-3.7)	11.2 (9.2-13.3)
Private	9.7 (8.6-10.7)	17.1 (13.5-20.7)	3.1 (3.0-3.2)	9.3 (7.4-11.1)
Uninsured	7.0 (4.8-9.2)	5.3 (1.1-9.5)	2.8 (2.6-3.1)	3.1 (1.2-5.0)

TABLE 5
Total Charges by Payer, Survival, and Transfer Status—2002 US Dollars

	Admitted on Transfer (95% CI)		Admitted Not on Transfer (95% CI)	
	Alive	Died	Alive	Died
Payer				
Medicaid	43,123 (34,570-51,675)	141,280 (104,881-177,679)	8,456 (7,3489-9,564)	73,798 (59,71-87,884)
Private	41,037 (33,420-48,653)	142,739 (110,122-175,355)	7,519 (6,597-8,441)	62,195 (50,722-73,667)
Uninsured	21,228 (15,389-27,068)	48,036 (28,974-67,099)	5,591 (4,372-6,810)	19,910 (13,342-26,479)

DISCUSSION

Children's Inpatient Mortality

This is the first study of which we are aware that examines EOL hospitalization patterns for children in a national sample, spanning a decade. Our data revealed that the pediatric inpatient mortality rate is consistently highest among children in the non-newborn infant age group over this time period, and that the burden of mortality is persistently greatest among newborns. These age-specific findings are consistent with vital statistics published separately for each of the study years regarding overall childhood mortality.¹⁸⁻²⁰

This study highlights what many health care providers may not recognize: to meet the needs of the greatest numbers of families with gravely ill children, EOL care efforts must focus on the very youngest. Many of these children may not have chronic conditions, which have been a central focus of many pediatric EOL efforts to date. In fact, the parents of most gravely ill children in the hospital may have had just a few days or hours to prepare to face the loss of their children.

In addition, children admitted on interhospital transfer are significantly more likely to die while hospitalized. This pattern likely represents referral of severely ill children to medical centers that offer tertiary and quaternary specialty care, rather than risks associated with the transfer event itself. Some parents and their children may be far away from home and their closest networks of social support.⁷ Overall, these findings strongly indicate that EOL efforts will meet the needs of greater proportions of parents if they actively incorporate considerations of age and transfer status as institutions reach out to families in need of support.

Of note, this analysis does not capture children who were discharged into hospice, or long-term care facilities, or who may have been discharged to home and may have died thereafter.

Discharge disposition is known to vary by age, with older children with chronic conditions being more likely to use hospice services compared with infants.⁸ A recent study suggests that deaths outside the hospital have become increasingly common for older children over time, with the expansion of EOL supportive services in communities to meet the needs of families with gravely ill children.⁸

Length of Stay, Hospital Charges, and Mortality Related to Insurance Status

In this study, insured children who were admitted and died had significantly longer hospital stays compared to uninsured children who were admitted and died. DRG diagnoses by payer were very similar among children who died, although it is possible that differences in length of stay by payer status may reflect differences in severity of illness at admission and/or processes of care during hospitalization, which could not be fully accounted for using diagnostic codes. Hospitalizations that ended in death were significantly more expensive than hospitalizations in which children survived to discharge, regardless of age, payer status, or transfer status. However, incremental differences in spending for those who died versus those who survived were much greater for children with health insurance than for children without, suggesting greater resource utilization for children with coverage. Resource utilization is reflected largely in length of stay, which explains why our findings for differences in length of stay were echoed so strongly in our findings regarding differences in hospital charges.

Several studies of EOL care for adults have indicated that uninsured patients sustained higher inpatient mortality and lower hospital resource use versus insured adults, across similar diagnoses.^{13,21-23} Among children, Braveman and colleagues found differences in hospital resource allocation among sick newborns according to insurance coverage that are echoed in the findings of our study.²⁴ Sick newborns without insurance received fewer inpatient services, with statistically significant shorter length of stay and total charges compared to insured newborns. In our study, disparities related to insurance coverage were consistent over the decade considered, and likely indicate ongoing challenges of broad disparities in access to care for children related to insurance coverage in the US health care system. Perhaps the greatest

disparity was in mortality itself, which was highest among the uninsured, although the gap in mortality rates by insurance status appeared narrower in 2002 than in the prior study years.

