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Children Who Are Medically Fragile in North Carolina: Prevalence and Medical Care Costs in 2002

by

Paul A. Buescher, Ph.D.
J. Timothy Whitmire, Ph.D.
Susan Brunssen, Ph.D., R.N.
Deborah Nelson, Ph.D., M.S.P.H.
Eleanor E. Howell, M.S. Stat.
Catherine E. Kluttz-Hile, B.S.N., M.A.

ABSTRACT

Objectives: Children with serious and complicated medical conditions often require intensive medical treatment and have very high medical care costs. This study estimates the total number of children in North Carolina of pre-school age who are medically fragile and profiles their medical care costs. Some of these children might be appropriately placed in a medical child care environment as a means of improving their health and reducing hospital and emergency room use.

Methods: Inpatient hospital discharge and Medicaid paid claims data for 2002 were used to estimate prevalence and medical care costs. The children who are medically fragile were identified through selected procedure and durable medical equipment codes. Using the Medicaid data, we profiled the expenditures for all medical services provided to these children during 2002, not just hospitalizations.

Results: From the hospital discharge data, 1,811 children ages 0-4 years in North Carolina were identified as medically fragile (0.32%). The hospital charges for these children during 2002 were \$109.4 million, or \$60,409 per child. From the Medicaid data, 1,126 children enrolled in Medicaid were identified as medically fragile (0.44%). The total amount paid by Medicaid for these children during 2002 (for all medical services, not just hospitalizations) was \$82.9 million, or \$73,669 per child. By comparison, the average expenditure by Medicaid during 2002 for a randomly selected group of children receiving well-child visits was \$2,016 per child. The \$82.9 million of Medicaid expenditures for the children who are medically fragile represents 14 percent of the \$598 million spent by Medicaid in 2002 for all medical services for all children ages 0-4.

Conclusions: A small number of children who are medically fragile use a large amount of medical care services. Medical child care facilities could provide some of these children with the necessary care that they need during the work day, allow parents to return to work, and provide families with the emotional and physical break that they need to cope with the high demands that come with the care of their child. Also, these facilities can help medical care systems, such as Medicaid, to better manage health care costs, particularly by reducing hospital and emergency room use.



Introduction

Advances in neonatal technology have made it possible to save the lives of premature newborns at greater levels of prematurity. Also, children with major birth defects or other serious health problems now often live past infancy.

These surviving infants sometimes have serious and complicated medical conditions requiring intense medical treatment and/or technology assistance. The children often require continuous assessment and frequent nursing and medical-crisis intervention. The parents are under enormous emotional and physical stress to provide the support that their child needs.¹⁻⁴ Medical care systems struggle to manage the increased costs associated with home health services, inpatient hospital stays, and physician and emergency room visits.

Some states, for example Georgia, have found it beneficial to children who are medically fragile, to their families, and to the Medicaid program to provide statewide medical child care facilities to care for children who are medically fragile. Advantages of these facilities are that they provide families with the necessary child care they need during the work day and the emotional and physical break they need to continue to cope with the high demands that come with the care of their child. Children have the opportunity to interact and socialize with other children, thereby reducing the effects of isolation due to being homebound. These facilities also provide daily medical and developmental care for children with complex medical conditions, as well as parental training. As a result, these facilities can help medical care systems, such as Medicaid, to better manage health care costs,⁴ particularly by reducing emergency room and hospital utilization.

The objectives of this study are to estimate the total number of children in North Carolina of pre-school age who are medically fragile and to profile

their medical care costs. Children ages 0-4 years were included because these are primarily the ages where medical child care services might be provided. These data will allow better medical and social planning for these children with severe disabilities and complex chronic illnesses. Some of these children could be appropriately placed in a medical child care environment.

