

Effectiveness of concurrent care to improve pediatric and family outcomes at the end of life: An analytic codebook

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Abstract

Implementation of the section 2302 of the 2010 Patient Protection and Affordable Care Act (ACA) enabled children enrolled in Medicaid/Children's Health Insurance Program with a prognosis of 6 months to live to use hospice care while continuing treatment for their terminal illness. Although concurrent hospice care became available more than a decade ago, little is known about the socio-demographic and health characteristics of children who received concurrent care; health care services they received while enrolled in concurrent care, their continuity, management, intensity, fragmentation; and the costs of care. The purpose of this study was to answer these questions using national data from the Centers of Medicare and Medicaid Services (CMS), which covered the first three years of ACA – from January 1, 2011, to December 31, 2013. The database included records of 18,152 children younger than the age of 20, who were enrolled in Medicaid hospice care in the sampling time frame. Children in the database also had a total number of 42,764 hospice episodes. Observations were excluded if the date of birth or death was missing or participants were older than 21 years. To create this database CMS data were merged with three other complementary databases: the National Death Index (NDI) that provided information on death certificates of children; the U.S. Census Bureau American Community Survey that provided information on characteristics of communities where children resided; CMS Hospice Provider of Services files and CMS Hospice Utilization and Payment files were used for data on hospice providers, and with a database of rural areas created by the Health Resources and Services Administration (HRSA). In total, 130 variables were created, measuring demographics and health characteristics of children, characteristics of health providers, community characteristics, clinical characteristics, costs of care, and other variables. **Keywords:** concurrent hospice care, end-of-life care, hospice care, Medicaid, pediatric.

Introduction

Purpose of the codebook

The codebook includes documentation for the research project *Effectiveness of Concurrent Care to Improve Pediatric and Family Outcomes*. This research project was sponsored by the National Institute of Nursing Research and Office of the Director, Grant Number R01NR017848 (PI: Lindley). Additional information about the project can be found online at www.pedeolcare.utk.edu.

This codebook was designed for researchers and analysts interested in using Medicaid data to investigate the utilization of hospice services by pediatric patients. Publications prepared using these variables are available free of charge at [PubMed](https://pubmed.ncbi.nlm.nih.gov/).

Data overview

Medicaid is an entitlement program that provides health care coverage to low-income families and is the most extensive health insurance program for children younger than 21.¹ All information about Medicaid enrollees and health services covered by the program are managed by the Medicaid Statistical Information System (MSIS).¹ It includes data on enrollees from all 50 states and the District of Columbia but excludes those residing in Puerto Rico or other U.S. territories.² Since MSIS was designed for administrative purposes and not research, the Medicaid Analytic Extract (MAX) data system was created as a research tool to provide information on Medicaid enrollment, service utilization, and expenditure at the enrollee level.

The quality of the MAX data is maintained by the Centers for Medicare & Medicaid Services (CMS). Although each state conducts data quality checks of Medicaid data before submission to CMS, CMS contracts with Mathematica Policy Research to review state data against tolerance criteria and assist states in making corrections, as necessary. Reports have found no evidence of incomplete data or gross miscoding errors. Medicaid managed-care encounter data has also been assessed for completeness and accuracy, and its quality guided the inclusion of states in our study.

For this study, the following CMS Medicaid data files were used:

- MAX Personal Summary Files (PS) combined demographic characteristics with eligibility information, summary claims, and payment data in one record per enrollee.
- MAX Other Therapy Files (OT) were used for diagnosis and procedure information. These files provided claims data on hospice care, along with the *International Classification of Diseases* (9th version ICD-9) and *Current Procedural Terminology* (CPT) codes.
- MAX Inpatient Files (IP) were included for hospitalization data on service dates and procedure codes
- MAX Prescription Drug (RX) files contained information on prescription fill date and national drug codes, grouped following the Medicaid RX or *Red Book* classification.

This codebook covers MAX versions from 2011 to 2013. This time frame was selected because it represents the first three full years of implementing the Affordable Care Act and provision 2302 that allowed pediatric Medicaid enrollees to enroll in concurrent hospice care. The major

limitation of this codebook is that it may be incompatible with CMS databases created after 2016 because starting that year CMS fully transitioned to T-MSIS Analytic Files (TAF), which has a data structure different from MAX.

Other data sources used for the study were:

- National Death Index (NDI) is a database maintained by the Centers for Disease Control and Prevention's National Center for Health Statistics.³ NDI is derived from information on death certificates and is updated annually. The database used in this study contained the date of death and causes of death for all US residents from 2011 to 2013. The database used in this study contained the dates and causes of death for all US residents from 2011 to 2013. It was manually linked to the MAX files using the social security numbers of pediatric patients.
- Publicly available U.S. Census Bureau American Community Survey provided information on community income and education.⁴ These data were manually linked to the Medicaid files using Federal Information Processing Standards (FIPS) code. Database from 2010 was used because it included data from the latest census.
- Publicly available CMS Hospice Provider of Services files⁵ and CMS Hospice Utilization and Payment files for 2013⁶ were used for information on hospice providers. These data were manually linked by the National Provider Identifier (NPI). Database from 2013 was used because it contained the largest number of hospices.
- A publicly available list of rural areas created by the Health Resources and Services Administration (HRSA) was used to identify rural communities.⁷ The database was merged with the MAX files using FIPS codes.

Data use restrictions

Medicaid data for this study contained protected health information (PHI) and personally identifiable information (PII) protected under the HIPAA Privacy Rule. The data files are NOT available for research activities because of the Data Use Agreement (DUA) between CMS and the research institution, the University of Tennessee, Knoxville.

