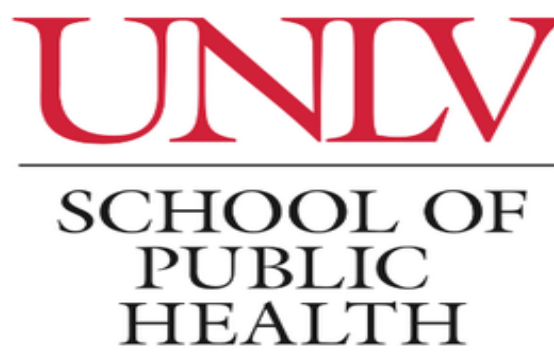


Palliative Care Services Among Hospitalized Children with Serious and Life-Limiting Conditions in the U.S.

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Significance

- Pediatric palliative care (PC) is primarily centered around enhancing the quality of life for children facing life-limiting illnesses and their families.
- The most common illnesses utilizing pediatric PC services included congenital anomalies, neurodegenerative disorders, genetic syndromes, and cancer.
- Although there is a body of knowledge regarding palliative care among adults, this is scarce when it comes to pediatric palliative care.
- The purpose of this study was to examine trends of palliative care among children with severe clinical conditions and disabilities, as well as sociodemographic and clinical factors associated with palliative care.

Methodology

- **Data:** The 2016-2020 national inpatient sample (NIS) were used in this cross-sectional study. A total of 648,746 hospital discharges under 18 years old with serious and life-limiting conditions were identified based on the ICD-10 codes.
- **Measures:** Sociodemographic characteristics were analyzed including gender (male and female), age, race/ethnicity (White, Black, Hispanic, and Native American), insurance type (private insurance, Medicaid, self-pay, and free care), and median income for patient’s ZIP codes. Clinical data included illness severity (1 to 4) and in-hospital death. Hospital-related variables included hospital bed size (large, small, medium), hospital status (urban teaching rural, urban nonteaching), and hospital divisions (from 1 to 9).
- **Analyses:** Multivariable regression models were used to find factors associated with palliative care, mortality, and numbers of procedures. Other factors included gender, age, race/ethnicity, insurance type, median household income using patients ZIP codes, APRDG, hospital bed size, and hospital status.

Results

- Neurologic/neuromuscular, cardiovascular, and premature/neonatal conditions were ranked in the top three of all pediatric conditions that they need PC, with the largest increase among children with premature/neonatal conditions.
- Use of PC increased from 1.47% in 2016 to 1.80% in 2020, with an average 7.8% annual increase in the odds of receiving PC.
- Females (odds ratio (OR) = 1.06 as compared to males), uninsured (OR = 1.73 as compared to patients with private insurance), and patients living in low-income areas were more likely to receive PC.
- Children residing with higher level of severity of illnesses (OR = 2.54 per level of increase), including neurologic/neuromuscular (OR – 2.63), and malignancy (OR = 3.29), were much more likely to receive PC.
- Children residing in rural areas were less likely to receive PC (OR =0.51 as opposed to patients living in non-rural areas.
- Children receiving PC were much more likely to die in hospital (OR = 23.16) and to incur a longer hospital stay (5.1 days) than their counterparts without PC.

Descriptive

Years	2016-2020	2016	2017	2018	2019	2020
Palliative Care	1.52	1.47	1.40	1.44	1.52	1.80
Died During Hospitalization	2.44	2.56	2.46	2.38	2.32	2.49
Palliative Care Services						
Neurology	20.71	20.56	20.82	20.94	20.98	20.18
Cardiology	19.74	19.70	19.51	19.62	19.92	19.97
Respiratory	8.91	8.70	9.09	9.29	9.21	8.17
Renal	10.58	10.29	10.32	10.55	10.60	11.24
Gastrointestinal	8.74	8.56	8.68	8.76	8.76	8.97
Hematology	12.37	12.84	12.68	12.24	12.08	11.96
Metabolic	10.39	9.96	10.35	10.31	10.34	11.09
Other Related Conditions	12.15	12.45	12.17	12.26	12.20	11.59
Malignancy	14.08	14.64	14.10	13.76	13.60	14.47
Neoplasms	21.00	19.41	20.20	20.82	21.39	23.43
Miscellaneous	2.83	2.13	2.94	3.19	3.24	2.61

