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# A Profile of Children with Complex Chronic Conditions at End of Life among Medicaid Beneficiaries: Implications for Health Care Reform

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## Abstract

**Background:** As the United States braces for full implementation of health care reform, the eyes of the nation are on Medicaid. The large number of newly eligible Medicaid beneficiaries may challenge health care resources and ultimately impact quality of care. This is a special concern among current Medicaid beneficiaries such as children with complex chronic conditions (CCCs) who have significant health care needs, especially at end of life (EOL). Yet, a comprehensive profile of these children is lacking.

**Objective:** To understand the demographic and health characteristics, health care utilization, and expenditures among Medicaid children with CCCs at EOL.

**Methods:** Our study used a retrospective cohort design with data from the 2007 and 2008 California Medicaid data files. Descriptive statistics were used to profile children in the last year of life.

**Results:** We found a diverse group of children who suffered with serious, multiple chronic conditions, and who accessed comprehensive, multidisciplinary care. Most children had neuromuscular conditions (54%), cardiovascular conditions (46%), and cancer (30%). A majority (56%) had multiple CCCs. Children with CCCs received comprehensive care including hospital inpatient (67%), primary (82%), ancillary (87%), and other acute care services (83%); however, few children utilized hospice and home health care services (26%). Significant age differences existed among the children.

**Conclusions:** The current California Medicaid system appears to provide comprehensive care for children at EOL. The underutilization of hospice and home health services, however, represents an opportunity to improve the quality of EOL care while potentially reducing or remaining budget neutral.

## Introduction

AS THE UNITED STATES BRACES for the full implementation of health care reform, the eyes of the nation are on Medicaid.<sup>1</sup> The Medicaid program generally provides comprehensive and affordable health care for children and low-income adults and is jointly financed by federal and state government. Under the 2010 Patient Protection and Affordable Care Act (ACA), Medicaid coverage for individuals will be expanded and payment to providers modified.<sup>2</sup> In light of these Medicaid changes, concerns have been voiced about access to health care.<sup>1</sup> The large number of newly eligible Medicaid beneficiaries may challenge health care resources and ultimately impact quality of care. This is a special concern

among current Medicaid beneficiaries such as children with complex chronic conditions (CCCs) who have significant health care needs, especially at end of life (EOL).<sup>3</sup>

There are more than 100 pediatric deaths in the United States daily.<sup>4</sup> Although many deaths are attributable to accidents and injuries, health-related mortality remains significant and typically involves CCCs such as cancer, congenital anomalies, and circulatory disease.<sup>5,6</sup> In California, for example, CCCs are the leading cause of death among children and account for 70% of all pediatric deaths.<sup>7</sup> Previous studies have found that deaths among children with CCCs vary widely by type of health condition and age group.<sup>5,8,9</sup> The prevalence of children with CCCs in the inpatient hospital setting has increased,<sup>10,11</sup> and their EOL care in this setting is

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highly technical.<sup>12</sup> Accordingly, the average cost of health care services for these children ranges from \$62,000 to \$110,000 annually.<sup>13</sup>

Although existing literature provides knowledge about children with CCCs, a comprehensive profile of their demographic and health characteristics, health care utilization, and expenditures at EOL is lacking. This study begins to fill the gap by providing a foundational examination of their demographic and health characteristics, which will provide a more complete picture of some of the sickest children in our health care system. In addition, investigating the health care utilization and expenditures of children with CCCs will provide timely baseline information necessary for policy makers, as they evaluate the impact of the ACA and ensure quality of EOL care for Medicaid children in the future. Therefore, the purpose of this study was to understand the demographic and health characteristics, health care utilization, and expenditures among Medicaid children with CCCs at EOL.

## Methods

### Data sources

Administrative data in this retrospective cohort study were primarily drawn from the 2007 and 2008 California Medicaid program's Medicaid Analytic Extract (MAX) files. The MAX files were prepared by the Center for Medicare and Medicaid Services from data submitted electronically by all 50 states. The MAX Person Summary File combines eligibility information, summary claims, and payment data into one record per enrollee. Other linked MAX files, such as the Other Services file, provide detail data on services, payment, and diagnoses. MAX files only include fee-for-service (FFS) data; thus, services provided in managed-care delivery systems were excluded. We selected California because it has the largest number of children enrolled in Medicaid of any state: 4.4 million.<sup>14</sup> We used data from 2007 and 2008 because 2007 was the first year the MAX files included the Social Security Administration date of death and 2008 was the latest year for which data were available. Other data sources included the 2004 United States Department of Agriculture typology codes for metropolitan residential status that were linked to the Medicaid data by the child's residential Federal Information Processing Standard (FIPS) code.

