Concurrent Care in Pediatric Hospice

11/17/2021

Palliative ECHO

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DISCLOSURES

We have no actual or potential conflicts of interest in relation to this presentation

Learner Objectives

By the end of today's presentation, the learner should be able to:

1. Describe the background for concurrent care as it applies to pediatric patients
2. Give at least 3 examples of when concurrent care should be pursued
3. Answer basic inquiries from patients and families regarding concurrent care

Background

- Over 55,000 children die each year in the United States, with a large proportion occurring in a PICU without accessing hospice services

- Often times these children will have multiple chronic, complex, life limiting conditions such as:
  - Chromosomal anomalies
  - Congenital malformations
  - Complications associated with prematurity
  - Degenerative neurologic conditions
  - Cancer

Background

- Many of these children have significant functional limitations and may be dependent on oxygen or ventilators, feeding tubes, or other assistive devices

- They often require substantial symptom management and complicated care plans, especially near end of life, resulting in significant caregiver burden and reliance on home health nursing

Background

- This presents a barrier to implementing hospice services and benefitting from their family centered model of care, symptom management assistance, psychosocial care, respite, and bereavement support

- In addition, the regulatory provision to forego curative therapies in order to enroll in hospice means altering long standing regimens in these children that are necessary for improved quality of life and symptom management

Background

- March 2010 – President Obama signed the Patient Protection and Affordable Care Act (ACA)

- Section 2302 of the ACA – Concurrent Care for Children Requirement (CCCR)
  - Requires that all state Medicaid programs pay for both curative and hospice services for children under the age of 21 who qualify
  - Physicians must still certify that the child is within the last six months of life, if the disease runs its normal course

Background

- Children who qualify for this benefit remain limited to the existing array of Medicaid hospice services and other existing Medicaid services covered by a state. However, a child may be simultaneously enrolled in other programs that provide supplemental services such as home and community-based service (HCBS) waivers.

Pediatric cases

Pediatric case 1

- 2 year old girl named Emma afflicted with a degenerative neurologic disorder of unclear etiology with profound cognitive impairment, hypotonic CP, intractable seizures, was non-verbal, and G-tube dependent
- Given her prognosis and the severity of her condition, parents elected to make her code status DNAR
- She had private duty nursing approved through her insurance but was not eligible for secondary Medicaid coverage

Pediatric case 1

- Her parents were interested in hospice but knew they could not manage Emma's health problems if it meant losing their private duty nursing
- However, thanks to the CCCR, they were approved for full hospice services in addition to their private duty nursing and intent-to-cure treatment
- As a result, in the 7 months between initiation of hospice and her death, she managed to have only 1 short inpatient stay and died peacefully at home in her mother's arms

Pediatric case 1 discussion

Pediatric case 2

- Olivia, a 13-year-old female with juvenile Huntington's Disease and intractable seizures, experienced a rapid worsening of her disease, reducing her quality of life, and increasing the frequency of hospitalizations, often requiring admission to the Pediatric Intensive Care Unit (PICU).
- Olivia's mother was interested in exploring palliative/hospice services to help improve Olivia's quality of life and keep her out of the hospital as much as possible.
- Because of Olivia's complex medication regimen, ketogenic diet, and home care needs, determining the best way to incorporate palliative/hospice care services into her existing private duty nursing care was challenging.

Pediatric Case 2

- After a few weeks of extensive discussion between the palliative team, insurers, hospice, primary physicians, and Olivia's mom, Olivia was approved for 20 hours per day of private duty nursing (authorized by her managed Medicaid secondary insurance) and full hospice services (authorized by her primary commercial insurance).
- Her secondary insurance also agreed to cover the cost of the ketogenic diet and seizure medication, which were too expensive for hospice to provide. Hospice did switch out all of Olivia's equipment (to be covered under their per diem rate).
- Since then, Olivia has not been readmitted to the hospital: she has remained home through difficult times and her family has been able to focus on her quality of life.

