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Trends in services among pediatric hospice providers during 2002 to 2008

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Over the past few decades, the medical complexities involved in caring for terminally ill children have increased. The prevalence of terminally ill children with diverse diagnoses such as congenital malformation, perinatal disease, cardiovascular disorders, and neoplasm has risen by 26%.[1,2] Their health status is often exacerbated by additional problems with feeding, upper airway obstruction, long-term mechanical ventilation, obstructive sleep apnea, and intracranial pressure as their health status declines.[3] In addition, children at end of life generally suffer significant symptom burdens in the form of fatigue, pain, dyspnea, constipation, and anxiety as a result of procedures and medication side-effects.[4]

For many of these children, the services provided in hospices are an essential component of their quality end-of-life care.[5] The Centers for Medicare and Medicaid Services (CMS) identifies three categories of hospice services: core services that must be provided by hospice staff (e.g., skilled nursing), noncore services that may be outsourced (e.g., medical equipment), and other services that are unreimbursed (e.g., inpatient care).[6] The delivery of these hospice services has been shown to provide physical and psychosocial benefits to terminally ill children, such as reduced suffering from pain and other symptoms and improved quality of end of life.[7,8] Families are often very satisfied with the services provided for their children by pediatric hospice providers.[9–11]

Despite the importance of hospice services to the quality of care for terminally ill children and their families, it is unclear what hospice services are available for children and whether or not hospice services have kept pace with the medically complex needs of terminally ill children. Past research has found that registered nursing care, chaplaincy, and social services were common in pediatric hospices during the 1990s,[12] whereas a current study has shown that bereavement, spiritual, respite, inpatient, and interpreter services are generally offered for children and families today.[13] Although this research has detailed the types of services available for children in the past and present, it has not comprehensively examined the hospice services as defined by CMS, nor has it examined trends in hospice services. Thus, there is a critical gap in our understanding of what hospice services are offered for children and how those services have changed over time in light of the increasing complexity of children's health at end of life. This study was designed to meet this gap by exploring the trends in the availability of CMS-defined hospice services among pediatric hospice providers.

Exploring CMS-defined hospice services available for children presents a more complete picture of the care being offered to children and families at end of life. By examining specific services offered, it becomes possible to identify service areas that are lacking, and

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ultimately to identify the unmet needs of terminally ill children and families. Understanding the trends in hospice services among pediatric hospice providers may assist policy makers and clinicians to better target interventions designed to improve access and delivery of pediatric hospice care. Therefore, the purpose of this study was to understand what specific CMS-defined hospice services were offered for children and their families and to examine the trends in hospice service availability among pediatric hospice providers over a 7-year (2002–2008) time period.

Methods

Design and Sample

This study was a longitudinal secondary analysis. The sample was organizations licensed as hospice providers in California from 2002 to 2008. Inclusion criteria were the provision of care for persons under 21 years of age and an active hospice program licensure. The exclusion criteria were the cessation of business operations and missing financial data. After applying the inclusion and exclusion criteria, the final sample was 459 hospice observations over 7 years.

Data Sources

The main data sources was the 2002 to 2008 *California State Utilization Data File of Home Health Agencies and Hospice Facilities* data sets that provide organizational data on pediatric hospices. The California Department of Finance *California Income Data* reports were used to provide data on per capita personal income and the California Employment Development Department *Monthly Labor Forces Data for Counties* were used to gather unemployment data.

Measures

Dependent variables—This study focused on the CMS-defined hospice services of core, noncore, and other hospice services.[6] Variables were created for the *availability of core*, *noncore*, and *other* hospice services based on the number of services offered by the hospice in each category. The four core hospice services measured included skilled nursing, physician, social, and counseling (i.e., spiritual, bereavement, and dietary) services. The six noncore hospice services measured were home-health or homemaker care, durable medical equipment and supplies, medication (e.g., drugs, biologicals, infusions), therapeutic care (i.e., physical therapy, occupational therapy, speech therapy), inpatient care (e.g., respite, general inpatient), and transportation services. Finally, the four other hospice services measured were imaging and laboratory, outpatient (e.g., emergency room), radiation therapy, and chemotherapy services.

Explanatory variable—The primary explanatory variable was *study years*. This variable was dummy-coded (0=no, 1=yes) and the year 2002 was the referent year.