Very few previous studies have attempted to estimate the population prevalence of children who are medically fragile. A paper by Pierce, et al.⁵ concluded that “the exact number of children with complex conditions is difficult to discern.” Their analysis of other studies indicated that approximately 10 percent of all children have a chronic condition, and of these, about 1 percent have disease manifestations requiring the kind of services available in a Prescribed Pediatric Extended Care Center (medical child care). This calculates to 0.10 percent of the total population of children estimated to be medically fragile or technology dependent. A 1990 study in Massachusetts⁶ found approximately 2,200 children in the state, ages 3 months to 18 years, with various forms of technology assistance (e.g., respirators, ostomies, dialysis, etc.). This represented 0.16 percent of all children in the state in this age range, consistent with the estimate of Pierce, et al.¹ However, this study relied on a special survey of medical and educational professionals, who were asked to fill out a form on each child known to them who was assisted by medical technology. A list of unique cases was generated after checking for duplicate reporting.

The present study uses existing statewide data bases to estimate the number of children who are medically fragile in North Carolina. Since special data collection efforts are not required, these results could be updated regularly, without extensive effort, to monitor trends and evaluate the results of interventions.

Methods

We used two sources of data to identify children who are medically fragile in North Carolina: the inpatient hospital discharge data base and the Medicaid paid claims data base.

North Carolina's hospital discharge data base captures information on all inpatient hospitalizations occurring in non-federal hospitals in North Carolina. We do not have information on hospitalizations of North Carolina residents that occur in other states. We selected all hospital discharge records for 2002 for North Carolina resident children ages 0-4 who had one or more of 176 specific ICD-9-CM

(International Classification of Diseases, 9th revision, Clinical Modification) principal procedure codes. These are procedures or operations that would indicate that the child had serious long-term medical problems.

A co-author of the study (Brunssen), who is a specialist in pediatric and neonatal nursing, chose the procedure codes after careful consultation with some of her colleagues. Table 1 shows the top ten of the 176 procedures, ranked by the number of discharge records in the data base with the procedure. At the bottom of the table is a list of all of the 176 ICD-9-CM procedure codes used to identify the children who are medically fragile.

Table 1: Top Ten of the 176 Principal Procedures (with ICD-9-CM Code) Used to Identify Children Ages 0-4 Who Are Medically Fragile in North Carolina in 2002 Who Were Hospitalized*

Procedure	ICD-9-CM Code
1. Continuous mechanical ventilation for 96 consecutive hours or more	96.72
2. Enteral infusion of concentrated nutritional substances	96.6
3. Replacement of ventricular shunt	02.42
4. Other procedures for esophagogastric sphincteric competence	44.66
5. Parenteral infusion of concentrated nutritional substances	99.15
6. Ventricular shunt to abdominal cavity and organs	02.34
7. Ureteroneocystostomy	56.74
8. Temporary tracheostomy	31.1
9. Closed [endoscopic] biopsy of bronchus	33.24
10. Other partial resection of small intestine	45.62

*Based on the number of hospital discharge records with the code.

Note: The codes below are in numerical order; the top 10 procedures (above) account for approximately one-half of all of the hospital discharges with these 176 principal procedure codes.