Pediatric case 2 discussion

Pediatric case 3

- NK is a 12 year old boy with Aicardi-Goutieres syndrome with resulting global developmental delay, GT-dependence, seizures, and dysautonomia.
- He has a POST (Physician Orders for Scope of Treatment) in place that identifies his code status as “DNAR/Limited interventions” and is enrolled on home hospice.
- However, for his quality of life, he continues to receive therapies (PT/OT) and Botox injections to help with spasticity

Pediatric Case 3

- He also gets admitted to the hospital infrequently for treatable illnesses, and his family is fine with disease-directed care so long as he is 1) not intubated and 2) expected to have meaningful recovering at or close to baseline
- With concurrent care, he is able to be enrolled on hospice and continue to receive routine care that contributes to his quality of life.
- He recently had an admission to the PICU for sepsis, and was able to maintain his DNAR/DNI status - without having to dis-enroll from hospice - while receiving excellent care.
- He is home and doing well.

Pediatric case 3 discussion

Benefits of concurrent care

- The ability to continue certain aspects of disease directed treatment such as chemotherapy, radiation, or dialysis that can result in better symptom management and improved quality of life
- Transition more smoothly from disease directed therapy to care focused on comfort and quality of life during that ~6 month timeframe
- To provide a sense of purposeful action while transitioning to end of life care to ease the guilt, anxiety, and trauma experienced by the parents and siblings of pediatric patients at the end of life

The ethics of concurrent care for children: A social justice perspective

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- Concurrent care allows children to secure the highest level of achievable health and limits their suffering from physical, emotional, psychological, and spiritual symptoms

- It also provides sufficient care to parents by not forcing them to make unthinkable decisions and live beyond their child with memories of poorly managed symptoms or unrelieved suffering

The Ethics of Concurrent Care for Children

- By providing a mechanism for ill children to achieve a greater level of well-being, society also acknowledges and promotes the well-being of the family, who will live on without the child after death

- This demonstrates respect for persons by providing a path for the child to potentially suffer less and have a longer life, but also respect for the parents in their role as protector, caregiver, decision-maker, and advocate

Pediatr Blood Cancer. 2021 September ; 68(9): e29106. doi:10.1002/pbc.29106.

Differences in Characteristics of Children with Cancer who Receive Standard versus Concurrent Hospice Care

- Retrospective study examining national Medicaid files provided by CMS
- Sample of 1,685 patients pediatric patients under age of 20 diagnosed with cancer and enrolled in hospice from 2011 to 2013
- 1008 were found to be receiving standard hospice and 655 to be receiving concurrent hospice care

TABLE 2

Health characteristics

	All Children (N = 1,685)		Standard Hospice Care (n = 1,023)		Concurrent Hospice Care (n= 662)			
	n	%	n	%	n	%	χ^2	*P*
Multiple Complex Chronic Conditions	1232	73.1%	684	66.9%	548	82.8%	51.8	< .001
Mental/Behavioral Health	860	51.0%	490	47.9%	370	55.9%	10.3	< .001
Technology Dependence	869	51.6%	473	46.2%	396	59.8%	29.7	< .001
Cancer Types								
Leukemia/lymphoma	296	17.0%	182	17.8%	114	17.2%	0.1	.764
Brain and orbital tumors	415	25.4%	203	19.8%	212	32.0%	32.1	< .001
Solid extracranial tumors	974	58.3%	638	62.4%	336	50.8%	22.2	< .001

TABLE 3

Community characteristics

	All Children (N = 1,685)		Standard Hospice Care (n = 1,023)		Concurrent Hospice Care (n= 662)			
	n	%	n	%	n	%	χ^2	*P*
Rurality	719	42.7%	408	39.9%	311	47.0%	8.3	.004
Low-income communities	737	43.7%	401	39.2%	336	50.8%	21.8	<.001
Region							109.1	<.001
Midwest	352	20.9%	213	20.8%	139	21.0%		
Northeast	468	27.8%	373	36.5%	95	14.4%		
South	632	37.5%	314	30.7%	318	48.0%		
West	233	13.8%	123	12.0%	110	16.6%		

A Comparison of Young Adults With and Without Cancer in Concurrent Hospice Care: Implications for Transitioning to Adult Health Care