Control variables—Organizational (i.e., affiliation, service area, ownership, organizational size), market (i.e., competition, per capita income, unemployment), and patient (i.e., child age) characteristics may be associated with service availability, so they were included in the model as covariates.[14,15] *Affiliation* was measured categorically as whether hospices were freestanding, hospital based, home-health based, or long-term care based. *Service area* was categorized by whether hospices delivered care in urban, rural, or mixed rural and urban locations. Dummy variables were created for *ownership*, which was operationalized as whether a hospice was for-profit or nonprofit. The *organization size* variable was created from calculating the average daily census. Using a method common in the hospice industry,[16] hospices were categorized as small if they had an average daily

census less than or equal to 25 patients per day, medium if they had an average daily census of 26 to 100 patients per day, and large if they had an average daily census of over 100 patients per day.

Competition was measured with the Herfindahl-Hirshman Index (HHI) and was reversed for this study (i.e., 1-HHI) to reflect the shift from monopoly to competition in the market of the hospice. *Per capita income* was defined as the total annual county income divided by the number of people in the county. The rate of *unemployment* was the percentage of the work force unemployed in the county annually. *Child age* was operationalized as whether a hospice enrolled children 0 to 1 year, 2 to 5 years, 6 to 10 years, and 11 to 20 years of age.

Data Analysis

Standard descriptive statistics were calculated for all study variables including frequencies of categorical variables, means for continuous variables, minimum, maximums, and standard deviations. In addition, a descriptive analysis of core, noncore, and other hospice services by year was conducted. For the multivariate analysis of service availability, a Poisson model was constructed that was well suited for estimation rates based on count data such as the number of hospice services available.[17] A goodness of fit indicator was used to determine that the data fit a Poisson distribution rather than a negative binomial distribution. This analysis showed that the dependent variables were not over dispersed and did not have an excessive number of zeros in their values. Additionally, in longitudinal data, observations are generally not independent across time periods. Thus, generalized estimating equations (GEE) were used to estimate the Poisson model.[18,19] The results were reported as incident rate ratios. The data were analyzed using Stata 11.0 (StataCorp LP).

Results

Sample Characteristics

The sample characteristics of the hospices are summarized in Table 1. Pediatric hospices providers, on average, offered three core hospice services, four noncore hospice services, and one other hospice service. Hospices were commonly freestanding (63%) and provided services in urban communities (55%). Over half of the hospices were nonprofit (65%) and medium sized (57%). The level of competition, as determined by the HHI, was 0.62, indicating a relatively competitive market (range = 0 [monopoly] to 1.0 [extremely competitive]). Hospice organizations operated in counties with an average per capita income of $35,194, and the average annual unemployment rate was 6.5%. Hospices most often admitted children 11 to 20 years of age (65%).

Offered Services

The results of the descriptive analysis of the core, noncore, and other hospice services available from 2002 to 2008 are presented in Table 2.

Core hospice services—Of the core hospice services, skilled nursing services were provided the most during all years of the study with over 90% of hospices offering nursing care. Physician services were the least common core hospice service ranging from 57% in 2003 to 82% in 2008. However, this service was one of the fastest growing services during the study with a 16.7% increase from 2002 to 2008. The proportion of hospices offering social services decreased from 95% in 2002 to 77% in 2003 and rose to 99% in 2008. Finally, 75% of hospices offered spiritual, bereavement, and dietary counseling services in 2002 which increased to 92% in 2008, representing a 17% change.

Noncore hospice services—For noncore hospice services, the proportion of hospices offering home-health aide and homemaker care services ranged from a low 72% in 2004 to a high 94% in 2007. The offering of durable medical equipment and supplies fluctuated. The availability of those services sunk to 82% in 2003 but rose to a high of 99% in 2006. Medication services were the most common noncore hospice service. Over 90% of hospices offered medication services over the study years. Therapeutic services (i.e., physical, occupational, speech) were the least common offered; slightly more than half of the hospices offered therapeutic services (range = 55% – 65%). Inpatient care services (range = 50% – 71%) and transportation services (range = 50% – 79%) were offered by at least half of the hospices.

Other hospice services—Other hospice services were the least common type of hospice services offered by pediatric hospice providers. Imaging and laboratory services were offered at 55% of hospices in 2002 and fluctuated to 73% in 2007, making them the most common other hospice service available during the study period. Approximately one-third of the hospices offered outpatient services, including emergency room visits. The availability of outpatient services increased from 2002 (15%) to 2008 (28%). Consistently, less than a quarter of the hospices offered radiation services. The least common other hospice service was chemotherapy. It ranged from a low of 1.6% in 2007 to a high of 5.6% in 2008.