### Sample

Children studied were those between the ages of 0 and 20 years, who died between January 1, 2007 and December 31, 2008, and were enrolled in the California Medicaid program for any part of their last year of life. Children were identified as having a CCC if they had a diagnosis of a neuromuscular, cardiovascular, respiratory, renal, gastrointestinal, hematologic, metabolic, congenital, or cancer health condition based on an *International Classification of Diseases, 9th Revision* (ICD-9-CM) code as recommended by Feudtner et al.<sup>8</sup> Duplicates and children who were not California residents were excluded from the sample. Our final sample size was 1423 children. The University of Tennessee at Knoxville Institutional Review Board approved this study.

### Measures

Demographic characteristics included age at death, gender, race/ethnicity, Medicaid eligibility type, private insurance

status, and location of residence. Health characteristics included a binary variable for each of the following CCC diagnosis categories in the last year of life: neuromuscular (brain/spinal cord malformation, intellectual disability, central nervous system [CNS] disease, cerebral palsy, epilepsy, and muscular dystrophy), cardiovascular (heart malformations, cardiomyopathies, and dysrhythmias), cancer, congenital anomalies (chromosomal abnormalities, bone/joint abnormalities, diaphragm/abdominal abnormalities, and other abnormalities), respiratory (respiratory malformations, chronic respiratory disease, and cystic fibrosis), gastrointestinal (congenital anomalies, liver disease, and inflammatory bowel disease), metabolic (amino acid, carbohydrate, lipid, storage disorders, and other disorders), hematologic (sickle cell disease, anemia, hereditary immunodeficiency, and human immunodeficiency virus [HIV]), and renal (congenital abnormalities and chronic renal failure). We also counted the number of CCCs for each child and categorized them from 1 to 4 and higher. Comorbidity was calculated with a weighted Charlson Comorbidity Index using ICD-9-CM codes. A weighted Charlson score of 3 or more reflects the presence of significant medical comorbidity.<sup>15</sup>

We created six binary measures for health care utilization by type of service<sup>16</sup>: hospital inpatient, prescription drugs, hospice/home health, primary care (i.e., physician, dental, clinic, and other practitioner—chiropractor, podiatrist, psychologist, and optometrist), other acute care (i.e., targeted case management, rehabilitation, private duty nursing, residential, psychiatric, therapy, and outpatient hospital), and ancillary care (i.e., transportation, equipment, lab/X-ray, personal care, and other services—prosthetics and eyeglasses). Health care expenditures were the sum of FFS payments to providers in the child's last year of life and were analyzed separately by service type categories. It is common for Medicaid enrollees to cycle on and off the program because of changes in their economic or personal circumstances, so expenditures were adjusted for the time in the Medicaid program during the last year of life. The expenditure estimates are presented as the average cost per month enrolled. All expenditure data were adjusted to 2007 dollars using the Consumer Price Index.

### Statistical analysis

The primary aim of our study was to profile children with CCCs at EOL. Descriptive statistics were calculated on demographic and health characteristics, health care utilization, and health care expenditures. Additionally, Pearson's  $\chi^2$  test for differences in proportions and analyses of variance (ANOVA) for differences in means were used to provide comparisons among pediatric age groups. We present our results in the form of univariate distributions and means. Analyses were conducted using Stata version 11.0 (StataCorp LP, College Station, TX).

## Results

Table 1 summarizes the demographics of the sample. Boys (52%) and girls (48%) were evenly represented with consistent distribution across the age groups. There were no significant differences between gender by age. The largest racial or ethnic segment was Hispanic (38%), followed by other races and ethnicities (37%) and white non-Hispanics (17%). Children under 1 year of age or 15 to 20 years old were more likely to be