Kim Mooney-Doyle, PhD, RN, CPNP-AC,[1] Jessica Keim-Malpass, PhD, RN,[2] Radion Svynarenko, PhD,[3] and Lisa C. Lindley, PhD, RN[3]

TABLE 1. DEMOGRAPHIC CHARACTERISTICS (*N*=226)

Variables	*Total*	*Cancer diagnosis*		p
		Cancer n=*48*	*Noncancer* n=*178*	
Gender				0.090
Female	60.6%	50.0%	63.5%	
Male	39.4%	50.0%	36.5%	
Race				**0.001**
Caucasian	53.5%	31.3%	59.6%	
Non-Caucasian	46.5%	68.7%	40.4%	
Ethnicity				0.747
Hispanic	22.6%	20.8%	23.0%	
Non-Hispanic	77.4%	79.2%	77.0%	
Comorbidities	42.6%	83.3%	30.3%	**0.001**
Mental/behavioral disorders	53.1%	64.6%	50.0%	0.073
Technology dependence	29.2%	47.9%	24.2%	**0.001**

TABLE 2. COMMUNITY CHARACTERISTICS (*N*=226)

Variables	*Total*	*Cancer diagnosis*		p
		Cancer n=*48*	*Noncancer* n=*178*	
Rural/urban				**0.010**
Urban	58.0%	41.7%	62.4%	
Rural	42.0%	58.3%	37.6%	
Region				**0.001**
Midwest	10.8%	14.6%	12.9%	
Northeast	38.2%	NA	58.4%	
South	19.8%	41.7%	20.8%	
West	31.2%	37.5%	NA	
Household income <$50,000/year	38.5%	50.0%	35.4%	0.066

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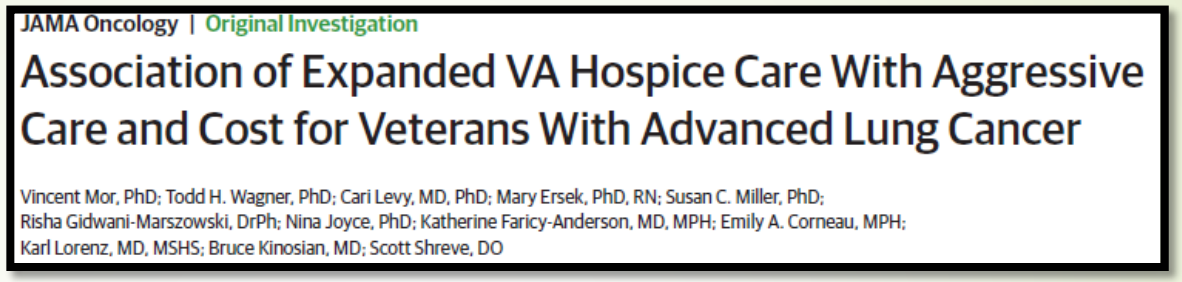
TABLE 4. CLINICAL CHARACTERISTICS (N=226)

Variables	*Total*	*Cancer diagnosis*		
		Cancer n=*48*	*Noncancer* n=*178*	p
Hospice live discharge	15.3 (11.9)	5.7 (11.5)	17.3 (12.0)	**0.001**
Hospice transition—ER	19.0%	22.9%	18.0%	0.444
Hospice length of stay	72.6 (129.9)	86.3 (100.5)	69.7 (136.4)	0.352
Nonhospice symptom management	18.6%	35.4%	14.0%	**0.001**

- The process of transitioning AYA patients in general is a challenging one, and can be especially challenging at the end of life
- Difficulties include:
  - A disorganized process providers and organizations,
  - Difficulty for patients to adjust to adult focused health care
  - The abrupt ending of long-time relationships with pediatric providers
  - **Loss of concurrent hospice services**

ADULT IMPLEMENTATION OF CONCURRENT CARE



JAMA Oncology | Original Investigation

Association of Expanded VA Hospice Care With Aggressive Care and Cost for Veterans With Advanced Lung Cancer