Trends in the Availability of Pediatric Hospice Services

Table 3 gives the results of the multivariate GEE analysis. Among years of the study, 2003, 2004, and 2008 were significant related to the availability of core hospice services among pediatric hospice providers while controlling for organizational, market, and patient characteristics. Compared to 2002, the number of core services available decreased in 2003 (IRR = 0.873, 95% CI [0.795,0.971]) and 2004 (IRR = 0.889, 95% CI [0.793,0.995]). In 2008, the number of core services increased (IRR = 1.130, 95% CI [1.038,1.230]).

The analysis of noncore and other hospice services revealed that only 2008 was significantly associated with service availability. Relative to 2002, the rates of noncore service availability (IRR = 1.117, 95% CI [1.013,1.231]) and other hospice services availability (IRR = 1.117, 95% CI [1.005,1.583]) both increased. The other years of the study had no significant relationship with the availability of core, noncore, and other hospice services.

Discussion

As one of the few studies to examine hospice services available for children at end of life, the goal of this study was to understand what specific CMS-defined services were offered for children and their families and to determine whether or not the availability of hospice services among pediatric hospice providers changed over time. The descriptive analysis revealed that the proportion of hospices offering nursing care, physician, social, counseling, medication, inpatient, transportation, imaging and laboratory, outpatient, and chemotherapy services increased in hospices that provided care for children. The results of this study support research documenting the availability of these hospice service among pediatric providers.[12,13] However, home-health aide and homemaker services, equipment and supplies services, and therapy services declined and radiation services remained unchanged from 2002 to 2008. Overall, these findings suggest that pediatric hospice providers in this study have been slower to improve the availability of noncore and other hospice services than core hospice services.

An unexpected finding of this study was that physician services were the least common core service available for children. Given the increases in disease complexity, diversity of diagnoses, and symptom burden seen in children at end of their lives, children likely have an

increased need for direct physician care.[20] Physician members of a hospice team help formulate and approve childrens' plans of care by approving all orders and evaluating the child's prognosis during hospice enrollment.[21] It is possible that childrens' primary care physicians or oncologists may continue providing ongoing medical care once enrolled in hospice. However, these physicians may not have the education, knowledge, or skills of a trained hospice physician.[22] Therefore, children in hospice care may not receive effective care planning or direct patient care at the end of their lives.

Another interesting finding from this analysis was the decline in therapy services from 2002 to 2008. The diminishing availability of therapy services is consistent with suggestions in the literature that workforce shortages may impede the offering of physical, occupational, and speech therapy.[23] Hospice physical therapists use techniques such as massage, ultrasound, and manual lymphatic drainage to control symptoms.[24] Occupational therapists assess and provide treatment programs aimed at activities of daily living and the use of adaptive equipment.[24] Speech therapists, on the other hand, work to improve communication, cognition, and swallowing functions.[24] These therapies are an important component of terminally ill children's care, and children generally respond to therapeutic strategies that provide relief from pain, decreased endurance, and dysphasia.[4] However, due to recent changes in the educational requirement (i.e., a doctorate of physical therapy is now required), reimbursement constraints, and shortage of faculty, there is a critical shortage of skilled therapist in the United States.[23,25] This shortage may impact the availability of therapy services for children in hospice care. Therefore, the quality of end of life care offered for children may not be sufficient to adequately address their increasing medical complexities. Future workforce research might examine the relationship between the therapist shortages and availability of care in the pediatric hospice setting.

The multivariate trend analysis showed that the number of core hospice services diminished in 2003 and 2004; however, by 2008 there were consistent increases in offering core, noncore, and other hospice services by pediatric providers. There are several possible reasons for the shift in service availability during the study, one being the economy during this time frame. From 2002 to 2008, the California economy experienced cycles of decline and growth.[26] California spent much of 2002 through 2004 recovering from the 2000 to 2001 recession.[27] Hospices may have reduced their service offerings in response to the economic recovery. In addition, the California economy experienced growth during 2005 and 2006 and the availability of hospice services also increased during that period. Using several key economic indicators, economists reported that residential construction peaked in 2005 and housing prices peaked in 2006.[27] Pediatric hospices may have again responded to the positive economic climate by increasing service availability in subsequent years.

Another explanation may relate to the issuance of the 2008 CMS Hospice Conditions of Participation (CoPs). The 2008 changes to the CoPs were the first wholesale changes in the basic rulebook of hospice services for Medicare-certified hospices in nearly 25 years, and they were underdevelopment during the study time frame.[6] In 2005, CMS printed the proposed Hospice CoPs in the Federal Register for public comment. By 2007, hospices expected the new CoPs to be issued.[28] However, the CoPs were not released until June 2008 and took effect in December 2008. The 2008 CoPs drew attention to hospice services by providing definitions of several core services and developing a mechanism for contracting core services.[6] In an environment of regulatory awareness, pediatric providers may have increased the availability of their core, noncore, and other services by 2008 in anticipation of the new CoPs.