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Short List of Variables

Characteristics	Variable names	Characteristics	Variable names
Demographics			
0. Age in years [con.]	age_yrs	46. Region [cat.]	region
1. Age groups [cat.]	age_groups	47. Northeast [bin.]	region_neast
2. 0 to 1 years [bin.]	age0_1	48. Midwest [bin.]	region_mwest
3. 1 to 5 years [bin.]	age1_5	49. South [bin.]	region_south
4. 6 to 14 years [bin.]	age6_14	50. West [bin.]	region_west
5. 15 to 20 years [bin.]	age15_20	51. Appalachia [bin.]	region_app
6. Gender [bin.]	gender	52. Southern Appalachia [bin.]	region_sapp
Race		53. Rurality [bin.]	ru_hrsa2
7. White [bin.]	white	54. U.S. States [str.]	state_cd
8. Black [bin.]	black	55. to 100. U.S.States [bin.]	AK, AL, AR, CA, CO, CT, DC, DE, FL, GA, HI, IA, ID, IL, IN, KS, KY, LA, MA, MD, ME, MI, MN, MO, MS, MT, NC, ND, NJ, NM, NV, NY, OH, OK, OR, PA, SC, SD, TN, TX, UT, VA, WI, WV, and WY.
9. Ethnicity [bin.]	hispanic		
Health Characteristics		Clinical characteristics	
10. Neurologic and neurom. [bin.]	ccc_neuro	101. Hospice LOS [con.]	total_los
11. Cardiovascular [bin.]	ccc_cardiac	102. Medical Team Size [con.]	coord_phy
12. Respiratory [bin.]	ccc_resp	103. Hospice Live Discharge [con.]	fhospice_live_disch_episode
		104. Symptom management [bin.]	sym_mgt_icd9
13. Renal and urologic [bin.]	ccc_renal	105. 1day Hospice [bin.]	care_intensity_1day
14. Gastrointestinal [bin.]	ccc_gastro	106. Hospice Transition ER [bin.]	transition_er
15. Hematologic and immun. [bin.]	ccc_hemat	107. Primary Care Visits [bin.]	physician_use
16. Metabolic [bin.]	ccc_metabolic	108. Hospice Transition Inpat [bin.]	transition_inpt
17. Congenital and Genetic [bin.]	ccc_congenital	109. Coordination Insurance [bin.]	coord_ins
18. Malignancy [bin.]	ccc_cancer	110. # of episodes per child [con.]	ftotal_epi
19. Premature and neonatal [bin.]	ccc_neonatal	111. Concurrent care (rx) [bin.]	concurrent_care_rx
20. Miscellaneous conditions [bin.]	ccc_mis	Costs	
21. Mental health [bin.]	mental_health	112. Total costs [con.]	icosts_tot
22. Technology dependent [bin.]	function_status	113. Fee-for-services [con.]	icosts_tot_ffs
23. Medical complexity [bin.]	med_complex	114. Premium payment [con.]	icosts_tot_prem
24. Any medical complexity [bin.]	med_complex_any	115. Inpatient [con.]	icosts_tot_ip
25. Increase medical compl. [bin.]	increase_med_complex	116. Outpatient [con.]	icosts_tot_ot
26. Health condition [bin.]	ccc	117. Prescription drugs [con.]	icosts_tot_rx
27. Health severity [bin.]	mccc	118. Labs [con.]	icosts_tot_lab
Provider Characteristics		119. Transportation [con.]	icosts_tot_transport
28. Live discharge [con.]	iTotal_Live_Dis	120. Therapies [con.]	icosts_tot_therapies
29. Short stay pts [con.]	iHbene_7orless_hospcaedays	121. Hospice benefits [con.]	icosts_tot_hb
30. Medicaid pts [con.]	iMedicElig_hospbene	122. Registered nurse visits [con.]	icosts_tot_RN
31. Hospice Size [cat.]	Hospice_size	123. Durable med. equip. [con.]	icosts_tot_dme
32. Less than 5 [bin.]	hospice_mini	Other Variables	
33. Micro 5-9 [bin.]	hospice_micro	124. Medicaid waiver [bin.]	waiver
34. Small 10-49 [bin.]	hospice_small	125. Palliative policy [bin.]	ped_pall_policy
35. Medium and large, >50 [bin.]	hospice_large	126. Hospice's postal ZIP code [str.]	ziphosp
36. Hospice Ownership [cat.]	hospice_ownership	127. Patient's postal ZIP code [str.]	ZIP
37. Hospice Age [con.]	hospice_age	Years	
38. Skilled RN visits [con.]	ihospice_rnvisits	128. 2011 [bin.]	y2011
39. Pediatric programs [bin.]	pediatric_prgrm	129. 2012 [bin.]	y2012
40. Care coordination [bin.]	care_coordination	130. 2013 [bin.]	y2013
Community Characteristics			
Education			
41. No high school diploma [con.]	edf_nohs_pc		
42. High school diploma [con.]	edf_hs_ps		
43. Some college [con.]	edf_college_pc		
44. College degree [con.]	edf_collegedegree_pc		
45. Income less than 50,000 [bin.]	iincome_less50k_bin		

Note. [con.] indicates a continuous variable, [bin.] – binary, [cat.] – categorical, and [str.] – a string variable with text.

Frequency Tables and Definitions of Variables

Demographic Characteristics

Hospice Episodes (N = 42,764)

#	Characteristic	Variable	n	%	M(SD)	Min.	Max.
0.	Age in years	age_yrs	-	-	7.45 (6.3)	0	20
1.	Age groups	age_groups				0	3
2.	Age 0 to 1 years	age0_1	5,536	12.95%			
3.	Age 1 to 5 years	age1_5	14,568	34.07%			
4.	Age 6 to 14 years	age6_14	14,437	33.76%			
5.	Age 15 to 20 years	age15_20	8,223	19.23%			
6.	Gender	gender				0	1
	0. Male		22,248	52.03%			
	1. Female		20,516	47.97%			
	Race						
7.	White	white				0	1
	0.non-White		22,697	53.08%			
	1.White		20,067	46.92%			
8.	Black	black				0	1
	1. Black		9,397	21.97%			
	0. non-Black		33,367	78.03			
9.	Ethnicity	hispanic				0	1
	1. Hispanic		12,074	28.23%			
	0. non-Hispanic		30,960	71.77%			

Children (N = 18,152)

#	Characteristic	Variable	n	%	M(SD)	Min.	Max.
0.	Age in years	age_yrs			7.08(6.3)	0	20
1.	Age groups	age_groups				0	3
2.	Age 0 to 1 years	age0_1	2,776	15.29%			
3.	Age 1 to 5 years	age1_5	6,552	36.10%			
4.	Age 6 to 14 years	age6_14	5,575	30.71%			
5.	Age 15 to 20 years	age15_20	3,249	17.90%			
6.	Gender	gender				0	1
	0. Male		9,297	51.22%			
	1. Female		8,855	48.78%			
7.	White	white				0	1
	0.non-White		8,385	46.19%			
	1.White		9,767	53.81%			
8.	Black	black				0	1
	1. Black		4,938	27.20%			
	0. non-Black		13,226	72.86%			
9.	Ethnicity	hispanic				0	1
	1. Hispanic		4,001	22.04%			
	0. non-Hispanic		14,151	77.96%			

Definitions of Variables

Variables 0 to 9. These variables indicate sociodemographic characteristics of hospice patients. They were created using MAX PS files.

0. Age in years variable ([age_yrs](#)) is calculated by subtracting birthdate ([s_el_dob_y](#)) from the year of data collection ([yr_num](#)).
1. Age groups ([age_groups](#)) is created by recording existing age groups ([el_age_grp_cd](#)) into four age categories: 0.) 0 to 1 years old, 1.) 1 to 5 years old, 2.) 6 to 14 years old, 3.) 15 to 20 years old. These categories were saved into separate dummies:
 2. Age 0 to 1 ([age0_1](#)),
 3. Age 1 to 5 years ([age1_5](#)),
 4. Age 6 to 14 years ([age6_14](#)),
 5. Age 15 to 20 years ([age15_20](#)).
6. Gender variable ([gender](#)) is created by recoding the existing variable ([el_sex_cd](#)) into a new with two categories: male and female
7. White race ([white](#)) is created by recoding the dummy variable ([race_code_1](#)).
8. Black race ([black](#)) is created by recoding the dummy variable ([race_code_2](#)).
9. Hispanic ethnicity ([hispanic](#)) is created by recoding a categorical variable ([ethnicity_code](#)) with value=1.

Health Characteristics

Hospice Episodes (N = 42,764)

#	Characteristic	Variable name	n	%	M(SD)	Min.	Max.
10.	Neurologic and neuromuscular	ccc_neuro	14,142	33.07%		0	1
11.	Cardiovascular	ccc_cardiac	13,698	32.03%		0	1
12.	Respiratory	ccc_resp	10,104	23.63%		0	1
13.	Renal and urologic	ccc_renal	3,921	9.17%		0	1
14.	Gastrointestinal	ccc_gastro	13,050	30.52%		0	1
15.	Hematologic and immun.	ccc_hemat	5,006	11.71%		0	1
16.	Metabolic	ccc_metabolic	7,082	16.56%		0	1
17.	Other congenital and Genetic	ccc_congenital	9,044	21.15%		0	1
18.	Malignancy	ccc_cancer	6,009	14.05%		0	1
19.	Premature and neonatal	ccc_neonatal	4,225	9.88%		0	1
20.	Miscellaneous	ccc_mis	18,457	43.20%		0	1
21.	Mental health	mental_all	20,257	47.37%		0	1
22.	Technology dependence	function_status	16,417	38.39%		0	1
23.	Med complexity	med_complex	11,745	27.46%		0	1
24.	Med complexity, any	med_complex_any	31,022	72.54%		0	1
25.	Increase medical complexity	increase_med_compl	-	-	1.23(1.28)	0	3
26.	Health condition	ccc	27,465	64.22%		0	1
27.	Health severity	mcc	19,464	45.51%		0	1

Children (N = 18,152)

