Matern Child Health J (2006) 10:461–466
DOI 10.1007/s10995-006-0081-3

ORIGINAL PAPER

Children Who Are Medically Fragile in North Carolina: Using Medicaid Data to Estimate Prevalence and Medical Care Costs in 2004

Paul A. Buescher · J. Timothy Whitmire ·
Susan Brunssen · Catherine E. Kluttz-Hile

Abstract *Objectives*: The purpose of this paper is to demonstrate a method of using medical insurance paid claims and enrollment data to estimate the prevalence of selected health conditions in a population and to profile associated medical care costs. The examples presented here use North Carolina Medicaid data to produce estimates for children ages 0–19 who are medically fragile. These children with serious health conditions are a small subset of all children with special health care needs. *Methods*: The children who are medically fragile were identified through selected procedure and durable medical equipment codes. We profiled the expenditures for all medical services provided to these children during 2004. *Results*: 1,914 children ages 0–19 enrolled in Medicaid were identified as medically fragile (0.22 percent). The amount paid by Medicaid for these children during 2004 for all medical services was $133.8 million, or $69,906 per child. By comparison, the average expenditure by Medicaid during 2004 for a randomly selected group of children receiving well-child care visits was $3,181 per child. The $133.8 million of Medicaid expenditures for the children who are medically fragile represents 6.8 percent of the nearly $2 billion spent by Medicaid in 2004 for all medical services for all children ages 0–19. *Conclusions*: This study presents a standard methodology to identify children with specific health conditions and describe their medical care costs. Our example uses Medicaid claims and enrollment data to measure prevalence and costs among children who are medically fragile. This approach could be replicated for other health care payer data bases and also in other geographic areas.

Keywords Children with special health care needs · Medically fragile children · Medical care costs · Medicaid · Population prevalence

Introduction

The purpose of this paper is to demonstrate a method of using medical insurance paid claims and enrollment data to estimate the prevalence of selected health conditions in a population and to profile associated medical care costs. The examples presented here use North Carolina Medicaid data to produce estimates for children in this low-income population who are medically fragile. These children with serious health conditions are a small subset of all children with special health care needs.

Estimating the number of children with special health care needs is important for planning programs and services for these children. Previous estimates of the percentage of children with special health care needs have varied widely, depending on the definition used [1, 2]. Based on an inclusive definition developed by the federal Maternal and Child Health Bureau [3], an estimated 14 percent of North Carolina children ages 0–17 have special health care needs [4]. There is of course a continuum of impact of the underlying health conditions. The percentage of children who experience

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P. A. Buescher (✉) · J. T. Whitmire
State Center for Health Statistics,
North Carolina Division of Public Health,
1908 Mail Service Center, Raleigh, NC 27699-1908
e-mail: paul.buescher@ncmail.net
e-mail: tim.whitmire@ncmail.net

C. E. Kluttz-Hile
Murdoch Center, North Carolina Division of Mental
Health, 1600 E. C Street, Butner, NC 27522

S. Brunssen
School of Nursing, University of North Carolina at Chapel Hill,
Chapel Hill, NC 27599-7460
e-mail: brunssen@email.unc.edu

limitations in social role activities, such as school or play, has been estimated at approximately 7 percent nationally [2, 5]. Approximately three percent of North Carolina children have a special health care need that affects their activities usually, always, or a great deal [4]. Less than one percent of children experience a need for assistance or special equipment in conducting the activities of daily living, such as eating, bathing, or dressing [1, 2, 5].

While no set definition exists, children who are medically fragile have very serious health problems and must often depend on technology for vital functions. They represent a small proportion of all children with special health care needs. Yet this small group of children accounts for a relatively large proportion of total Medicaid expenditures for children in North Carolina.

Advances in medical knowledge and technology have made it possible for infants born with major birth defects or other serious health problems, including the consequences of extreme prematurity, to live past infancy. These surviving infants sometimes have serious and complicated chronic conditions requiring intense monitoring of physiological status, ongoing medical treatment, and/or technology assistance that may last for years [6, 7].