TABLE 1. DEMOGRAPHIC AND HEALTH CHARACTERISTICS OF CHILDREN WITH COMPLEX CHRONIC CONDITIONS AT END OF LIFE BY AGE GROUP

Characteristics	All children (n=1423)	<1 year (n=133)	1–5 years (n=463)	6–14 years (n=412)	15–20 years (n=415)	P value
<b>Demographic characteristics</b>						
Gender						
Male (%)	52.42	53.38	48.81	52.43	56.14	0.189
Female (%)	47.58	46.62	51.19	47.57	43.86	
Race/ethnicity						
White non-Hispanic (%)	16.58	9.77	9.29	17.72	25.78	0.001
Black non-Hispanic (%)	7.94	10.53	6.26	7.52	9.40	
Hispanic (%)	38.16	42.11	31.32	35.92	46.75	
Other (%)	37.32	37.59	53.13	38.84	18.07	
Medicaid eligibility						
Disabled (%)	67.53	36.09	64.79	81.07	67.23	0.001
Nondisabled (%)	32.47	63.91	35.21	18.93	32.77	
Private insurance (%)	11.31	3.01	7.78	15.78	13.49	0.001
Residence						
Urban (%)	98.59	98.50	98.27	98.79	98.80	0.899
Rural (%)	1.41	1.50	1.73	1.21	1.20	
<b>Health characteristics</b>						
Complex chronic conditions (CCCs)						
Neuromuscular (%)	53.83	29.32	54.64	62.38	52.29	0.001
Cardiovascular (%)	46.38	75.19	59.61	28.88	39.76	0.001
Cancer (%)	29.87	7.52	23.97	37.14	36.39	0.001
Congenital (%)	22.84	29.32	34.34	18.93	11.81	0.001
Respiratory (%)	12.30	24.06	22.25	7.28	2.41	0.001
Gastrointestinal (%)	12.02	10.53	16.63	8.98	10.36	0.003
Metabolic (%)	10.40	7.52	12.10	8.74	11.08	0.257
Hematologic (%)	8.85	4.51	11.45	7.52	8.67	0.048
Renal (%)	4.08	4.51	9.50	1.00	1.20	0.001
Number of CCCs						
One CCC (%)	44.06	44.36	30.67	49.27	53.73	0.001
Two CCCs (%)	28.25	33.08	26.78	29.61	26.99	
Three CCCs (%)	15.95	12.03	20.52	14.56	13.49	
Four or more CCCs (%)	11.74	10.53	22.03	6.55	5.78	
Avg. Charlson Comorbidity Index	2.19	0.72	2.08	2.48	2.51	0.001

Hispanic (42%, 47%, respectively), and children aged 1 to 5 and 6 to 14 were more often from other races/ethnicities (53%, 39%, respectively). A majority of children were eligible for Medicaid through their disability status (68%). Infants were generally eligible for Medicaid because of their nondisability status (64%) compared with older children. Relatively few children received assistance from private health insurance (11%). It was rare for children younger than 6 to have private health insurance (3% for children less than 1 year, 8% for 1 to 5 years). The sample resided almost exclusively in urban counties (99%).

The sample was most often diagnosed with neuromuscular diseases (54%) and infrequently with renal problems (4%) (Table 1). A majority of infants under 1 year had cardiovascular conditions (75%), followed by congenital (29%), neuromuscular (29%), and respiratory (24%). The most common conditions among children 1 to 5 years old were cardiovascular (59%), neuromuscular (55%), congenital (34%), cancer (24%), and respiratory (22%). Neuromuscular (62%, 52%), cancer (37%, 36%), and cardiovascular (29%, 40%) were the most frequent CCCs of children 6 to 14 and 15 to 20 years old. Approximately 44% had one CCC, 28% had two CCCs, 16% had three CCCs, and 12% had four or more CCCs. Children aged 1 to 5 years averaged three CCCs. The average Charlson

Comorbidity Index value was 2.19, which indicates a relatively high level of comorbidity. The Charlson Comorbidity Index score varied significantly by age from 0.72 for infants under 1 year to more than 2.0 for children older than 1 year of age.

Table 2 indicates the utilization and expenditures for selected health care services. Total FFS payments in the last year of life averaged \$82,000 per child annually (data not shown). In keeping with this high level of spending, the sample was composed of heavy users of health care services. Service utilization was highest in ancillary (87%), acute (83%), and primary (82%) care services and lowest in hospice and home health care (26%). Hospital inpatient care and primary care services dominated health care spending for this group, comprising 82% of the expenditures.

Approximately two-thirds of the children in the sample were hospitalized in the last year of life with an average cost of \$10,753 per month, which is the highest spending category. Children under 6 years of age were slightly more likely to have been hospitalized (77% for ages less than 1 year, 75% for ages 1 to 5, 59% for ages 6 to 14, 62% for ages 15 to 20, respectively), and their expenditures were almost twice that of older children (\$15,630/month, \$13,545/month, \$8,436/month, and \$8,374/month, respectively). Although utilization of prescription

TABLE 2. HEALTH CARE UTILIZATION AND EXPENDITURES AMONG CHILDREN WITH COMPLEX CHRONIC CONDITIONS AT END OF LIFE BY AGE GROUP