#	Characteristic	Variable name	n	%	M(SD)	Min.	Max.
10.	Neurologic and neuromuscular	ccc_neuro	13053	16.82%		0	1
11.	Cardiovascular	ccc_cardiac	3694	20.35%		0	1
12.	Respiratory	ccc_resp	2024	11.15%		0	1
13.	Renal and urologic	ccc_renal	893	4.92%		0	1
14.	Gastrointestinal	ccc_gastro	2695	14.85%		0	1
15.	Hematologic and immun.	ccc_hemat	1312	7.23%		0	1
16.	Metabolic	ccc_metabolic	1956	10.78%		0	1
17.	Congenital and genetic	ccc_congenital	1954	10.76%		0	1
18.	Malignancy	ccc_cancer	1690	9.31%		0	1
19.	Premature and neonatal	ccc_neonatal	629	3.47%		0	1
20.	Miscellaneous	ccc_mis	4974	27.40%		0	1
21.	Mental health	mental_all	6,195	34.13%		0	1
22.	Technology dependence	function_status	4,160	22.92%		0	1
23.	Med complexity	med_complex	2,357	12.98%		0	1
24.	Med complexity, any	med_complex_any	10,856	59.81%		0	1
25.	Increase medical complexity	increase_med_compl	-	-	.74(1.10)	0	3
26.	Health condition	ccc	8784	48.39%		0	1
27.	Health severity	mcc	5088	28.03%		0	1

Definitions of Variables

Variables 10 to 20. All health characteristics of patients were extracted from MAX IP files which retained ICD-9 codes for each medical condition (variables [diag_cd_*](#)). Using this data and definitions of complex chronic conditions variables published by [Feudtner et al., \(2014\)](#), our team created 11 dummy variables ([ccc_*](#)) for each primary complex chronic condition including:

10. Neurologic and neuromuscular ([ccc_neuro](#)),
11. Cardiovascular ([ccc_cardiac](#)),
12. Respiratory ([ccc_resp](#)),
13. Renal and urologic ([ccc_renal](#)),
14. Gastrointestinal ([ccc_gastro](#)),
15. Hematologic or immunologic ([ccc_hemat](#)),
16. Metabolic ([ccc_metabolic](#)),
17. Congenital or genetic defect ([ccc_congenital](#)),
18. Malignancy ([ccc_cancer](#)),
19. Premature and neonatal ([ccc_neonatal](#)),
20. Miscellaneous ([ccc_misc](#)).

Variables 21 to 27. Our team also created seven additional health variables including:

21. Mental health ([mental_all](#)) indicates having any mental and behavioral health conditions: anxiety (ICD-9-CM: 300, 308), neurodevelopment disorders (ICD-9-CM: 299, 314), psychotic disorders (ICD-9-CM: 293-295, 297, 298, 316), substance misuse (ICD-9-CM: 291-292, 303-305), cognitive (ICD-9-CM: 290, 310, 315, 317-319), mood disorders (ICD-9-CM: 300.4, 296.1-296.9, 311), behavioral disorders (ICD-9-CM: 312-313), and other mental health conditions (ICD-9-CM: 301-302, 306-307).⁸
22. Technology dependency ([function_status](#)) is defined according to Feudtner's definition.⁹
23. Medical complexity ([med_complex](#)) indicates having all four medical conditions, including [ccc](#), [mccc](#), [function_status](#), and [mental health](#)
24. Any Medical complexity ([med_complex_any](#)) indicates having any one of the four complex conditions (including [ccc](#), [mccc](#), [function_status](#), and [mental health](#)).
25. Increased medical complexity ([increase_med_compl](#)) indicates the number of complex conditions (including [ccc](#), [mccc](#), [function_status](#), and [mental health](#)).
26. Health conditions ([ccc](#)) indicates having any of the 11 primary complex chronic conditions.
27. Health severity ([mccc](#)) indicates having two or more of the 11 primary complex chronic conditions.

Provider Characteristics

Hospice Episodes (N = 42,764)

#	Characteristics	Variable name	n	%	M(SD)	Min.	Max.
28.	Live discharge patients	iTotal_Live_Dis	-	-	114.8(130.34)	11	2,217
29.	Short-stay patients	iHbene_7orless_hospcaresdays	-	-	345.92(405.59)	0	5,383
30.	Medicaid patients	iMedicElig_hospbene	-	-	329.19(528.49)	11	6,744
31.	Hospice size, employees	Hospice_size				0	3
32.	Less than 5	hospice_mini	7,527	17.60%			
33.	Micro, 5 to 9	hospice_micro	6,303	14.74%			
34.	Small, 20 to 49	hospice_small	11,262	26.34%			
35.	Medium to large, 50+	hospice_large	17,672	41.32%			
36.	Hospice ownership	hospice_ownership				0	1
	1.Non-profit/ Government		16,605	38.83%			
	0.For profit		26,159	61.17%			
37.	Hospice age, years	hospice_age			18.30(10.04)	.70	30.2
38.	Hospice RN visits	ihospice_rnvisits			.34(.12)	0	2.7
39.	Pediatric program	pediatric_prgrm	15,037	35.16%		0	1
40.	Care coordination	care_coordination	42,744	99.95%			

Children (N = 18,152)

#	Characteristics	Variable name	n	%	M/SD	Min.	Max.
28.	Live discharge patients	iTotal_Live_Dis	-	-	103.95/128.88	11	2,217
29.	Short-stay patients	iHbene_7orless_hospcaresdays	-	-	310.52/393.43	0	5,383
30.	Medicaid patients	iMedicElig_hospbene	-	-	295.23/464.80	11	6,744
31.	Hospice size, employees	Hospice_size	-	-			
32.	Less than 5	hospice_mini	4,019	22.14%		0	1
33.	Micro, 5 to 9	hospice_micro	3,986	21.63%		0	1
34.	Small, 20 to 49	hospice_small	3,710	21.96%		0	1
35.	Medium to large, 50+	hospice_large	6,437	35.46%		0	1
36.	Hospice ownership	hospice_ownership					
	1.Non-profit/ Government		7,011	38.62%		0	1
	0.For profit		11,141	61.38%		0	1
37.	Hospice age, years	hospice_age			16.56/9.82	.70	30.2
38.	Hospice RN visits	ihospice_rnvisits			.34/.13	0	2.7
39.	Pediatric program	pediatric_prgrm	6,090	33.55%		0	1
40.	Care coordination	care_coordination	18,148	99.98%		0	1

Definitions of Variables

Provider characteristics were extracted from the publicly available CMS Hospice Provider of Services files (POS) and CMS Hospice Utilization and Payment files (PUF).⁵ The following variables were created:

28. Live discharge patients (*iTotal_Live_Dis*) indicates the number of distinct patients with live discharges from hospice care. “A hospice beneficiary was considered to have a live discharge if the hospice beneficiary did not die in hospice care and was not receiving hospice care. Includes live discharges for any reason including revocation” (PUF manual, p.7). It was created using (*iTotal_Live_Dis*) from the PUF file.
29. Short-stay patients (*iHbene_7orless_hospicedays*) indicates the number of patients with 7 or fewer hospice care days. Excludes hospice beneficiaries whose hospice care continued from a previous calendar year or into the next calendar year (PUF manual, p.7). It was created using (*Total_Live_Dis*) from the PUF file.
30. Medicaid patients (*iMedicElig_hospbene*) indicates the number patients eligible for Medicaid for at least one month and receiving at least one day of hospice care in the calendar year (PUF manual, p.7). It was created using (*MedicElig_hospbene*) from the PUF file.
31. Hospice size (*hospice_size*) indicates the number of employees working in the hospice. It was created using the Employee Count variable (*emplyee_cnt*) from the POS file. Four subcategories of hospices were identified: 1.) Mini hospice with less than 7 employees; 2.) Micro hospice with 5 to 9 employees; 3.) Small hospice with 20 to 49 employees, and 0.) Medium to large hospice with 50 or more employees. These categories were also saved as respective dummies:
32. Mini hospice with less than 7 employees (*hospice_mini*).
33. Micro hospice with 5 to 9 employees (*hospice_micro*).
34. Small hospices with 20 to 49 employees (*hospice_small*).
35. Medium to large hospices with 50 employees or more (*hospice_large*).
36. The hospice ownership (*hospice_ownership*) indicates two types of hospice ownership: 1.) Non-profit or Governmental, and 0.) For-profit. It was created using the Ownership type of the provider variable (*gnrl_cntl_type_cd*) from the POS file.
37. Hospice age in years (*hospice_age*) indicates the age of the hospice. It was calculated by subtracting the date when the provider was first approved to provide Medicare and/or Medicaid service variable (*orgnl_ptcptn_dt*) from the last day of 2013 and divided by 365.25.¹⁰ The (*orgnl_ptcptn_dt*) variable was extracted from the POS file.

