




Pediatric Palliative Care

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History of Pediatric palliative care

The Age of Ignorance: Before the 1970s

- Before the 20th century, 1/3 children died acutely before they turned 16
- After WWII, advancing medical technology allowed children with serious illnesses to survive longer → prolonged the process of dying → creating the potential for prolonged suffering
- Concept of suffering as a complex state of distress that cannot be reduced to individual symptoms did not emerge in pediatrics until recent decades
- clinicians focused narrowly on anxiety. This was due to societal preoccupation with anxiety as the source of many maladies at that time, limited understanding of depression, and widespread belief that children lacked an awareness of death and did not experience existential loss

Bryan A. Sisk, Chris Feudtner, Myra Bluebond-Langner, Barbara Sourkes, Pamela S. Hinds, Joanne Wolfe; Response to Suffering of the Seriously Ill Child: A History of Palliative Care for Children. *Pediatrics* January 2020; 145 (1): e20191741. 10.1542/peds.2019-1741

- Clinicians caring for dying children rarely mentioned pain in the 1950s
 - Assumption that children did not experience pain to the same extent as adults
 - Even when severe pain was recognized, the fear of causing serious harm with opioids led to prescriptions of miniscule doses. This hesitance was due, in part, to lacking literature or recommendations for dosing of opioids in children
- 1960s - a few clinicians began to challenge the broad resistance to prescribing opioids in children
- Around this time, Cicely Saunders was revolutionizing terminal care for adults and promoting the concept of total pain.
 - Adult hospice philosophy was making its way into pediatrics.

The 1970s: Making visible the suffering of children

- opposing views about how to communicate with dying children about prognosis - “protective approach” vs “open approach”
- In 1973, Spinetta, a psychologist, began a series of landmark studies of dying children’s awareness of death.
 - Spinetta’s work showed that children with fatal illnesses demonstrated an awareness of their impending death, whether told or not.
- Complementing Spinetta’s work, Bluebond-Langner, an anthropologist, addressed the social and relational roots of the protective approach.

Awareness of Suffering and the Rise of Pediatric Palliative Care

- Late 1970s- pediatrics was incorporating several concepts from adult hospice.
- Publications addressing suffering in children with serious illness proliferated.
 - Smith et al in 1979 described their approach to providing “total care” for children with cancer, noting the necessity of a broad team to meet the emotional, financial, and physical needs of the family.
 - By 1983, Lewis argued that such principles should be applied to all seriously ill children as a continuum of care, not just those dying.
- Changes in the actual management of suffering lagged behind
- Symptom and pain control were based on experience and best guesses, allowing misperceptions about children’s pain to persist.
- 1980s- pediatric textbooks began incorporating sections on the care of dying children.
- 1990s- this persistent discrimination sparked the framing of adequate pain management in children as an ethical issue

- 1978- Martinson et al's work demonstrated the feasibility of children dying at home, if desired. Before this time, the hospital was the assumed place of death for most children.
- In England, Sister Frances Dominica, a nurse and Anglican nun, recognized that some children could not be constantly cared for at home, with acute care hospitals providing the only alternative.
 - This spurred the development of the first pediatric hospice in 1982: Helen's House.
- 1986- Goldman (a pediatric oncologist) developed the first multidisciplinary inpatient pediatric palliative care team

From aspiration to practice: palliative care in recent history

- Little evidence regarding actual practice until the 21st century, when a series of studies showed that aspirations had not broadly translated into practice
- National medical organizations began developing guidelines for the care of suffering and dying children
- By 2008, the American Academy of Pediatrics had developed a provisional section for hospice and palliative medicine, which became permanent in 2010
- early training curricula for pediatric palliative care were being developed
 - the Initiative for Pediatric Palliative Care in 2001 and End-of-Life Nursing Education Consortium Pediatric Palliative Care in 2004
- HPM became an informal subspecialty in 2006, with formal recognition in 2008
- Since this designation, pediatric palliative care has expanded in clinical practice, education, and research
- By 2013, 69% of children's hospitals surveyed reported having a palliative care team