Few previous studies have attempted to estimate the population prevalence of children who are medically fragile. Pierce *et al.* [8] conducted an analysis of other studies and suggested that approximately 0.10 percent of the total population of children are medically fragile or technology dependent. A 1990 study in Massachusetts [9] found approximately 2,200 children in the state, ages three months to 18 years, assisted by various forms of technology (e.g., respirators, ostomies, dialysis, etc.). This number represented 0.16 percent of all children in the state in this age range, consistent with the estimate of Pierce *et al.* [8]. However, the Massachusetts study relied on a special survey of medical and educational professionals, who were asked to supply information on each child known to them who was assisted by medical technology. A list of unique cases was generated after checking for duplicate reporting. While highly specific, the Massachusetts approach would be relatively expensive and time-consuming.

The present study uses existing statewide Medicaid data to estimate the number of children ages 0–19 who are medically fragile in North Carolina and their medical care costs. Since these results apply only to the Medicaid population, they are not representative of all children in North Carolina. But the method presented here could be applied to other populations for which medical insurance paid claims and enrollment data are available. An advantage of this general approach is that special data collection efforts are not required, and the results can be updated regularly without extensive effort to monitor trends and evaluate the results of interventions. This methodology could also be applied in other state or local geographic areas.

Methods

Definition of study population

North Carolina's Medicaid paid claims database captures information on all health care services provided to persons enrolled in Medicaid. This database includes information on medical services received outside of North Carolina. Our approach was to select certain CPT (Current Procedural Terminology) codes and DME (durable medical equipment) codes that would identify children with serious long-term medical problems. We chose primarily procedure and durable medical equipment codes that indicate a need for ongoing assistance with feeding, respiration, digestion, or excretion.

We considered using diagnosis codes to identify this population, but it is very difficult to determine impact from the diagnosis alone [10]. Our approach of using procedure and durable medical equipment codes targets the consequences of childhood health conditions. A variety of diagnoses and health conditions could lead to the need for a given medical procedure or the use of a specific piece of equipment. This method is consistent with a non-categorical approach to identifying children with chronic health conditions, which stresses the consequences of health conditions, such as level of functioning or need for assistance [1, 10, 11].

We selected paid claims records for calendar year 2004 for North Carolina resident children ages three months through 19 years who had one or more of 79 specific CPT procedure codes or one or more of 26 specific DME codes. To avoid including children who were physically disabled but not medically fragile, codes associated with management of physical disabilities (e.g. wheelchairs) were not selected. These procedure and DME codes result in a rough estimation of children enrolled in Medicaid who are medically fragile, and the exact codes used could certainly be debated. This process illustrates our general method of using paid claims and enrollment data to estimate prevalence and medical care costs for selected conditions. This method could also be applied to children (or adults) with other health conditions, for example asthma [12] or diabetes.

Table 1 shows the ten most frequent CPT and DME categories, ranked by the number of children in the database (ages 0–19) who had a paid claim with that code. These ten codes identify more than 65 percent of all of the children identified through the 79 procedure codes and more than 85 percent of all of the children identified through the 26 DME codes. Table 1 includes a listing of all of the CPT and DME

Table 1 Ten most frequent CPT and DME codes used to identify Medicaid-enrolled children ages 0–19 as medically fragile in North Carolina in 2004

Procedure	CPT Code[a]
1. Change of gastrostomy tube	43760
2. Introduction of long gastrointestinal tube	73430,44500
3. Esophagogastric fundoplasty	43324
4. Temporary opening of stomach	43830
5. Tracheotomy tube change prior to establishment of fistula tract	31502
6. Enterectomy, resection of small intestine; single resection and anastomosis with enterostomy	44125
7. Incision of windpipe	31600
8. Laparoscopy, surgical esophagogastric fundoplasty	43280
9. Dialysis procedure other than hemodialysis	90945
10. Replace brain cavity shunt	62258