38. Hospice RN visits ([ihospice_rnvisits](#)) indicates the average number of hours per day of skilled nursing hospice care provided. Skilled nursing visits were identified using Revenue Codes 0550, 0551, 0552, and 0559 (PUF manual, p.6). It was created using ([hospice_rnvisits](#)) variable from the PUF file.
39. Pediatric program ([pediatric_prgrm](#)) indicates whether a hospice provided any pediatric services and was created using publicly available data.
40. Care coordination ([care_coordination](#)) indicates any transitional care management (TCM), patient-centered medical home care, or managed care. It was created using variables ([enctr_rec_cnt_31](#); [ffs_clm_cnt_31](#); [ffs_pymt_amt_31](#); [ffs_chrg_amt_31](#); [ffs_tp_amt_31](#); [cltc_ffs_pymt_amt_17](#); [cltc_ffs_pymt_amt_37](#); [mc_combo_mo_1](#) through 12; [el_pph_pln_mo_cnt_cmcp](#)) from the PS MAX file.

Community Characteristics

Hospice Episodes (N = 42,764)

#	Characteristic	Variable name	n	%	M(SD)	Min.	Max.
<i>Education</i>							
41.	No high school	edf_nohs_pc	-	-	14.01(4.39)	3.41	38.21
42.	High school	edf_hs_ps	-	-	24.17(9.59)	12.35	52.46
43.	Some college	edf_college_pc	-	-	24.49(6.88)	14.34	45.44
44.	College degree	edf_collegedegree_pc	-	-	37.33(14.95)	5.83	59.98
45.	Income less than \$50,000	income_less50k_bin	11,874	27.77%			
46.	Region	region				0	3
47.	Northeast	region_neast	22,207	51.93%		0	1
48.	Midwest	region_mwest	6,965	16.29%		0	1
49.	South	region_south	4,260	9.96%		0	1
50.	West	region_west	9,332	21.82%		0	1
51.	Appalachia	region_app	4,350	10.17%		0	1
52.	Southern Appalachia	region_sapp	1,860	4.35%		0	1
53.	Rurality	ru_hrsa2				0	1
	1. Urban		24,873	58.16%			
	0. Rural		17,891	41.84%			
54.	U.S. States	state_cd					
55.		AK	2	0%		0	1
56.		AL	66	0.15%		0	1
57.		AR	125	0.29%		0	1
58.		CA	8107	18.96%		0	1
59.		CO	219	0.51%		0	1
60.		CT	12	0.03%		0	1
61.		DC	2	0%		0	1
62.		DE	22	0.05%		0	1
63.		FL	817	1.91%		0	1
64.		GA	349	0.82%		0	1
65.		HI	17	0.04%		0	1
66.		IA	54	0.13%		0	1
67.		ID	15	0.04%		0	1
68.		IL	84	0.20%		0	1
69.		IN	185	0.43%		0	1
70.		KS	87	0.20%		0	1
71.		KY	402	0.94%		0	1
72.		LA	78	0.18%		0	1
73.		MA	305	0.71%		0	1
74.		MD	575	1.34%		0	1
75.		ME	2	0%		0	1
76.		MI	680	1.59%		0	1
77.		MN	38	0.09%		0	1
78.		MO	77	0.18%		0	1
79.		MS	130	0.30%		0	1
80.		MT	13	0.03%		0	1

81.	NC	157	0.37%	0	1
82.	ND	4	0.01%	0	1
83.	NJ	14	0.03%	0	1
84.	NM	598	1.4%	0	1
85.	NV	39	0.09%	0	1
86.	NY	19,238	44.99%	0	1
87.	OH	5,147	12.04%	0	1
88.	OK	101	0.24%	0	1
89.	OR	21	0.05%	0	1
90.	PA	2,632	6.15%	0	1
91.	SC	79	0.18%	0	1
92.	SD	16	0.04%	0	1
93.	TN	424	0.99%	0	1
94.	TX	680	1.59%	0	1
95.	UT	300	0.70%	0	1
96.	VA	141	0.33%	0	1
97.	VT	4	0.01%	0	1
98.	WI	593	1.39%	0	1
99.	WV	112	0.26%	0	1
100.	WY	1	0.00%	0	1

Children (N = 18,152)

#	Characteristic	Variable name	n	%	M(SD)	Min.	Max.
Education							
41.	No high school	edf_nohs_pc	-	-	13.39(4.09)	3.41	38.21
42.	High school	edf_hs_ps	-	-	24.93(9.35)	12.35	52.46
43.	Some college	edf_college_pc	-	-	23.71(6.87)	14.34	45.44
44.	College degree	edf_collegedegree_pc	-	-	37.98(15.87)	5.83	59.98
45.	Income, less than \$50,000	income_less50k_bin	6,455	35.56%			
46.	Region	region	-	-	-	1	4
47.	Northeast	region_neast	4,404	24.26%		0	1
48.	Midwest	region_mwest	10,431	57.46%		0	1
49.	South	region_south	2,132	11.75%		0	1
50.	West	region_west	1,185	6.53%		0	1
51.	Appalachia	region_app	1,788	9.85%		0	1
52.	Southern Appalachia	region_sapp	869	4.79%			
53.	Rurality	ru_hrsa2					
	1.Urban		12,089	66.60%			
	0.Rural		6,063	33.40%			
54.	U.S.States	state_cd					
55.		AK	1	0.01%		0	1
56.		AL	43	0.24%		0	1
57.		AR	59	0.33%		0	1
58.		CA	853	4.7%		0	1
59.		CO	36	0.2%		0	1
60.		CT	12	0.07%		0	1
61.		DC	2	0.01%		0	1
62.		DE	13	0.07%		0	1
63.		FL	241	1.33%		0	1
64.		GA	204	1.12%		0	1
65.		HI	10	0.06%		0	1
66.		IA	36	0.2%		0	1
67.		ID	13	0.07%		0	1
68.		IL	73	0.4%		0	1
69.		IN	158	0.87%		0	1
70.		KS	58	0.32%		0	1
71.		KY	86	0.47%		0	1
72.		LA	60	0.33%		0	1
73.		MA	27	0.15%		0	1
74.		MD	390	2.15%		0	1
75.		ME	2	0.01%		0	1
76.		MI	201	1.11%		0	1
77.		MN	25	0.14%		0	1
78.		MO	52	0.29%		0	1
79.		MS	74	0.41%		0	1
80.		MT	12	0.07%		0	1
81.		NC	115	0.63%		0	1

82.	ND	2	0.01%	0	1
83.	NJ	11	0.06%	0	1
84.	NM	57	0.31%	0	1
85.	NV	33	0.18%	0	1
86.	NY	9,608	52.93%	0	1
87.	OH	3,604	19.85%	0	1
88.	OK	26	0.14%	0	1
89.	OR	10	0.06%	0	1
90.	PA	767	4.23%	0	1
91.	SC	59	0.33%	0	1
92.	SD	13	0.07%	0	1
93.	TN	156	0.86%	0	1
94.	TX	472	2.6%	0	1
95.	UT	159	0.88%	0	1
96.	VA	95	0.52%	0	1
97.	VT	4	0.02%	0	1
98.	WI	182	1%	0	1
99.	WV	37	0.2%	0	1
100.	WY	1	0.01%	0	1

Definitions of Variables

Variables 41 to 44. Education level in the community is measured using data from the U.S. Census Bureau American Community Survey. It includes four variables representing proportions of populations with different educational levels, such as:

41. No high school diploma ([edf_nohs_pc](#))

42. High school diploma ([edf_hs_ps](#))

43. Some college ([edf_college_pc](#)), and

44. College degree ([edf_collegedegree_pc](#))

45. Income in the community is measured using data from the U.S. Census Bureau American Community Survey, which was recoded into a dummy variable whether the median income in less than \$50,000 ([income_less50k_bin](#)).