(All 176 ICD-9-CM procedure codes: 01.0, 02.2, 02.3, 03.7, 14.2, 14.3, 14.4, 14.5, 29.0, 30.2, 31.1, 31.2, 31.3, 35.4, 35.6, 35.8, 37.5, 37.6, 37.7, 37.8, 41.0, 42.1, 42.4, 42.5, 42.8, 42.9, 43.0, 43.1, 43.6, 43.8, 43.9, 44.3, 44.5, 45.6, 45.7, 45.8, 45.9, 46.0, 46.1, 46.2, 46.3, 46.4, 46.5, 50.3, 50.4, 50.5, 51.0, 51.1, 51.2, 51.5, 51.6, 52.5, 52.9, 53.7, 53.8, 54.5, 55.5, 55.6, 56.2, 56.4, 56.5, 56.6, 56.7, 57.2, 57.7, 57.9, 59.0, 59.9, 65.3, 65.4, 87.5, 89.4, 92.3, 96.6, 97.0, 97.4, 97.5, 97.6, 01.52, 01.53, 01.59, 02.42, 02.43, 02.93, 03.52, 03.97, 30.09, 31.41, 31.42, 31.49, 31.72, 31.73, 31.74, 31.75, 31.79, 33.21, 33.22, 33.23, 33.24, 33.91, 35.51, 35.53, 35.54, 35.73, 35.92, 35.93, 35.94, 35.95, 38.95, 39.65, 39.95, 42.23, 44.62, 44.63, 44.65, 44.66, 45.33, 46.74, 46.76, 46.85, 46.93, 46.94, 50.22, 51.31, 51.32, 51.36, 51.37, 51.39, 53.80, 53.81, 54.61, 54.62, 54.71, 54.93, 54.94, 54.95, 54.98, 55.01, 55.02, 55.12, 55.82, 55.93, 56.83, 56.84, 57.82, 57.83, 57.84, 57.86, 57.87, 57.89, 58.42, 58.43, 81.91, 86.06, 86.07, 89.32, 89.37, 89.38, 89.50, 96.06, 96.07, 96.08, 96.24, 96.34, 96.35, 96.56, 96.57, 96.70, 96.72, 97.23, 97.37, 97.39, 97.51, 97.87, 97.89, 99.15)

After these discharges were selected, they were unduplicated to count the number of children in a year with one or more discharges, rather than the number of discharges. The hospital discharge data base does not contain explicit information that identifies individuals (such as name or Social Security number), so we had to unduplicate the discharges using a combination of each child's date of birth, gender, and an insurance ID number. In addition to counting the number of children who are medically fragile and their discharges, we profiled the hospital charges for the hospitalizations where these procedures were performed.

An advantage of the hospital discharge data base for identifying children who are medically fragile is that it covers the vast majority of North Carolina children and all sources of payment. A disadvantage is that it covers only inpatient hospital discharges,

so that a child who is medically fragile would not be identified if he/she was not hospitalized during the year with one of the specified procedures.

North Carolina's Medicaid paid claims data base captures information on all health care services provided to persons enrolled in Medicaid. This data base includes information on medical services received outside of North Carolina. We selected paid claims records for calendar year 2002 for North Carolina resident children ages 0-4 who had one or more of 79 specific CPT (Current Procedural Terminology) procedure codes or one or more of 26 specific DME (Durable Medical Equipment) codes. Again, Dr. Brunssen chose these codes in consultation with her colleagues. Tables 2 and 3 show the top ten CPT and DME categories, ranked by the number of children in the data base who had a paid claim with the code. At the bottom of these tables

Table 2: Top Ten of 79 Procedures (with CPT Code) Used to Identify Children Ages 0-4 Who Are Medically Fragile in North Carolina in 2002 Who Were Enrolled in Medicaid*

Procedure	CPT Code
1. Insertion of implantable venous access port	36533
2. Change of gastrostomy tube	43760
3. Removal of implantable venous access port	36535
4. Esophagogastric fundoplasty	43324
5. Introduction of long gastrointestinal tube	74340,44500
6. Temporary opening of stomach	43830
7. Percutaneous placement gastrostomy tube	43750
8. Replacement of brain cavity shunt	62258
9. Replacement or irrigation, ventricular catheter	62225
10. Tracheostomy under two years	31601

*Based on the number of children who had a paid claim with the code.

Note: The codes below are in frequency order; the top 10 procedures (above) identify more than 70% of all of the children identified through these 79 procedure codes.

(All 79 CPT procedure codes: 36533, 43760, 36535, 43324, 74340, 44500, 43830, 43750, 62258, 62225, 31601, 31600, 90945, 31502, 43280, 44125, 44310, 33960, 43832, 43870, 33961, 49606, 90947, 31610, 36534, 43312, 44144, 43456, 33200, 63706, 90918, 90923, 31820, 43880, 61215, 90922, 33615, 43450, 47700, 47701, 47780, 33201, 43314, 43325, 43752, 90937, 31630, 31825, 33210, 33236, 33608, 33776, 33779, 33945, 43820, 44015, 44160, 47135, 49425, 31613, 31760, 33213, 33218, 33610, 33660, 33771, 33786, 43352, 43360, 43425, 43453, 43860, 44150, 44201, 44373 47120, 47122, 90920, 90925)