Item	DME Code[b]
1. Enteral feeding supply kit, pump fed – daily	B4035
2. Low profile gastrostomy kit	W4210
3. Enteral infusion pump – with alarm	B9002
4. Tracheal suction catheter, any type	A4624
5. Enteral feeding supply kit, syringe – monthly	B4034
6. Suction pump, home model, portable	E0600
7. Moisture exchanger, disposable for use with invasive mech ventilation	A4483
8. Gastrostomy/jejunostomy tube	B4084
9. Tracheostomy care kit for established tracheostomy	A4629
10. Compressor, air power not self contained/cyln drive	E0565

[a] The other 68 CPT procedure codes, in frequency order: 62225, 31601, 36533, 43870, 33960, 49606, 43832, 44310, 43750, 90920, 36535, 33961, 90947, 43450, 31610, 44015, 44160, 90937, 43314, 47780, 47135, 61215, 33200, 43880, 44144, 31825, 33201, 63706, 47120, 47701, 31613, 31820, 33945, 43453, 43456, 90918, 90922, 90923, 33210, 33608, 43312, 43820, 44150, 47700, 31630, 33213, 33660, 36534, 44373, 33615, 43325, 43752, 33236, 33776, 33779, 49425, 31760, 33218, 33610, 33771, 33786, 43352, 43360, 43425, 43860, 44201, 47122, 90925

[b] The other 16 DME codes, in frequency order: E0601, E0781, B4036, E0450, B4081, A4625, B9004, A4618, A4622, A4621, B9006, E0441, W4045, W4004, W4116, A4613

codes used to identify the children who are medically fragile in the Medicaid data base. In 2004 in North Carolina, no claims were paid with the last 19 CPT codes or the last four DME codes listed in the table. The ten most frequent codes for each of four age groups were very similar to the ten codes shown in Table 1 for the entire 0–19 population.

Exclusions

Children who had paid claims with one of these CPT or DME codes only when they were less than three months old were excluded from the study. This approach is consistent with the Massachusetts study, where the survey began with children at least three months old "to exclude children placed transiently on devices in the newborn period" [9].

Children in North Carolina who were identified as medically fragile and who died in 2004 were not excluded from the results presented here.

Analysis

The paid claims were unduplicated to count the number of children in 2004 with one or more of the CPT and/or DME codes. The Medicaid database contains a unique 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 2004, not just the claims with the selected CPT or DME codes. This allowed us to portray the total utilization of services and amounts paid by Medicaid during the year for these children who are medically fragile. If a child was identified as medically fragile by having a claim with one of the selected CPT or DME codes after three months of age, we included all of that child's 2004 medical care costs, even for medical services occurring earlier than three months of age.

The data on children who are medically fragile are presented separately for four age groups: 0–4, 5–9, 10–14, and 15–19. For ease of presentation, the youngest group is referred to as "0–4," even though children who had an identifying claim only when they were less than three months old are not included. Prevalence estimates, total expenditures, average total expenditures per child, expenditures by major claim types, and average expenditures per claim are presented for each age group.

Finally, we selected for each age group an equal-size random sample of children enrolled in Medicaid who received a Health Check (EPSDT/well-child care) visit during 2004. This comparison group represents children enrolled in Medicaid who are receiving at least some basic preventive services and thus are participating in the health care system. This group may not be representative of all children enrolled in Medicaid. We compared the average expenditures per child for the children identified as medically fragile with the average expenditures for this randomly selected comparison group.