Health care services	All children (n = 1423)	Under 1 year (n = 133)	1–5 years (n = 463)	6–14 years (n = 412)	15–20 years (n = 415)	P value
Hospital inpatient care						
Used services (%)	66.55	76.69	74.51	58.50	62.41	0.001
Avg. monthly expenditures	\$10,753	\$15,630	\$13,545	\$8,436	\$8,374	0.001
Prescription drugs						
Used services (%)	65.21	45.11	63.28	74.03	65.06	0.001
Avg. monthly expenditures	\$498	\$47	\$471	\$631	\$539	0.001
Hospice/Home health care						
Used services (%)	25.58	23.31	28.29	27.67	21.20	0.064
Avg. monthly expenditures	\$466	\$175	\$337	\$727	\$444	0.001
Primary care <sup>a</sup>						
Used services (%)	82.29	93.23	87.26	79.61	75.90	0.001
Avg. monthly expenditures	\$874	\$1,472	\$1,017	\$683	\$711	0.001
Other acute care <sup>b</sup>						
Used services (%)	83.13	81.20	85.53	87.62	76.63	0.001
Avg. monthly expenditures	\$803	\$1,327	\$884	\$828	\$519	0.001
Ancillary care <sup>c</sup>						
Used services (%)	87.42	84.96	86.83	90.05	86.27	0.265
Avg. monthly expenditures	\$751	\$297	\$569	\$927	\$923	0.001

<sup>a</sup>Primary care included physician, dental, clinic, and other practitioners (chiropractors, podiatrists, psychologists, and optometrists).

<sup>b</sup>Other acute care included targeted case management, rehabilitation, private duty nursing, residential, psychiatric, therapy, and outpatient hospital.

<sup>c</sup>Ancillary care included transportation, equipment, lab/X-ray, personal care, and other services (prosthetics and eyeglasses).

drugs was relatively high (65%), expenditures on prescription drugs were some of the lowest (\$498/month). Infants under 1 year of age were significantly less likely to utilize prescription drugs than were children over 1 year of age (45%, 63%, 74%, and 65%, respectively). Additionally, infant health care spending on prescription drugs was low compared with the other children (\$47, \$471, \$631, and \$539, respectively).

Hospice and home health services were the least utilized services and the smallest spending category. Only 26% of the sample used hospice or home health services with an average monthly cost of \$466, and there were no differences in utilization by age. Average monthly home health and hospice expenditures, however, varied significantly from \$727 per month for children 6 to 14 years old to \$175 per month for infants under 1 year old. The second highest expenditure category was primary care. More than 80% of children visited physicians, dentists, and other practitioners, and this care accounted for 6% of total spending. Children under 6 years old were significantly more likely to have used primary care services compared with the older age groups (93%, 87%, 80%, and 76%, respectively). Indeed, this group incurred twice the costs in primary care services as did the older children (\$1,472, \$1,017, \$683, and \$711, respectively).

After primary care services, expenditures for other acute care was the next largest spending category. More than 80% of children used other acute care services. The average spending on other acute care services was \$803 per month. Children 6 to 14 years old were more likely to use acute care services (88%), and children 15 to 20 years old were least likely to utilize these services (77%). However, infants under 1 year of age had the highest other acute care expenditures of any age group (\$1,327/month). Ancillary services were the most frequently utilized service (87%), and they cost approximately \$750 per month. Although there was no difference in utilization by age

group, the cost of ancillary services for children over 6 years of age was almost 3 times higher than for younger children.

## Discussion

The primary goal of our study was to provide a profile of the demographic and health characteristics, health care utilization, and expenditures of children with CCCs at EOL, and we sought to compare differences in these factors based on pediatric age groups. From the analysis of California's Medicaid data, we found a diverse group of children who suffered with serious, multiple chronic conditions, and who accessed comprehensive, multidisciplinary care.

Children with CCCs in the study were medically complex. Neuromuscular conditions such as intellectual disabilities, brain/spinal cord malformation, CNS disease, cerebral palsy, muscular dystrophy, and epilepsy were very prevalent among this group of children. Our results are consistent with other researchers who found that neuromuscular conditions were common among children with CCCs and reports that the number of children with neurodevelopment disabilities has climbed over the past decade to nearly 1 in 6.<sup>17,18</sup> In addition, these children suffered from multiple CCCs. We found that more than 50% of the children had two or more CCCs, which was higher than Feudtner et al. reported in their study of hospitalized children with CCCs.<sup>9</sup> These health findings suggest that children in our sample may be very medically fragile. Indeed, the nature of their impairments and the presence of multiple CCCs may complicate the care children receive at EOL. Children and their families may encounter communication issues with clinicians about medical decisions and care goals,<sup>19,20</sup> poor care coordination,<sup>21,22</sup> and problems with prognosis.<sup>23</sup> Therefore, it may be challenging for children with complicated disease processes to receive quality EOL care.