Potential limitations of this study should be noted. First, these results are not generalizable to hospices outside of California. However, California tends to have influential hospice care

practices and often implemented services before other states.[29] In addition, this study included only hospice-level data and no client-level information about services actually received. Although the *California State Utilization Data File of Home Health Agencies and Hospice Facilities* data files provide comprehensive information on hospice organizations, the lack of patient-level data is a limitation of using secondary data in analysis.

Despite its drawback, the findings of this study have important policy implications. Effective March 23, 2010, the Concurrent Care for Children provision of the Patient Protection and Affordable Care Act of 2010 allows terminally ill children to concurrently receive treatments for their terminal illness (e.g., chemotherapy, radiation therapy) while enrolled in hospice care services.[30] Although hospice care has always been designed to provide any and all services necessary for management of the terminal illness,[21] this study revealed that prior to the enactment of health care reform, hospices generally did not provide imaging, laboratory, outpatient, radiation, or chemotherapy services for children to manage or palliate symptoms at end of life. Therefore, this study may provide important baseline data for policy makers and researchers as they assess the impact of the Concurrent Care for Children provision on the availability of hospice services for children in the future.

The analysis of trends in hospice services among pediatric providers also has implications for children and their families. This analysis showed that the services available for children among pediatric hospice providers varied during a period when children had increasingly complex medical needs at end of life. The hospices in this study have been slower to improve the availability of noncore and other hospice services critical for medically complex children. Families interested in admitting their children to hospice care may benefit from discussing services needed with their attending physician first and examining the array of services provided by hospices prior to admission.

In summary, this trend analysis of hospice service availability showed that pediatric hospice providers have only recently improved their offering of core, noncore, and other hospice services. Given the economic conditions of the recession of 2009 to 2010 and the recent policy changes in health care reform, continually monitoring the availability of hospice services for children over time is recommended.

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Table 1

Characteristics of the Sample (N = 459)

Variable	Percentage/Mean	Standard Deviation	Minimum	Maximum
Dependent Variables				
Core Hospice Services	3.309	1.140	0	4
Noncore Hospice Services	4.490	1.537	0	6
Other Hospice Services	1.092	1.049	0	4
Control Variables				
Affiliation				
Freestanding (%)	62.75	---	0	1
Hospital based (%)	16.78	---	0	1
Home-health based (%)	19.39	---	0	1
Long-term care based (%)	1.09	---	0	1
Service Area				
Urban (%)	55.34	---	0	1
Rural (%)	9.59	---	0	1
Mixed (%)	35.08	---	0	1
Ownership				
Profit (%)	34.86	---	0	1
Nonprofit (%)	65.14	---	0	1
Organization Size				
Large (%)	30.28	---	0	1
Medium (%)	56.86	---	0	1
Small (%)	12.85	---	0	1
Competition	0.621	0.318	0	0.96
Per capita income	35.194	10.180	18.83	86.06
Unemployment	6.48	2.196	3.4	22.4
Child Age				
0–1 year (%)	55.77	---	0	1
2–5 years of age (%)	30.28	---	0	1
6–10 years of age (%)	34.64	---	0	1
11–20 years of age (%)	65.14	---	0	1

Table 2

Percentage of Hospice Providing Services by Year, 2002–2008 (N=459)

	Year (*n*)						
	2002 (60)	**2003 (74)**	**2004 (67)**	**2005 (58)**	**2006 (67)**	**2007 (62)**	**2008 (71)**
Core hospice services							
Skilled nursing care (%)	96.7	85.1	83.6	94.8	97.0	98.4	98.6
Physician care (%)	65.0	56.8	65.7	72.4	70.2	75.8	81.7
Social services(%)	95.0	77.0	79.1	86.2	91.0	95.2	98.6
Counseling (%)	75.0	66.2	68.7	81.0	85.1	90.3	91.6
Noncore hospice services							
Home-health aide/homemaker (%)	88.3	73.0	71.6	77.6	86.6	93.6	87.3
Equipment/supplies (%)	96.7	82.4	85.1	93.1	98.5	98.4	95.8
Medication (%)	93.3	78.4	85.1	96.6	97.0	96.8	97.2
Therapy (%)	65.0	62.2	64.2	55.2	59.7	58.1	57.8
Inpatient care (%)	50.0	59.5	56.7	70.7	59.7	61.3	62.0
Transportation (%)	50.0	50.0	56.7	62.1	65.7	79.0	71.8
Other hospice services							
Imaging/laboratory (%)	55.0	60.8	55.2	56.9	67.2	72.6	69.0
Outpatient (%)	15.0	23.8	32.8	36.2	31.3	32.3	28.2
Radiation therapy (%)	18.3	10.8	13.4	13.8	10.5	17.7	18.3
Chemotherapy (%)	1.7	5.4	3.0	3.5	4.5	1.6	5.6