Results

The selection of the 2004 Medicaid paid claims resulted in an estimate of 1,914 children who are medically fragile, i.e., those who had one or more paid claims during the year with the selected CPT and/or DME codes. These 1,914 children represented 0.22 percent of all children ages 0–19 who were enrolled in Medicaid in 2004. Table 2 shows the

Table 2 Number and percent of children ages 0–19 enrolled in Medicaid in North Carolina in 2004 who were identified as medically fragile, by age group

	Number who are medically fragile[a]	Percent of all children enrolled in Medicaid (%)
Total	1,914	0.22
Age group		
0–4	880	0.26
5–9	471	0.23
10–14	403	0.22
15–19	384	0.27

[a]Note: Numbers for the four age groups add to more than the total because some children who aged from one group to the next during the year had claims in both age groups. Children are not duplicated in the "Total" row

Table 4 Total use of Medicaid services during 2004 for the children ages 0–19 who were identified as medically fragile, by age group

	Number of claims	Total paid by Medicaid (millions)	Average paid per claim
Total	324,715	$133.8	$412
Claim type			
Medical	213,071	$60.8	$285
Home health	11,501	$13.8	$1,200
Outpatient	15,725	$5.9	$375
Inpatient	2,471	$39.7	$16,066
Prescription drug	75,197	$9.7	$129
Nursing home	1,961	$3.4	$1,734
All other	4,789	$0.5	$104

numbers of children who are medically fragile by age group and the percentage that they represent of all children in the age group who were enrolled in Medicaid. In addition to the 880 children ages 0–4 who were identified as medically fragile, there were 203 children who had claims in 2004 with one or more of the CPT/DME codes only when they were less than three months old; these children are excluded from the study results.

Using these 1,914 unique Medicaid ID numbers to extract all paid claims during 2004, we found 324,715 claims for these children who were identified as medically fragile, with a total amount paid by Medicaid of $133.8 million. The average number of paid claims per child during 2004 was 170. The average amount paid per child during 2004 was $69,906. The $133.8 million of Medicaid expenditures for the children who are medically fragile represents 6.8 percent of the nearly $2 billion spent by Medicaid in 2004 for all medical services for all children ages 0–19. Table 3 shows the information broken out for each of the four age groups. Use of medical services by these children was highest in the youngest age group.

Table 4 shows the expenditure results for ages 0–19 broken out by Medicaid claim type. Medical (primarily physician) claims represented 66 percent of the total claims during 2004 for these children defined as medically fragile. The second largest number of claims was for prescription drugs, which accounted for 23 percent of the total. Inpatient hospitalizations accounted for a small percentage of the total claims, but nearly one-third of the total Medicaid expenditures – $39.7 million during 2004. The average amount paid by Medicaid for an inpatient hospital claim was more than $16,000. Of the 1,914 children who were identified as medically fragile, 1,037 or 54 percent were hospitalized one or more times during 2004. Included in the $5.9 million of expenditures for outpatient services is $406,000 paid for emergency room visits. Of the 1,914 children, 965 (or 50 percent) went to the emergency room one or more times during 2004.

Table 3 Total use of Medicaid services during 2004 for the children ages 0–19 who were identified as medically fragile, by age group

	Number of claims	Total paid by Medicaid (millions)	Average paid per child	Percent of total paid by Medicaid for all children (%)
Total	324,715	$133.8	$69,906	6.8
Age group				
0–4	143,840	$63.3	$71,932	9.8
5–9	70,243	$24.8	$52,654	7.6
10–14	57,901	$24.1	$59,801	4.9
15–19	52,731	$21.6	$56,250	4.3

Table 5 shows the comparison, by age group, between the children who are medically fragile and a random sample of the same size of children enrolled in Medicaid who had a Health Check visit during 2004. For the age 0–19 group as a whole, the average cost to the Medicaid program during 2004 for each child who is medically fragile was $69,906, compared to $3,159 for the sample of children receiving well-child care services. Costs for the medically fragile group were highest in the 0–4 age group. In contrast, among the Health Check samples used for comparison, average Medicaid expenditures were highest for the age 15–19 age group ($6,435) and lowest for the 5–9 age group ($1,980).