Children with CCCs generally received comprehensive care including hospital inpatient, primary, ancillary, and other acute care services; however, very few children utilized hospice and home health care services. Only 356 or 25% of children in the study accessed care designed to meet the physical and psychosocial needs of terminally ill children and their families. In a white paper produced by the Children's International Project on Palliative/Hospice Services (ChiPPS) for the National Hospice and Palliative Care Organization (NHPCO), experts in the field of pediatric, EOL care reported that less than 10% of children receive hospice care.<sup>24</sup> Others have drawn similar conclusions in studies of children with cancer and acquired immune deficiency syndrome (AIDS).<sup>25,26</sup> One possible reason for the low utilization may be families' acceptance of the child's prognosis. The impending death of a child may be difficult for families to acknowledge and thus may prevent the initiation of EOL care.<sup>27</sup> An alternative explanation may relate to clinicians' referral practices to pediatric hospice and home health care. Pediatric clinicians generally lack an understanding of and experience with pediatric EOL care. Most physicians have limited or no training in core EOL competencies,<sup>28,29</sup> less than 50% of residents are taught how to hold conversations about pediatric EOL,<sup>29</sup> and more than 25% of pediatricians do not even know whether local pediatric hospice services exist.<sup>30</sup> Finally, obtaining hospice and home health care may also depend on whether or not organizations provide care for children. Our previous research has shown that approximately two-thirds of California hospices and home health agencies do not provide pediatric EOL care, and the percentage of agencies providing care for children has declined from 40% in 2002 to 28% in 2008.<sup>31</sup> Thus, children with CCCs may not be receiving high-quality EOL care. Future research design should explore and clarify the influence of child demographic and health characteristics on EOL care utilization.

There are several limitations of this study to note including the lack of information on cause of death, symptoms, and family characteristics in the Medicaid files dataset. However, Medicaid paid claims require providers report data for reimbursement. As a result, there is an incentive for complete and accurate data.<sup>32</sup> The focus was on a sample of pediatric patients who were eligible for FFS Medicaid in California, so the findings are not generalizable. However, California has the largest population of children enrolled in Medicaid at 4.4 million and California Medicaid policies and practices are often a model for other states.<sup>14</sup> Finally, the use of a Medicaid dataset is a limitation because children less than 1 year of age may be less likely to have been enrolled in Medicaid prior to death, as previous studies have shown they have the highest mortality.<sup>4</sup>

Nevertheless, our data may contribute to current and future discussions regarding health policy for children with CCCs by advancing our knowledge and understanding of hospice and home health services for them, underscoring the relevance of recent policy efforts to update the Medicaid and Children's Health Insurance Benefit (CHIP) hospice benefit for children. Section 2302 Concurrent Care for Children became law with the passage of health care reform. Concurrent Care permits children on the Medicaid or CHIP hospice benefit to continue receiving treatments related to their terminal illness (e.g., chemotherapy, dialysis, antiretroviral regimens, and radiation).<sup>33</sup> The intent of health care reform was

to improve access to and ultimately quality of EOL care by eliminating a hospice eligibility criteria,<sup>34</sup> a need further supported by the results of this study, which indicate that prior to the ACA children generally did not utilize hospice and home health services at EOL. Due to the staggered implementation schedule of ACA provisions, future research might compare the influence of ACA 2302 with other health care reform provisions such as Medicaid expansion on access to hospice and home health care among children at EOL using longitudinal data. Our study provides critical baseline data for future research on the impact of health policy aimed at Medicaid and CHIP children. Therefore, the change in the federal law to allow concurrent curative care may be an important health care reform policy initiative aimed at improving the utilization and quality of care for children at EOL.

## Conclusion

This study is the first to profile children with CCCs in the last year of life. As states continue to be challenged to provide quality health care to a growing Medicaid population in spite of decreased allocation of resources and the nation prepares for full implementation of health care reform in 2014, this analysis is timely. The current Medicaid FFS payment system in California appears to be providing comprehensive care for children and their families. Nevertheless, the underutilization of hospice and home health services, with their consistently low average monthly cost, represents an opportunity to improve the quality of EOL care while potentially reducing or remaining budget neutral.

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## Author Disclosure Statement

No competing financial interests exist.

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