Table 3: Top Ten of 26 Durable Medical Equipment Items (with Code) Used to Identify Children Ages 0-4 Who Are Medically Fragile in North Carolina in 2002 Who Were Enrolled in Medicaid*

Item	DME Code
1. Enteral feeding supply kit, pump fed – daily	B4035
2. Enteral infusion pump – with alarm	B9002
3. Low profile gastrostomy kit	W4210
4. Tracheal suction catheter, any type	A4624
5. Suction pump, home model, portable	E0600
6. Tracheostomy or laryngectomy tube	A4622
7. Enteral feeding supply kit, syringe – monthly	B4034
8. Humid vents	W4045
9. Compressor, air power not self contained/cyln drive	E0565
10. Tracheotomy mask or collar	A4621

*Based on the number of children who had a paid claim with the code.

Note: The codes below are in frequency order; the top 10 items (above) identify more than 85% of all of the children identified through these 26 DME codes.

(All 26 DME codes: B4035, B9002, W4210, A4624, E0600, A4622, B4034, W4045, E0565, A4621, B4084, A4629, B9004, E0781, B4036, A4618, A4625, E0450, E0441, B4081, W4004, W4116, B9006, A4483, A4613, E0601)

are lists of all of the medical procedure and durable medical equipment categories used to identify the children who are medically fragile in the Medicaid data base.

The paid claims were unduplicated to count the number of children in 2002 with one or more of the CPT and/or DME codes. The Medicaid data base does contain a Medicaid ID number for each enrollee that is included on all paid claims records. The Medicaid ID numbers for these children were used to select paid claims for **all** medical services for the children during 2002, not just the claims with the specific CPT or DME codes. This allowed us to portray the total utilization and amounts paid by Medicaid during the year for these children who are medically fragile. Also, we selected a random sample of children ages 0-4 enrolled in Medicaid who received a Health Check (EPSDT/well-child care) visit during 2002 and compared their average

Medicaid expenditures with the average expenditures for the children who are medically fragile.

An advantage of the Medicaid paid claims data base for identifying children who are medically fragile is that it provides information about all medical services, not just hospitalizations. A disadvantage is that it provides information only about children enrolled in Medicaid.

Results

Table 4 shows the hospital discharge data results. In 2002, 1,811 children ages 0-4 in North Carolina were identified as medically fragile, based on having one or more of the 176 procedures during an inpatient hospitalization. More than 60 percent of these children were under age 1. These 1,811 children represented 0.32 percent of all children in

Table 4: Estimated 2002 Number of Children Ages 0-4 in North Carolina Who Are Medically Fragile with Percentage by Age and Expected Source of Payment*

	Number	Percentage
Total	1,811	100.0
Age		
Less than 1 year	1,137	62.8
1 year old	283	15.6
2 years old	171	9.4
3 years old	132	7.3
4 years old	88	4.9
Expected Source of Payment		
Medicaid	975	53.8
Medicare	3	0.2
Other government	102	5.6
HMO	219	12.1
Other private insurance	480	26.5
Self pay	32	1.8

*Estimates are based on the number of children who had one or more hospital discharge records during 2002 with the selected ICD-9-CM principal procedure codes.

North Carolina ages 0-4 in 2002. This percentage is substantially higher than the percentages from the two studies cited here,^{5,6} despite being based only on hospitalization data.

Table 4 also shows the results broken out by payment source. In 2002, 54 percent of the children who were hospitalized had Medicaid as the expected source of payment.

For the 1,811 children in 2002, there were 2,129 hospital discharges with one or more of the selected procedures, or an average of 1.2 discharges for each child defined as medically fragile. The total hospital charges for the 1,811 children during 2002 were \$109.4 million, with the average charges per discharge being \$51,386. This calculates to \$60,409

of charges for each child who is medically fragile, just for inpatient hospital services involving these specific procedures in 2002.