Table 3

Multivariate Trends in the Availability of Hospice Services Among Pediatric Hospice Providers, (N=459)

	Core Hospice Services		Noncore Hospice Services		Other Hospice Services	
	IRR(95%CI)	***P*-value**	**IRR(95%CI)**	***P*-value**	**IRR(95%CI)**	***P*-value**
Study Years						
2002	(ref)		(ref)		(ref)	
2003	0.874 (0.784–0.971)	0.012 *	0.952 (0.851–1.066)	0.397	1.090 (0.891–1.334)	0.399
2004	0.889 (0.793–0.995)	0.041 *	0.965 (0.854–1.091)	0.571	0.929 (0.720–1.199)	0.571
2005	0.987 (0.895–1.088)	0.792	1.048 (0.959–1.145)	0.303	0.944 (0.749–1.190)	0.625
2006	0.998 (0.905–1.100)	0.972	1.035 (0.941–1.138)	0.482	0.879 (0.713–1.084)	0.227
2007	1.069 (0.989–01.156)	0.093	1.086 (0.989–1.192)	0.084	0.979 (0.794–1.207)	0.840
2008	1.130 (1.038–1.230)	0.005 **	1.117 (1.013–1.231)	0.027 *	1.261 (1.005–1.583)	0.046 *
Control Variables						
Affiliation						
Freestanding	(ref)		(ref)		(ref)	
Hospital based	0.929 (0.813–1.061)	0.277	0.982 (0.828–1.137)	0.809	0.743 (0.512–1.078)	0.117
Home-health based	1.003 (0.921–1.092)	0.945	1.124 (1.029–1.229)	0.009 **	0.901 (0.710–1.144)	0.392
Long-term care based	1.393 (1.129–1.718)	0.002 **	1.131 (0.985–1.298)	0.080	1.674 (0.818–3.427)	0.158
Service Area						
Urban	(ref)		(ref)		(ref)	
Rural	1.145 (1.015–1.293)	0.028 *	1.001 (0.865–1.159)	0.988	1.522 (1.059–2.187)	0.023 *
Mixed	0.962 (0.858–1.079)	0.512	0.868 (0.775–0.972)	0.014 *	1.038 (0.775–1.390)	0.804
Ownership						
Profit	(ref)		(ref)		(ref)	
Nonprofit	1.020 (0.920–1.131)	0.700	1.122 (1.016–1.238)	0.023 *	1.267 (0.940–1.712)	0.119
Organization Size						
Large	(ref)		(ref)		(ref)	
Medium	0.916 (0.828–1.015)	0.093	0.904 (0.832–0.982)	0.017 *	0.705 (0.538–0.924)	0.011 *
Small	0.896 (0.759–1.059)	0.199	0.780 (0.674–0.903)	0.001 **	0.452 (0.391–0.680)	0.001 **

	Core Hospice Services		Noncore Hospice Services		Other Hospice Services	
	IRR(95%CI)	***P*-value**	**IRR(95%CI)**	***P*-value**	**IRR(95%CI)**	***P*-value**
Competition	0.937 (0.796–1.104)	0.439	0.806 (0.686–0.947)	0.009**	0.500 (0.320–0.782)	0.002**
Per capita income	0.999 (0.995–1.003)	0.498	0.998 (0.995–1.002)	0.345	1.000 (0.990–1.009)	0.931
Unemployment	0.982 (0.960–1.004)	0.116	0.968 (0.949–0.988)	0.002**	0.871 (0.810–0.937)	0.001**
Child Age						
Less than 1 year	1.012 (0.954–1.074)	0.694	1.006 (0.943–1.072)	0.862	0.904 (0.778–1.051)	0.187
2–5 years of age	0.974 (0.917–1.033)	0.378	0.978 (0.930–1.028)	0.382	1.017 (0.880–1.177)	0.816
6–10 years of age	1.103 (1.039–1.170)	0.001**	1.013 (0.957–1.073)	0.640	0.986 (0.876–1.109)	0.811
11–20 years of age	1.024 (0.959–1.094)	0.479	1.014 (0.954–1.079)	0.652	0.911 (0.780–1.039)	0.163

Note. IRR = incident rate ratio. CI = confidence interval.

*$p<0.05$,

**$p<0.01$

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