Vincent Mor, PhD; Todd H. Wagner, PhD; Cari Levy, MD, PhD; Mary Ersek, PhD, RN; Susan C. Miller, PhD; Risha Gidwani-Marszowski, DrPh; Nina Joyce, PhD; Katherine Faricy-Anderson, MD, MPH; Emily A. Corneau, MPH; Karl Lorenz, MD, MSHS; Bruce Kinosian, MD; Scott Shreve, DO

- This study evaluated 13,085 veterans newly diagnosed with stage IV non–small cell lung cancer (NSCLC) from 113 VAMCs between 2006 and 2012
- Concurrent care was defined as receiving radiation therapy or chemotherapy after initiation of hospice care
- The article reported on five outcomes: Two or more hospital admissions, tube feeding, mechanical ventilation, intensive care unit admission, and total costs
- The authors found that increasing the availability of concurrent care was related to less aggressive medical treatments and significantly lower costs at end of life

Adult implementation of concurrent care

First Medicare Demonstration of Concurrent Provision of Curative and Hospice Services for End-of-Life Care

- Section 3120 of the ACA authorized a demonstration project to test the effect of concurrent care on patient care, quality of life, and cost-effectiveness in adults via the Medicare Care Choices Model (MCCM)
- To participate patients must be eligible for hospice and have advanced cancer, COPD, CHF, or HIV/AIDS
- In May 2015 the Centers for Medicare & Medicaid Services (CMS) invited 141 hospices to participate in the 5 year demonstration with half starting in 2016 and the other half in 2018
- Limited by the fact that it is estimated only 15% of the patients enrolled in hospice would be eligible and reimbursement for hospices is significantly less than what they traditionally get; first 3 or 15 days under the Medicare Hospice Benefit pays $480 or $2400 respectively vs $200 or $400 under MCCM

Concurrent Care for the Medically Complex Child: Lessons of Implementation

Elissa G. Miller, M.D.,[1] Gwenn LaRagione, R.N., B.S.N., C.C.M.,[1]
Tammy I. Kang, M.D., MSCE,[1] and Chris Feudtner, M.D., Ph.D., M.P.H.[1–3]

1. Lack of knowledge regarding end-of-life care among private duty nurses
2. Different perspectives on end-of-life care between palliative care practitioners, hospice clinicians, and private duty nurses
3. Lack of experience with complex care coordination among hospice providers
4. Durable medical equipment cost increases for hospices
5. Insurance complexities of coordinating private and Medicaid insurance for children

Health Aff (Millwood). 2020 October ; 39(10): 1770–1775. doi:10.1377/hlthaff.2020.01192.

Variation in state Medicaid implementation of ACA: The case of Concurrent Care for Children

- State-level uptake of ACA section 2302 by state Medicaid plans has varied significantly, with some implementing ACA section 2302 in 2010 and others as late as 2017

- Concurrent care guideline implementation has been sparse and significantly varied across the different states:
  1. Definitions (35%)
  2. Payment (29%)
  3. Care coordination (27%)
  4. Staffing guidelines (6%)
  5. Eligibility Criteria (4%)
  6. Clinical Guidelines (2%)

Health Aff (Millwood). 2020 October ; 39(10): 1770–1775. doi:10.1377/hlthaff.2020.01192.

Variation in state Medicaid implementation of ACA: The case of Concurrent Care for Children