The selection of the 2002 Medicaid paid claims resulted in an estimate of 1,126 children who were medically fragile, i.e., those who had one or more paid claims during the year with the specific CPT and/or DME codes. These 1,126 children represented 0.44 percent of all children ages 0-4 who were enrolled in Medicaid in 2002. This percentage may be higher than that found using the hospital discharge data because: 1) we searched claims for all medical services including claims for durable medical equipment, not just claims for hospitalizations; and 2) children enrolled in Medicaid are at

higher medical risk than the total population of children in North Carolina.

We then used these 1,126 unique Medicaid ID numbers to extract **all** paid claims for these children during 2002. We found 167,486 claims for these children, with a total amount paid by Medicaid of \$82.9 million. The average number of paid claims per child was 149. The average amount paid per claim was \$495 and the average amount paid per child during 2002 was \$73,669. The \$82.9 million of Medicaid expenditures for the children who are medically fragile represents 13.9 percent of the \$598 million spent by Medicaid in 2002 for all medical services for all children ages 0-4.

Table 5 shows the expenditure results broken out by Medicaid claim type. Medical (primarily physician) claims represented 69 percent of the total claims during 2002 for these children defined as medically fragile. The second largest number of claims was for prescription drugs, which accounted for 17 percent of the total. Inpatient hospitalizations accounted for a small percentage of the total claims, but nearly half of the total Medicaid expenditures – more than \$40 million during 2002. There

was an average of two hospitalizations per child during the year.

The 2,135 hospitalizations of these 1,126 children who are medically fragile and enrolled in Medicaid compares to 2,129 hospital discharges for the 1,811 children who are medically fragile identified from the statewide hospital discharge data base. But one difference is that the Medicaid data represent **all** hospitalizations for these children, while the hospital discharge data are only for the hospitalizations involving the specific ICD-9-CM principal procedures used to identify the children as medically fragile.

The average amount paid by Medicaid for an inpatient hospital claim was \$18,829. This is much lower than the figure of \$51,384 derived from the hospital discharge data. This difference could be explained in at least two ways: 1) the Medicaid data show the average amount **paid** by Medicaid, while the hospital discharge data contain only the amount **charged** by the hospital; and 2) the hospital discharge data are only for those hospitalizations involving the complicated procedures used to identify the children as medically fragile (the top ten are

Table 5: Total Use of Medicaid Services During 2002 for the 1,126 Children Ages 0-4 Who Were Identified as Medically Fragile, by Claim Type

	Number of Claims	Average Number of Claims per Child	Total Amount Paid by Medicaid	Average Amount Paid per Claim
Total Claim Type	167,486	149	\$82.9 million	\$495
Medical	115,248	102	\$22.2 million	\$193
Home Health	7,368	7	\$12.2 million	\$1,656
Outpatient	11,110	10	\$4.2 million	\$378
Inpatient	2,135	2	\$40.2 million	\$18,829
Dental	287	0.25	\$36,700	\$128
Health Check	1,431	1	\$111,200	\$78
Prescription Drug	28,478	25	\$3 million	\$105
All Other	1,429	1	\$952,100	\$666

Table 6: Total Use of Medicaid Services During 2002: Comparison of Children Ages 0-4 Who Are Medically Fragile with a Random Sample of Children Ages 0-4 with Health Check (ESPDT/Well-Child Care) Visits

	Children Who Are Medically Fragile	Random Sample of Children with Health Check Visits
Number of Children	1,126	1,000
Number of Claims	167,486	37,508
Average Claims per Child	149	38
Total Amount Paid by Medicaid	\$82.9 million	\$2 million
Average Amount Paid per Claim	\$495	\$54
Average Amount Paid per Child	\$73,669	\$2,016

listed in Table 1), while the Medicaid data are for all hospitalizations for these children.