Variables 46 to 52. Four regions are identified following the U.S. Postal service distinction and include North-East which comprised of 7 states: ME, VT, PA, NY, NJ, MA, CT; Midwest with 11 states: ND, SD, KS, MN, IA, MO, WI, IL, MI, IN, OH; South with 17 states: TX, OK, AR, LA, KY, TN, WV, MD, DE, DC, VA, NC, SC, GA, FL, AL, MS; and West with 11 states: MT, WY, ID, OR, CO, UT, NV, CA, NM, AK, HI. These regions are recoded into two sets of variables:

46. A categorical variable ([region](#)) coded as 0.) Northeast, 1.) Midwest, 2.) South, and 3.) West

And 4 dummy variables:

47. Northeast ([region_neast](#))

48. West ([region_mwest](#))

49. South ([region_south](#))

50. West ([region_west](#))

Also, two sets of dummy variables identify regions of Appalachia in accordance with the distinction of the [Appalachian Regional Commission \(ARC\)](#):

51. A dummy variable indicating Appalachia region ([region_app](#))

52. A dummy variable indicating Southern Appalachia region ([region_sapp](#))

53. Rurality of the community was measured using the rural-urban distinction of the [Health Resources and Services Administration \(HRSA\)](#). It was saved as a dummy variable ([ru_hrsa2](#)) with two categories: 1. Urban, and 0. Rural

Variables 54 to 100. State of residence is coded using two sets of variables:

54. A string variable ([state_cd](#))

55 to 100. A set of a dummy variable, including [AK](#), [AL](#), [AR](#), [CA](#), [CO](#), [CT](#), [DC](#), [DE](#), [FL](#), [GA](#), [HI](#), [IA](#), [ID](#), [IL](#), [IN](#), [KS](#), [KY](#), [LA](#), [MA](#), [MD](#), [ME](#), [MI](#), [MN](#), [MO](#), [MS](#), [MT](#), [NC](#), [ND](#), [NJ](#), [NM](#), [NV](#), [NY](#), [OH](#), [OK](#), [OR](#), [PA](#), [SC](#), [SD](#), [TN](#), [TX](#), [UT](#), [VA](#), [WI](#), [WV](#), and [WY](#).

Clinical Characteristics

Hospice Episodes (N = 42,764)

#	Characteristic	Variable name	n	%	M(SD)	Min.	Max.
101.	Hospice LOS	total_los	-	-	57.85 (72.45)	1	1099
102.	Medical Team Size	coord_phy	-	-	1.29 (1.50)	1	28
103.	Hospice Live Discharge	fhospice_live_disch_episode	-	-	20.39 (6.69)	0	216
104.	Symptom management	sym_mgt_icd9	9,482	22.17%	-	0	1
105.	1day Hospice	care_intensity_1day	9,146	21.39%	-	0	1
106.	Hospice Transition ER	transition_er	3,611	8.44%	-	0	1
107.	Primary Care Visits	physician_use	14,418	33.72%	-	0	1
108.	Hospice Transition Inpatient	transition_inpt	2,633	6.16%	-	0	1
109.	Coordination Insurance	coord_ins	12,377	28.94%	-	0	1
110.	# of episodes per child	ftotal_epi	-	-	21.39(6.70)	1	217
111.	Concurrent care (rx)	concurrent_care_rx	9,725	22.74%	-	0	1
Costs							
112.	Total costs	icosts_tot	-	-	4,833(9,237)	0	352,029
113.	Fee-for-services	icosts_tot_ffs	-	-	4,490(9228)	0	352,029
114.	Premium payment	icosts_tot_prem	-	-	342(744)	0	31,373
115.	Inpatient	icosts_tot_ip	-	-	1,555(5808)	0	349,426
116.	Outpatient	icosts_tot_ot	-	-	76(431)	0	27,710
117.	Prescription drugs	icosts_tot_rx	-	-	455(1928)	0	76,480
118.	Labs	icosts_tot_lab	-	-	59(254)	0	9,442
119.	Transportation	icosts_tot_transport	-	-	16(113)	0	10,000
120.	Therapies	icosts_tot_therapies	-	-	4(44)	0	1,657
121.	Hospice benefits	icosts_tot_hb	-	-	619(1950)	0	30,980
122.	Registered nurse visits	icosts_tot_RN	-	-	57(658)	0	29,835
123.	Durable medical equipment	icosts_tot_dme	-	-	250(765)	0	13,373

Children (N = 18,152)

#	Characteristic	Variable name	n	%	M(SD)	Min.	Max.
101.	Hospice LOS	total_los	-	-	57.85 (72.45)	1	1099
102.	Medical Team Size	coord_phy	-	-	1.29 (1.50)	1	28
103.	Hospice Live Discharge	fhospice_live_disch_episode	-	-	20.39 (6.69)	0	216
104.	Symptom management	sym_mgt_icd9	2,605	14.35%	-	-	-
105.	1day Hospice	care_intensity_1day	9,146	50.39%	-	0	1
106.	Hospice Transition ER	transition_er	2,990	16.47%	-	0	1
107.	Primary Care Visits	physician_use	9,657	53.20%	-	0	1
108.	Hospice Transition Inpatient	transition_inpt	1,806	9.95%	-	0	1
109.	Coordination Insurance	coord_ins	6,232	34.33%	-	0	1
110.	# of episodes per child	ftotal_epi	-	-	21.39(6.70)	1	217
111.	Concurrent care	concurrent_care_rx	62,43	34.39%	-	0	1
Costs							
112.	Total costs	icosts_tot	-	-	2,566(8,374)	0	352,029
113.	Fee-for-services	icosts_tot_ffs	-	-	2,281(8,382)	0	352,029
114.	Premium payment	icosts_tot_prem	-	-	285(610)	0	31,373
115.	Inpatient	icosts_tot_ip	-	-	1,260(6,799)	0	349,426
116.	Outpatient	icosts_tot_ot	-	-	59(492)	0	27,710
117.	Prescription drugs	icosts_tot_rx	-	-	142(1062)	0	76,480
118.	Labs	icosts_tot_lab	-	-	43(252)	0	9,442
119.	Transportation	icosts_tot_transport	-	-	16(139)	0	10,000
120.	Therapies	icosts_tot_therapies	-	-	3(37)	0	1,656
121.	Hospice benefits	icosts_tot_hb	-	-	254(943)	0	30,980
122.	Registered nurse visits	icosts_tot_RN	-	-	38(578)	0	29,834
123.	Durable medical equipment	icosts_tot_dme	-	-	65(370)	0	13,373

Definitions of Variables

Variables 101 to 112. Clinical characteristics were computed based on episodes. For detailed information on how episodes were created see Appendix 1. All variables were created using MAX PS, OT, RX, and IP files.

101. Hospice LOS ([total_los](#)) is a continuous measure of the total length of all episodes in days.

102. Medical Team Size ([coord_phy](#)) is a continuous measure of the number of providers who provided services during a hospice episode and had respective National Provider Identifier numbers (NPIs).

103. Hospice live discharge ([fhospice_live_disch_episode](#)) is a dummy indicator of hospital admission within after 2 days of hospice discharge.