Mortality Rates by Transfer Status

Mortality rates stratified by transfer status revealed that children transferred between hospitals had a significantly higher mortality rate, compared to children admitted not on transfer. Literature evaluating adult intensive care units found that transferred patients have more comorbid conditions, greater severity of illness, and 1.4-fold to 2.5-fold higher hospital mortality rates compared to direct admissions.²⁵ Similar challenges face pediatric patients who are transferred to intensive care settings, where children at higher clinical risk have a higher mortality rate and utilize greater resources compared with less critically ill children.¹⁴ Hospital EOL support personnel must be cognizant of the high mortality rate for transferred patients, and services may need to be adjusted to address the needs of these families. Additionally, further research is needed to better understand and remedy these potential disparities in care for children based on insurance status.

Limitations

This study is potentially limited by the accuracy of hospital discharge data, which may have influenced our outcomes. Further, not all states participate in the NIS; 11 states participated in 1992, 22 states participated in 1997, and 35 states participated in 2002. Although NIS data are weighted to be nationally representative in each year, it is possible that the participating states may have differed in systematic ways from nonparticipating states. However, the external validity of our data with regard to patterns of mortality by age and diagnoses, and the stability of patterns across a span of several years, suggest strongly that our findings are likely robust to these potential biases in this dataset.

As with any hospital resource use data, we are mindful that the distribution of data regarding length of stay and charges are typically right-skewed, and therefore mean values should be interpreted with caution. In using mean values to test our hypotheses, we have followed the stand-

ard method of comparison for nationally weighted data.¹⁶

CONCLUSION

This national study of inpatient mortality patterns among US children over the span of a decade presents a new framework of challenges to clinicians and investigators regarding EOL care for children. As health care providers and institutions expand

their efforts to meet the needs of severely ill children and their families, such efforts must be cognizant of the high burden of mortality among the youngest children, as well as those who are transferred between hospitals, and children without insurance coverage. These children and their families may require expanded EOL care and support services, beyond those typically available in most hospitals and communities.

APPENDIX: DIAGNOSIS-RELATED GROUPS BY TRANSFER AND SURVIVAL STATUS

1992	%	1997	%	2002	%
Transferred - Survived					
Neonate*	26.2	Neonate*	23.2	Neonate*	24.6
Bronchitis and Asthma	6.4	Bronchitis and Asthma	7.4	Bronchitis and Asthma	8.0
Seizure and Headache	3.7	Simple Pneumonia	3.3	Seizure and Headache	4.2
Simple Pneumonia	3.4	Seizure and Headache	3.2	Simple Pneumonia	3.7
Esophagitis and Gastroenteritis	3.0	Psychoses	3.2	Esophagitis and Gastroenteritis	3.0
Transferred - Died					
Neonate†	35.1	Neonate†	38.2	Neonate†	40.5
Cardiac Disease and/or Cardiothoracic surgery	9.6	Cardiac Disease and/or Cardiothoracic surgery	12.2	Cardiac Disease and/or Cardiothoracic surgery	10.9
Respiratory diagnosis with ventilatory support	6.8	Respiratory diagnosis with ventilatory support	7.7	Respiratory diagnosis with ventilatory support	7.0
Craniotomy	3.5	Septicemia	2.8	Injury, Poisoning	2.4
Injury, Poisoning	3.3	Tracheostomy with ventilatory support	2.8	Craniotomy	2.2
Not Transferred - Survived					
Neonate*‡	60.6	Neonate*‡	63	Neonate*‡	66.4
Bronchitis and Asthma	4.9	Bronchitis and Asthma	5.3	Bronchitis and Asthma	4.7
Esophagitis and Gastroenteritis	3.1	Simple Pneumonia	2.9	Simple Pneumonia	2.5
Simple Pneumonia	2.7	Esophagitis and Gastroenteritis	2.6	Esophagitis and Gastroenteritis	2.0
Vaginal Delivery	2.2	Vaginal Delivery	2.3	Nutritional and Metabolic Disorder	1.8
Not Transferred - Died					
Neonate†	61.5	Neonate†	66.2	Neonate†	69.0
Traumatic Coma or Operative Procedure for Traumatic Injury	3.3	Traumatic Coma or Operative Procedure for Traumatic Injury	4.8	Traumatic Coma or Operative Procedure for Traumatic Injury	4.7
Cardiac Disease and/or Cardiothoracic surgery	2.9	Cardiac Disease and/or Cardiothoracic surgery	2.7	Respiratory diagnosis with ventilatory support	2.7
Craniotomy	2.3	Respiratory diagnosis with ventilatory support	2.5	Craniotomy	2.4
Respiratory diagnosis with ventilatory support	2.0	Septicemia	1.4	Septicemia	1.2

*Includes full term and premature infants, with and without medical complications.

†DRG 385 Neonates, died or transferred.

‡Normal Newborn (DRG 391) comprised 41.6% in 1992, 43.0% in 1997, and 49.4% in 2002 of neonate.

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