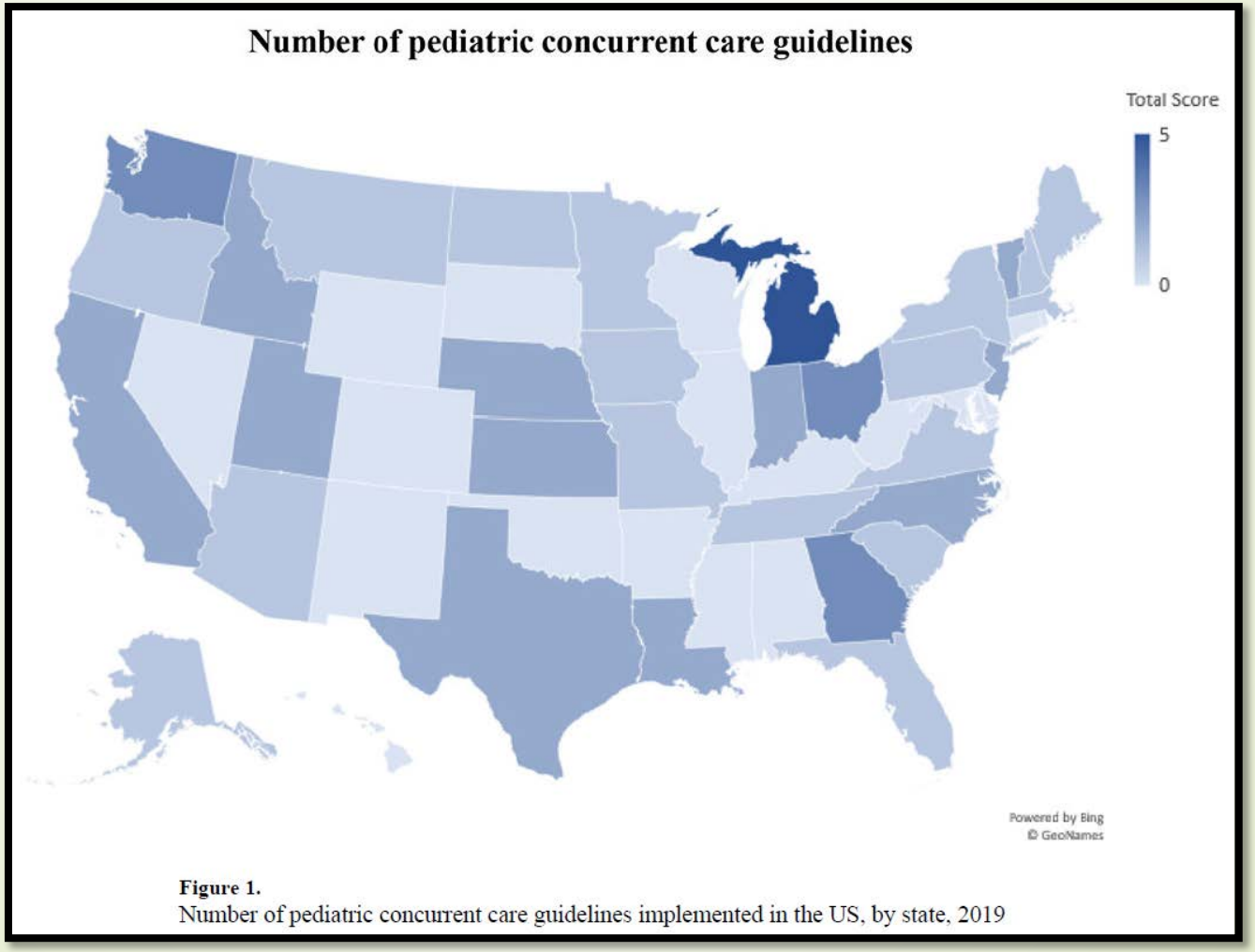


Figure 1.
Number of pediatric concurrent care guidelines implemented in the US, by state, 2019

CONCLUSIONS

J Hosp Palliat Nurs. 2020 June ; 22(3): 238–245. doi:10.1097/NJH.0000000000000648.

Pediatric concurrent hospice care: A scoping review and directions for future nursing research

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- A decade has passed since enactment of concurrent hospice care, yet few studies have examined the use of this care model in practice or research
- Pediatric or adult literature on concurrent care is rarely cited in end-of-life literature and it remains common for pediatricians, pediatric specialists, and hospice clinicians, along with families, to be unaware of concurrent hospice care
- There is still a paucity of research within pediatric concurrent hospice care looking at outcomes data including access to care, quality of health, cost of care, disparities, and effectiveness of concurrent hospice care

OBJECTIVES

1. Describe the background for concurrent care as it applies to pediatric patients
2. Give at least 3 examples of when concurrent care should be pursued
3. Answer basic inquiries from patients and families regarding concurrent care.

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QUESTIONS?