Using a death indicator in the Medicaid enrollment records, we found that 76 of the 1,914 children identified as medically fragile from the 2004 Medicaid data died at some time during 2004. Twenty-three of these 76 deaths occurred to children under one year of age. For the 0–19 age group, this represents a mortality rate of 3,971 deaths per 100,000 children (4.0 percent). This high death rate reflects the ongoing physiological instability of the children who are medically fragile across all age groups. Their death rate is much higher than the overall child mortality rate for North Carolina of 102 deaths per 100,000 population for ages 0–19

Table 5 Total use of Medicaid services during 2004: comparison of children ages 0–19 years identified as medically fragile with a same-size random sample of children with health check (ESPDT/well-child care) visits

	Children identified as medically fragile	Random sample of children with Health Check visits
Ages 0–19		
Number of claims	324,715	95,811
Total paid by Medicaid (millions)	$133.8	$6.8
Average paid per child	$69,906	$3,181
Ages 0–4		
Number of claims	143,840	34,415
Total paid by Medicaid (millions)	$63.3	$1.9
Average paid per child	$71,932	$2,125
Ages 5–9		
Number of claims	70,243	18,854
Total paid by Medicaid (millions)	$24.8	$0.9
Average paid per child	$52,654	$1,980
Ages 10–14		
Number of claims	57,901	19,969
Total paid by Medicaid (millions)	$24.1	$1.5
Average per child	$59,801	$3,674
Ages 15–19		
Number of claims	52,731	22,573
Total paid by Medicaid (millions)	$21.6	$2.5
Average paid per child	$56,250	$6,435

in 2003. We did not assess the net effect of including the 2004 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.

Discussion

These results show that approximately 0.25 percent of children enrolled in Medicaid in North Carolina in 2004 were medically fragile, according to our specific definition using procedure and durable medical equipment codes. This percentage is consistent with the percentages from the two studies cited earlier [8, 9]. The results also show that the 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 nearly 7 percent of the total expenditures by Medicaid for all services for all children ages 0–19. Understanding the cost of care is an important issue in designing and delivering services for children with special health care needs.

Of the 1,914 children in this study who were identified as medically fragile, 80 percent were enrolled in Medicaid for the full 12 months of 2004 and 95 percent were enrolled for 6 or more months during the year. Thus, the utilization and cost data shown here for services paid by Medicaid represent a large proportion of the total health care utilization and costs for these children.

In 2004, children younger than age 1 were eligible for Medicaid if the family's income was less than 185 percent of the federal poverty level. For children ages 1–5, the eligibility level was 133 percent of the federal poverty level and for children age 6 and older it was 100 percent. Thus the socioeconomic status of the children will not be exactly comparable across the four age groups used here. However, this attrition might affect the Health Check comparison group more than the children who are medically fragile, many of whom would qualify for Medicaid based on disability and not only financial need.

A limitation of using the Medicaid paid claims is that they represent only a low-income subset of the population, not all children in North Carolina. Also, there are sometimes coding and other errors in the data, particularly for diagnoses [13]. We used the procedure and DME codes, which are more likely to be accurate since they are the basis for payments to providers. However, providers may sometimes submit procedure codes on billings to Medicaid that maximize their reimbursement.

Our definition of children who are medically fragile is not exact. We identified these children primarily through selected procedure and durable medical equipment codes that indicate an ongoing need for assistance with feeding, respiration, digestion, or excretion. A different set of codes could be chosen for other child health measurement projects. Also, diagnosis and/or drug codes could be used to define some populations of interest [12].

This study demonstrates how existing, widely available statewide data can be used to estimate the number of children with selected health conditions and their medical care costs. 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 programmatic interventions. These methods could serve as a model for similar estimation efforts for other states and also for sub-state geographic areas. 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 with serious health problems. This approach could also be used with paid claims and enrollment data for health insurance organizations other than Medicaid.

Acknowledgment The authors would like to thank Kathryn Kerkering, M.D., of the Brody School of Medicine at East Carolina University, for help in developing the methodology for this paper.

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