104. Symptom management ([sym_mgt_icd9](#)) is an indicator of any services for constipation received during hospice episode. Constipation is defined using Rx_NDC codes 0904-7889; 0121-1154-00; 45802-868; 49348-189; 21130-693-38; ICD-9 codes: 564.0, 560.32, 787.61, 306.40, 87.79, 88.19; and procedure codes 45915, 99511, 74000, 74010, and 74020.

105. 1-day hospice variable ([care_intensity_1day](#)) is a dummy indicator of a 1-day hospice episode.

106. The hospice transition ER variable ([transition_er](#)) is an indicator of the use of the ER office during hospice enrollment. ER use is defined by codes 99281; 99282; 99283; 99284; 99285.

107. The primary care visits variable ([physician_use](#)) is an indicator of the use of physician's office during hospice enrollment. Physician's use is defined by OT procedure codes 99205; 99215; 99211; 99212; 99213; 99214; 99215; 99201; 99202; 99203; 99204.

108. Hospice transition inpatient ([transition_inpt](#)) is a dummy indicator of transition to inpatient services

109. Coordination insurance ([coord_ins](#)) is a dummy variable indicating whether a patient had private health insurance coverage for the each of 12 months of the year (el_pvt_ins_cd_1 to el_pvt_ins_cd_12)

110. The number of episodes per child ([ftotal_epi](#)) is defined as the total number of episodes per child.

125. The concurrent care ([concurrent_care_rx](#)) is a dummy vindicator of receiving concurrent hospice care services. It is defined as receiving any medication during a hospice episode.

Variables 113 to 124. Costs of care were created using data from the MAX PS file. Each variable is calculated using a proportion where the numerator is the appropriate cost measure and the denominator is the total number of months the patient is eligible for Medicaid during the calendar year ([el_elgblty_mo_cnt](#)).

113. For the total costs variable ([icosts_tot](#)) the numerator is the total amount of money paid by Medicaid for the recipient during the calendar year for all types of service and any type of claim ([tot_mdcd_pymt_amt](#)).

114. For the fee-for-services cost variable ([icosts_tot_ffs](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year ([tot_mdcd_ffs_pymt_amt](#)) for the following types of services ([TOS](#)):

- 01 = inpatient hospital
- 02 = mental hospital services for the aged
- 04 = inpatient psychiatric facility for individuals under the age of 21
- 05 = intermediate care facility (ICF) for the mentally retarded
- 07 = nursing facility services (NFS)
- 08 = physicians
- 09 = dental
- 10 = other practitioners
- 11 = outpatient hospital
- 12 = clinic
- 13 = home health
- 15 = lab and x-ray
- 16 = drugs
- 19 = other services
- 24 = sterilizations
- 25 = abortions
- 26 = transportation services
- 30 = personal care services
- 31 = targeted case management
- 33 = rehabilitation services
- 34 = PT, OT, speech, hearing services
- 35 = hospice benefits
- 36 = nurse midwife services
- 37 = nurse practitioner services
- 38 = private duty nursing
- 39 = religious non-medical health care institutions
- 51 = durable medical equipment and supplies (including emergency response systems and home modifications)
- 52 = residential care
- 53 = psychiatric services (excluding adult day care)
- 54 = adult day care
- 99 = unknown

115. For the premium payment cost variable ([icosts_tot_prem](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year ([tot_mdcd_prem_pymt_amt](#)), for the following TOS:

20 = Capitated payments to HMO, HIO, or PACE plans

21 = Capitated payments to prepaid health plans - PHPS

22 = Capitated payments for primary care case management - PCCM

116. For the inpatient cost ([icosts_tot_ip](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year for the inpatient hospital services ([ffs_payment_amt_01](#)).

117. For the outpatient cost ([icosts_tot_ot](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year for the outpatient hospital services ([ffs_payment_amt_11](#)).

118. For the prescription drugs cost ([icosts_tot_rx](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year for the drug prescriptions ([ffs_payment_amt_16](#)).

119. For the labs cost ([icosts_tot_lab](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year for the lab and x-ray services ([ffs_payment_amt_15](#)).

120. For the transportation cost ([icosts_tot_transport](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year for the transportation services ([ffs_payment_amt_26](#)).

121. For the therapies cost ([icosts_tot_therapies](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year for the PT, OT, speech, hearing services ([ffs_payment_amt_34](#)).

122. For the Hospice benefits ([icosts_tot_hb](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year for the hospice benefits ([ffs_payment_amt_35](#)).

123. For the registered nurse visits cost ([icosts_tot_rn](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year for the nurse practitioner ([ffs_payment_amt_37](#)) and private duty nursing services ([ffs_payment_amt_38](#)).

124. For the durable medical equipment cost ([icosts_tot_dme](#)) the numerator is the amount of money paid by Medicaid for the recipient during the calendar year, for the durable medical equipment and supplies, including emergency response systems and home modifications ([ffs_payment_amt_51](#)).

Other Variables

Hospice Episodes (N = 42,764)

#	Characteristic	Variable name	n	%	M(SD)	Min.
124.	Medicaid waiver	waiver	34,833	81.45%	0	1
125.	Palliative policy	instrument_pall_policy	9,532	22.29%	0	1
126.	Hospice's postal ZIP code	-	-	-	-	-
127.	Patient's postal ZIP code	-	-	-	-	-
<i>Years</i>						
128.	2011	y2011	10,121	23.67%	0	1
129.	2012	y2012	7,472	17.47%	0	1
130.	2013	y2013	25,171	58.86%	0	1

Children (N = 18,152)

#	Characteristic	Variable name	n	%	M(SD)	Min.
124.	Medicaid waiver	waiver	13,215	72.80%	0	1
125.	Palliative policy	instrument_pall_policy	1,230	6.78%	0	1
126.	Hospice's postal ZIP code	-	-	-	-	-
127.	Patient's postal ZIP code	-	-	-	-	-
Years						
128.	2011	y2011	5,328	29.35%	0	1
129.	2012	y2012	2,111	11.63	0	1
130.	2013	y2013	11,218	61.80	0	1

Definitions of Variables

Other variables were created using MAX PS files.

124. Medicaid waiver ([waiver](#)) is a dummy indicator of patient waiver enrollment for each of 12 months of the year ([max_waiver_type_1_mo_1](#) to [max_waiver_type_3_mo_12](#)).

125. Instrument pall policy ([instrument_pall_policy](#)) is a dummy indicator of States with palliative policies, including California, Colorado, Illinois, Florida, Massachusetts, and Washington.

126. The hospices postal ZIP code ([ziphosp](#)) is a string variable that includes ZIP codes from the CMS PUF file.

127. The patient's postal ZIP code variable ([ZIP](#)) is a string variable that includes ZIP codes from the PS MAX file.

Variables 128-130. The year of data collection is coded into three dummy variables: [y2011](#), [y2012](#), and [y2013](#).

Annotated List of Publications

Cozad, M., Lindley, L. C., Eaker, C., Carlosh, K. A., & Profant, T. L. (2019). Debunking myths about health insurance claims data for public health research and practice. *American Journal of Public Health*, 109(11), 1584–1585. <https://doi.org/10.2105/AJPH.2019.305317>

This paper examined three prevailing myths regarding claims data to raise awareness about their use in creating reliable evidence that supports public health practice.

Keim-Malpass, J., Cozad, M. J., Svyrenko, R., Mack, J. W., & Lindley, L. C. (2021). Medical complexity and concurrent hospice care: A national study of Medicaid children from 2011 to 2013. *Journal for Specialists in Pediatric Nursing*, e12333. <https://doi.org/10.1111/jspn.12333>

The objectives of this study were to examine the prevalence of concurrent hospice care over time and investigate the relationship between medical complexity and concurrent hospice care among Medicaid children.