Multivariable Analysis of Palliative Care

Effects	Odds Ratio	95% CI	p-value
Year	1.078	[1.061, 1.095]	<.0001
Demographic			
Age	0.992	[0.987, 0.996]	0.0002
Female	1.059	[1.016, 1.105]	0.0068
Race: White, referent			
Black	1.057	[0.995, 1.123]	0.3648
Hispanic	0.984	[0.928, 1.045]	0.0008
Asian/Pacific Islander	1.099	[0.985, 1.226]	0.8285
Native	1.221	[0.985, 1.514]	0.2037
Other	1.183	[1.084, 1.292]	0.0372
House Insurance: Private Insurance, referent			
Medicaid	1.027	[0.977, 1.079]	<.0001
Uninsured	1.727	[1.518, 1.966]	<.0001
Other	1.017	[0.921, 1.123]	0.0008
APRDRG Severity	2.541	[2.459, 2.626]	<.0001
Median Household Income for Patient’s ZIP Code: 76th to 100th percentile, referent			
0-25th percentile	1.126	[1.052, 1.205]	0.1735
26th to 50 th percentile	1.207	[1.130, 1.290]	<.0001
51st to 75 th percentile	1.068	[0.998, 1.142]	0.1556
Palliative Care Services			
Neurology	2.631	[2.512, 2.756]	<.0001
Cardiology	1.264	[1.202, 1.330]	<.0001
Respiratory	1.350	[1.272, 1.432]	<.0001
Renal	1.075	[1.002, 1.152]	0.0426
Gastrointestinal	0.962	[0.892, 1.036]	0.3040
Hematology	0.887	[0.827, 0.952]	0.0009
Metabolic	1.327	[1.251, 1.408]	<.0001
Other Related Conditions	1.577	[1.491, 1.668]	<.0001
Malignancy	3.290	[3.108, 3.483]	<.0001
Neoplasms	1.464	[1.380, 1.553]	<.0001
Miscellaneous	1.433	[1.317, 1.559]	<.0001
Hospital Bed size: Large Hospital Bed size, referent			
Small Hospital Bed size	0.655	[0.615, 0.697]	<.0001
Medium Hospital Bed size	0.731	[0.690, 0.774]	0.0007
Hospital Location and Hospital Status			
Rural Hospital	0.508	[0.390, 0.663]	<.0001
Non-teaching Hospital	0.503	[0.435, 0.581]	<.0001

Multivariable Analysis of Died During Hospitalization

Effects	Odds Ratio	95% CI	p-value
Year	0.967	[0.954, 0.980]	<.0001
Palliative Care	23.160	[21.733, 24.680]	<.0001
Demographic			
Age	0.954	[0.949, 0.959]	<.0001
Female	0.989	[0.953, 1.026]	0.5503
Race: White, referent			
Black	1.373	[1.306, 1.444]	<.0001
Hispanic	1.090	[1.033, 1.150]	0.0583
Asian/Pacific Islander	1.128	[1.022, 1.246]	0.7024
Native	1.042	[0.848, 1.280]	0.2684
Other	1.299	[1.208, 1.396]	0.0003
House Insurance: Private Insurance, referent			
Medicaid	0.876	[0.838, 0.915]	<.0001
Uninsured	3.418	[3.153, 3.705]	<.0001
Other	1.049	[0.959, 1.149]	<.0001
APRDRG Severity	3.706	[3.576, 3.840]	<.0001
Median Household Income for Patient’s ZIP Code: 76th to 100th percentile, referent			
0-25th percentile	1.265	[1.190, 1.344]	<.0001
26th to 50 th percentile	1.222	[1.150, 1.298]	<.0001
51st to 75 th percentile	1.086	[1.022, 1.155]	0.0070
Palliative Care Services			
Neurology	1.576	[1.505, 1.650]	<.0001
Cardiology	0.860	[0.821, 0.902]	<.0001
Respiratory	0.771	[0.726, 0.819]	<.0001
Renal	0.857	[0.726, 0.819]	<.0001
Gastrointestinal	0.656	[0.609, 0.707]	<.0001
Hematology	0.720	[0.666, 0.778]	<.0001
Metabolic	1.264	[1.190, 1.343]	<.0001
Other Related Conditions	1.089	[1.026, 1.155]	0.0048
Malignancy	0.751	[0.694, 0.813]	<.0001
Neoplasms	3.621	[3.449, 3.801]	<.0001
Miscellaneous	0.352	[0.309, 0.401]	<.0001
Hospital Bed size: Large Hospital Bed size, referent			
Small Hospital Bed size	0.824	[0.778, 0.873]	<.0001
Medium Hospital Bed size	0.999	[0.954, 1.046]	<.0001
Hospital Location and Hospital Status			
Rural Hospital	1.358	[1.197, 1.540]	<.0001
Non-teaching Hospital	1.280	[1.190, 1.376]	<.0001

Discussion

- The significant increase in the odds of utilizing palliative care services among hospitalized children with serious and life-limiting conditions in the U.S. could be attributed to the growing availability as well as awareness among healthcare providers and families about the benefits of palliative care in improving quality of life for children with complex medical conditions.
- Disparities in palliative care utilization based on sociodemographic and hospital-related factors highlights the need for targeted intervention to ensure the optimum utilization of palliative care in hospital settings.
- The increase of palliative care utilization for pediatric patients underscores the importance of ongoing efforts to integrate palliative care into standard medical practice for pediatric population. This ensures that early-stage patients receive palliative care services, addresses disparities associated with palliative care utilization, and promote implementation of policy initiatives focusing on equitable access to palliative care across diverse patient population.
- Mitigating disparities related to hospital characteristics on palliative care underscores the importance of better resource allocation and workforce training to strengthen palliative care utilization in hospitals with varying sizes and teaching statuses.

Limitations

- The discharge-based NIS data lack detailed clinical information and cannot not be used to track patients with multiple hospital admissions
- The NIS data cannot not be used to track patients’ pre-admission conditions and post-discharge outcomes
- Non-hospital setting palliative care cannot be examined
- Patient prevalence to palliative care was not available

Conclusions

- This study provides valuable insights into the current state of inpatient palliative care for hospitalized children with serious and life-limiting conditions in the U.S.
- A temporal trend of palliative care in pediatric inpatients increased between 2016 and 2020.
- Hospital palliative care was associated with more severe clinical conditions, uninsured, rural residence, in-hospital death and LOS.
- Earlier referral to palliative care for hospitalized children with serious and life-limiting conditions may improve those children’s quality of life and disease management.

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