Table 6 shows the comparison between the 1,126 children who are medically fragile and a random sample of 1,000 children ages 0-4 enrolled in Medicaid who had a Health Check (EPSDT/well-child care) visit during 2002. The average number of claims per child was 149 for the children identified as medically fragile versus 38 for the comparison group. The average amount paid per claim was \$495 for the children who are medically fragile, compared to \$54 for the random sample. The average cost to the Medicaid program during 2002 for each child who is medically fragile was \$73,669, compared to \$2,016 for the sample of children receiving well-child care services.

Discussion

These results show that a very small number of children who are medically fragile use a very large amount of medical care services. The expenditures by Medicaid for these children represent 14 percent of the total expenditures by Medicaid for all services for all children ages 0-4. Prevention of even a few hospitalizations could save money for Medicaid and other health care payers.

An advantage of the methodology in this study is that it uses existing, statewide data bases to estimate the number of children in North Carolina who are medically fragile. Since special data collection efforts are not required, these results could be updated regularly, without extensive effort, to monitor trends and evaluate the results of interventions. These methods could serve as a model for similar estimation efforts in other states.

With a unique patient ID number included on each paid claim, we were able to use the Medicaid data to profile the total medical care utilization for these children who are medically fragile. This approach could also be used with paid claims data sets for other health insurance organizations.

The estimates of the number of children who are medically fragile in North Carolina are roughly consistent between the hospital discharge data and the Medicaid data. We estimated from the hospital discharge data that there were 975 children who are medically fragile in 2002 who had Medicaid as the expected source of payment for the hospital services. The Medicaid paid claims data, which cast a wider net by capturing all types of medical services, showed 1,126 children who are medically fragile enrolled in Medicaid during the same year.

We noted before that the Medicaid cost per hospitalization was much lower than that shown in the statewide hospital discharge data base, because the former represents payments and latter represents charges and because the hospital discharge data are only for those hospitalizations involving the complicated procedures used to identify the children as medically fragile. In addition, the Medicaid paid amount underrepresents the true cost to the Medicaid program because it does not include “disproportionate share” payments made to hospitals by Medicaid outside of the normal claims payment process.

The results from this study may over-represent to some degree the number of children who are long-term medically fragile because it includes all children from birth through age four who had the selected procedure and/or durable medical equipment codes. In the Massachusetts study, the survey began with children at least three months old “to exclude children placed transiently on devices in the newborn period.”⁶

Children in North Carolina who were identified as medically fragile and who subsequently died were included in the results presented here. We were not able to track mortality through the hospital discharge data unless the patient died in the hospital. In the Medicaid data set, there is a death indicator in the enrollment records. We found that, of the 1,126 children identified from the 2002 Medicaid data, 74 died at some time during 2002. This represents a mortality rate of 65.7 per 1,000 children (6.6%), much higher than the 2002 overall infant mortality rate for North Carolina of 8.2 infant deaths per 1,000 live births. In addition, 49 of these 1,126 children died during 2003 and part of 2004. We did not assess the net effect of including the 2002 data on medical care costs for the children who died. Death shortens the period during

which the children incur medical care costs, but these children were also likely to be very sick and incur high medical care costs while they were still alive.

The large majority of these children who are medically fragile are cared for in their home,¹ and parents must often quit work to take on caregiver responsibilities. Medical child care facilities could provide some of these children with the necessary care that they need during the work day, allow parents to return to work, and provide families with the emotional and physical break that they need to cope with the high demands that come with the care of their child. These facilities also provide daily medical and developmental care for children with complex medical conditions, as well as parental training. As a result, these facilities can help medical care systems, such as Medicaid, to better manage health care costs, particularly by reducing emergency room and hospital utilization.

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Note: Paul Buescher and Tim Whitmire are with the State Center for Health Statistics. Susan Brunssen is with the School of Nursing at the University of North Carolina at Chapel Hill. Deborah Nelson is with Nelson, Radley, and Finch Consulting. Eleanor Howell is with the Early Intervention Branch and Kathy Kluttz-Hile is with the Children and Youth Branch of the North Carolina Division of Public Health.

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