Laird, J., Cozad, M. J., Keim-Malpass, J., Mack, J. W., & Lindley, L. C. (2020). Variation in state Medicaid implementation of the ACA: The case of concurrent care for children. *Health Affairs*, 39(10), 1770–1775. <https://doi.org/10.1377/hlthaff.2020.01192>

This paper examined the state-level implementation of concurrent care for Medicaid beneficiaries and found significant variability in guidelines across the US.

Lindley, L. C., Cozad, M. J., Mack, J. W., Keim-Malpass, J., Svyrenko, R., & Hinds, P. S. (2021). Effectiveness of pediatric concurrent hospice care to improve continuity of care. *The American Journal of Hospice & Palliative Care*, 10499091211056040 <https://doi.org/10.1177/10499091211056039>

The purpose of this study was to test the hypotheses that children who used concurrent hospice care would have a longer length of stay in hospice, reduced disenrollment from hospice, and fewer transitions to the emergency room or inpatient setting, compared to those using standard hospice care.

Lindley, L. C., Cozad, M. J., Svyrenko, R., Keim-Malpass, J., & Mack, J. W. (2021). A national profile of children receiving pediatric concurrent hospice care, 2011 to 2013. *Journal of Hospice and Palliative Nursing*, 23(3).

This study conducted a descriptive analysis of the demographic, community, hospice, and clinical characteristics of children who received concurrent hospice care between 2011 and 2013.

Lindley, L. C., Cozad, M. J., & Fortney, C. A. (2020). Pediatric complex chronic conditions: Evaluating two versions of the classification system. *Western Journal of Nursing Research*, 42(6), 454–461. <https://doi.org/10.1177/0193945919867266>

The purpose of this study was to generate data on the complex chronic conditions (CCC) classification applied to infants by examining the prevalence of CCCs and investigating the characteristics related to a CCC classification in a national sample of infants less than 1 year.

Lindley, L. C., & Fortney, C. A. (2019). Pediatric complex chronic conditions: Does the classification system work for infants? *American Journal of Hospice and Palliative Medicine*®, 104990911983898. <https://doi.org/10.1177/1049909119838985>

This research examined the prevalence of complex chronic conditions (CCC) and the infant characteristics related to a CCC classification

Lindley, L. C., Fortney, C. A., & Cozad, M. J. (2021). Predictive ability of an illness severity measure: Implications for nursing research. *Journal of Nursing Measurement*. <https://doi.org/10.1891/JNM-D-19-00106>

The objective of this study was to compare the predictive performance of the original (Feudtner et al., 2000; Feudtner et al., 2001) versus the revised (Feudtner et al., 2014) complex chronic conditions (CCC) measure among infants.

Lindley, L. C., Keim-Malpass, J., Cozad, M. J., Mack, J. W., Svynarenko, R., Fornehed, M. L. C., Stone, W., Qualls, K., & Hinds, P. S. (2022). A national study to compare effective management of constipation in children receiving concurrent versus standard hospice care. *Journal of Hospice and Palliative Nursing: JHPN: The Official Journal of the Hospice and Palliative Nurses Association*, 24(1), 70–77. <https://doi.org/10.1097/NJH.0000000000000810>

The purpose of this study was to evaluate the effectiveness of pediatric concurrent hospice versus standard hospice care to manage constipation.

Lindley, L. C., Keim-Malpass, J., Svynarenko, R., Cozad, M. J., Mack, J. W., & Hinds, P. S. (2020). Pediatric concurrent hospice care: A scoping review and directions for future nursing research. *Journal of Hospice & Palliative Nursing*, 22(3), 238–245. <https://doi.org/10.1097/NJH.0000000000000648>

The purpose of this study was to systematically collect the evidence on concurrent hospice care, critically appraise the evidence, and identify areas for future nursing research.

Lindley, L. C., Svynarenko, R., & Beebe, L. H. (2021). Mental health and developmental disabilities in US children admitted in hospice care. *International Journal of Palliative Nursing*, 27(3), 124–130. <https://doi.org/10.12968/ijpn.2021.27.3.124>

This paper aimed to describe the mental health and developmental disabilities of children who were admitted to hospice care and compare them across age groups.

Lindley, L. C., Svynarenko, R., Mooney-Doyle, K., Mendola, A., Naumann, W. C., & Fortney, C. A. (2021a). End-of-life healthcare service needs among children with neurological conditions: A latent class analysis. *The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses*. <https://doi.org/10.1097/JNN.0000000000000615>

This paper had 2 aims: to apply latent class analysis to identify patterns of nonhospice, healthcare service needs among children with neuro- logical conditions; and to assess the characteristics of latent class membership.

Lindley, L. C., Svynarenko, R., Mooney-Doyle, K., Mendola, A., Naumann, W., & Keim-Malpass, J. (2021b). Patterns of health care services during pediatric concurrent hospice care: A national study. *American Journal of Hospice & Palliative Medicine*, 1-7. <https://doi.org/10.1177/10499091211018661>

The purpose of this study was to examine the health care services received by children enrolled in concurrent hospice care, unique clusters of health care services, and characteristics of the children in the clusters.

Lindley, L. C., Svyrenko, R., & Profant, T. L. (2020). Data infrastructure for sensitive data: Nursing's role in the development of a secure research enclave. *Computers, Informatics, Nursing: CIN*, 38(9), 427–430. <https://doi.org/10.1097/CIN.0000000000000677>

This paper describes the development of a secure data infrastructure designed to work with protected health information (PHI), personally identifiable information (PII), or sensitive data.

Mendola, A., Naumann, W. C., Mooney-Doyle, K., & Lindley, L. C. (2021). Social determinants of comfort: A new term for end-of-life care. *Journal of Palliative Medicine*, 24(8), 1130–1131. <https://doi.org/10.1089/jpm.2021.0209>

This study proposed the term social determinants of comfort to describe structural conditions that influence whether, to what degree, and in what forms comfort measures are offered to and accepted by patients and their families.

Mooney-Doyle, K., Keim-Malpass, J., Svyrenko, R., & Lindley, L. C. (2021). A comparison of young adults with and without cancer in concurrent hospice care: Implications for transitioning to adult health care. *Journal of Adolescent and Young Adult Oncology*. <https://doi.org/10.1089/jayao.2021.0004>

This study compared young adults with and without cancer in concurrent hospice care.

Stone, W., Keim-Malpass, J., Cozad, M. J., Fornehed, M. L. C., & Lindley, L. C. (2021). Pediatric end-of-life care in rural America: A systematic review. *The American Journal of Hospice & Palliative Care*, 10499091211064202. <https://doi.org/10.1177/10499091211064202>

The purpose of this study was to comprehensively review and summarize the evidence regarding end-of-life care for children living in rural areas, identify key findings and gaps in the literature, and make recommendations for future research.

Svyrenko, R., Beebe, L. H., & Lindley, L. C. (2021). Identifying patterns of pediatric mental and behavioral health at end of life: A national study. *Journal of Hospice & Palliative Nursing*, Publish Ahead of Print. <https://doi.org/10.1097/NJH.0000000000000800>

the purpose of this study was to identify patterns of mental and behavioral health of children enrolled in hospice care and describe the demographic and health characteristics of children in these groups.

Svyrenko, R., & Lindley, L. (2021). Defining rurality in end-of-life research: Evaluation of common measures. *The Journal of Health Care for the Poor and Underserved*, 32(4), 2167–2180. <https://doi.org/10.1353/hpu.2021.0189>

The purpose of this study was to conduct a comprehensive evaluation of eight rural-urban classifications against the gold standard of the Office of Budget and Management to determine the utility of alternative measures in hospice research.

Svynarenko, R., Mack, J. W., & Lindley, L. C. (2021). Differences in characteristics of children with cancer who receive standard versus concurrent hospice care. *Pediatric Blood & Cancer*. <https://doi.org/10.1002/pbc.29106>

The purpose of the study was to compare demographic, health, and community characteristics of children who received standard hospice care versus concurrent hospice care.

Lindley, Lisa C., Radion Svynarenko, Kim Mooney-Doyle, Annette Mendola, Wendy C. Naumann, and Robin Harris. "A National Study of Healthcare Service Patterns at the End of Life among Children with Cardiac Disease." *The Journal of Cardiovascular Nursing*, December 21, 2021. <https://doi.org/10.1097/JCN.0000000000000875>.

The aims of this study were to identify patterns of nonhospice healthcare services used in concurrent hospice care and describe the profile of children with cardiac disease in these clusters.

Appendix: Creating Hospice Episodes

First, our team presents rules for episodes and then how to make episodes using manual transformation and syntax.

Rules for hospice episodes:

1. A hospice episode is a period of time when a patient receives hospice services.
2. There are two types of episodes: (a) single-day episodes and (b) multiple-day episodes with subsequent days of service.
3. An episode begins on the first day of service and ends when consecutive days of services come to end.
4. For single-day episodes, the first and the last day are the same days.
5. If there is a break between services for more than one day, these services belong to different episodes.
6. Episodes do not have duplicate dates.
7. The same person may have multiple episodes.

Manual transformations

We have three people (#6, #7, #8) with nine service days. They are sorted by ID and DATE.

ID	Date
6	20120205
6	20120206
6	20120207
7	20111209
7	20120101
7	20120102
8	20110103
8	20110103
8	20110104

We can identify four episodes:

1, 2, 3, 4.

Episode #4 for person #8 has one duplicate record: 20110103. It must be eliminated (rule #5)

ID	Date	Episode #
6	20120205	1
6	20120206	1
6	20120207	1
7	20111209	2
7	20120101	3
7	20120102	3
8	20110103	4
8	20110103	4
8	20110104	4

Then, we can reshape it wide based on episode #.

Episode #	ID	Start	End	LOS, days
1	6	20120205	20120207	4
2	7	20111209	20111209	1
3	7	20120101	20120102	2
4	8	20110103	20110104	1

Transformations with syntax¹:

¹ Syntax is borrowed from STATA's forum <https://www.statalist.org/forums/forum/general-stata-discussion/general/1415997-identifying-spells> More example on episodes management are in STATA's stset manual <https://www.stata.com/manuals13/ststset.pdf>

First: generate STATA readable dates, variable **date2**

```
. gen date2= date (date, "YMD")
. format %td date2
. drop date
```

ID	date	date2
6	20120205	05feb2012
6	20120206	06feb2012
6	20120207	07feb2012
7	20111209	09dec2011
7	20120101	01jan2012
7	20120102	02jan2012
8	20110103	03jan2011
8	20110103	03jan2011
8	20110104	05jan2011

Second: sort by **id** and **date2**, and then identify gaps between observations within each ID.

```
. sort id date2
/*sorting*/
. by id: gen gap = date2 - date2[_n-1]
/*gaps between observations within each ID*/
```

ID	date	Date 2	gap
6	05feb2012		.
6	06feb2012		1
6	07feb2012		1
7	09dec2011		.
7	01jan2012		23
7	02jan2012		1
8	03jan2011		.
8	03jan2011		0
8	04jan2011		1

How it works:

The third ($_n=3$) record in id#6 is 07feb2012 minus the previous record ($_n-1$) is 06feb2012, and the difference between them is equal to a 1-day gap.

Eighth ($_n=8$) record in id#8 is 03jan2011 minus previous record ($_n-1$) is 03jan2011 and equal to a 0-day gap, a duplicate record. Lines 1,4 and 7 are missing because they are the first ones within each new ID

*Third: identify uninterrupted episodes (i.e., spells) within each ID.

Interrupted episodes do not have time gaps of more than one day (see rule#4). In other words, if a gap is longer than one day, a new episode must be started.

```
.by id: gen spell = sum (gap > 1)
```

ID	date2	gap	spell
6	05feb2012	.	1
6	06feb2012	1	1
6	07feb2012	1	1
7	09dec2011	.	1
7	01jan2012	23	2
7	02jan2012	1	2
8	03jan2011	.	1
8	03jan2011	0	1
8	04jan2011	1	1

Don't get confused. Mathematically, the gap between 06feb2012 and 07feb2012 is equal to 1. Because $07-06=1$. But we understand that it is just the next day's event, and both days belong to the same spell. This is why the syntax says $\text{gap} > 1$; in syntax, the gap should be at least two days to start a new spell.

Fourth: grouping observations by **spell** and **id**, in other words order-numbering all spells

```
.egen spellid = group(id spell)
```

ID	date2	gap	spell	spellid
6	05feb2012	.	1	1
6	06feb2012	1	1	1
6	07feb2012	1	1	1
7	09dec2011	.	1	2
7	01jan2012	23	2	3
7	02jan2012	1	2	3
8	03jan2011	.	1	4
8	03jan2011	0	1	4
8	04jan2011	1	1	4

Fifth: identify start- and end- dates, and also length of service

```
.bysort spellid (date2): egen start = min(date2)
/*start date is the minimum value in the column date2 within each ID*/
. bysort spellid (date2): egen end = max(date2)
/*end date is the maximum value in the column date2 within each ID*/
.format start end %td /*making sure it is in stata's time format*/
.gen length= end-start+1
```

ID	date2	gap	spell	spellid	start	end	LOS
6	05feb2012	.	1	1	05feb2012	07feb2012	3
6	06feb2012	1	1	1	05feb2012	07feb2012	3
6	07feb2012	1	1	1	05feb2012	07feb2012	3
7	09dec2011	.	1	2	09dec2011	09dec2011	1
7	01jan2012	23	2	3	01jan2012	02jan2012	2
7	02jan2012	1	2	3	01jan2012	02jan2012	2
8	03jan2011	.	1	4	03jan2011	04jan2011	2
8	03jan2011	0	1	4	03jan2011	04jan2011	2
8	04jan2011	1	1	4	03jan2011	04jan2011	2

Sixth: dropping duplicates. We could separately drop duplicate record for 03jan2011 (rule #5). But because we have to drop duplicates anyways, one command will do both jobs. This is the last line.

```
.duplicates drop spellid start end, force
```

ID	date2	gap	spell	spellid	start	end	LOS
6	05feb2012	.	1	1	05feb2012	07feb2012	3
6	06feb2012	1	1	1	05feb2012	07feb2012	3
6	07feb2012	1	1	1	05feb2012	07feb2012	3
7	09dec2011	.	1	2	09dec2011	09dec2011	1
7	01jan2012	23	2	3	01jan2012	02jan2012	2
7	02jan2012	1	2	3	01jan2012	02jan2012	2
8	03jan2011	.	1	4	03jan2011	04jan2011	2
8	03jan2011	0	1	4	03jan2011	04jan2011	2
8	04jan2011	1	1	4	03jan2011	04jan2011	2

Merging databases

Episode #	Msis_ID	Start	End	Ot	npi	procedure	date
1	6	20120205	20120207	.	.		20120207
				1	1		20120207
				1	3		20120207
				1	4		20120207
				1	3		20120207
2	7	20111209	20111209	.			20111209
				1	4		20111209
				1	5		20111209
				1	6		20111209
				1	4		20111209
3	7	20120101	20120102	.			20111209
				1	5		20120102
				1	7		20120102
				1	8		20120102
				1	9		20120102
4	8	20110103	20110104	1	8		20120102
				.			20110104
				1	9		20110104
				1	10		20110104
				1	10		20110104
				1	9		20110104
				1	9		20110104

* creating database with services

1. create a database with procedures, which has two variables: msis_id and date.

* working with episodes

**removing cases that do not fit within the episode's time frame

2. append procedures with episodes
3. refill empty dates with the START date
4. sort by msis_id and date
5. expand episode's id down to all cases within the person
6. drop episode's id that have missing values
7. within episode's id remove cases with the date that is later than the END date
8. remove cases that have dates later than the END date

**counting NPIs

9. sort by episodes and NPIs
10. Remove duplicate NPI within each episode
11. count total number of cases within each episode.