NHPCO's Facts and Figures

Pediatric Palliative & Hospice Care in America

2015 Edition

- According to the Centers for Disease Control and Prevention's most recent Annual Summary of Vital Statistics:
- In 2013 there were nearly 2.6 million deaths
 - Children aged 0-19 years accounted for 1.6% of all deaths in 2013 with 42,328 total deaths
 - 55% occurred in infancy
 - 66% of infant deaths occurred in the neonatal period

https://www.nhpco.org/wp-content/uploads/2019/04/Pediatric_Facts-Figures-1.pdf

NHPCO's Facts and Figures

Pediatric Palliative & Hospice Care in America

2015 Edition

Table 3. Causes of Death, Children Birth - 19 years

All Infants	Infants with CCC	All Children 1-19 Years	All Children 1-19 Years with CCC
1. Congenital malformations	1. Cardiovascular	1. Accidents	1. Malignancy
2. Short gestation / LBW	2. Congenital / genetic	2. Suicide	2. Neuromuscular*
3. Maternal complications	3. Respiratory	3. Assault	3. Cardiovascular
4. SIDS	4. Neuromuscular*	4. Malignancy	
5. Accidents/unintentional injury		5. Congenital malformations, deformations and chromosomal abnormalities	
6. Complications of placenta, cord, or membranes		6. Heart disease	
		7. Influenza and pneumonia	

* Includes static neurologic and neurodegenerative conditions

EPSDT

- In 1967, Congress introduced the Medicaid benefit for children and adolescents, known as Early and Periodic Screening, Diagnostic and Treatment (EPSDT).
- Hospice benefits that are provided to adult patients insured by Medicaid can vary widely from state to state and are an optional benefit.
- However, for children younger than 21 years of age, the EPSDT provision requires Medicaid and Children's Health Insurance Programs (CHIPs) operating as Medicaid expansions to provide all medically necessary services, including hospice services.

Concurrent care

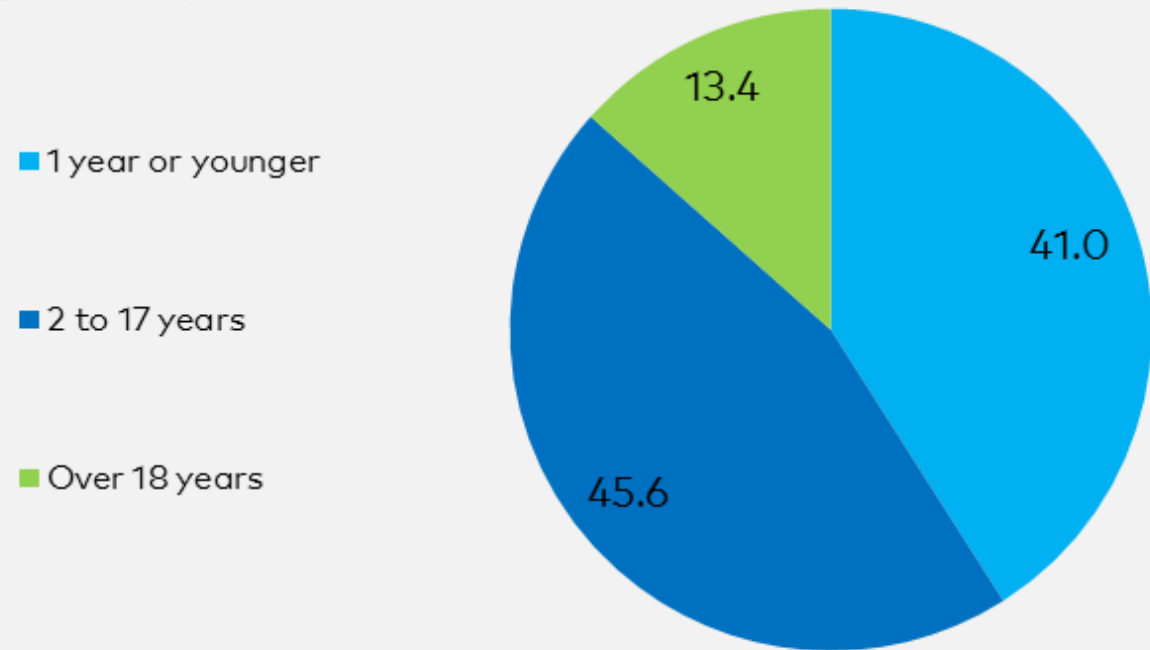
Patient Protection and Affordable Care Act (ACA) 2010

- Section 2302
 - Mandates that children in a state Medicaid or Children's Health Insurance Program who are eligible for hospice care also be eligible to receive coverage for curative, disease-directed therapy
 - different with every state and with every program
 - case by case interaction with insurance companies, can be resource intensive and difficult

Key findings from 52 Pediatric Palliative Care Programs

- On average, 41.0% of pediatric palliative care patients were under one year of age, including perinatal patients, and 45.6% were between the ages of two and seventeen.

Percentage of Pediatric Palliative Care Patients by Age Group

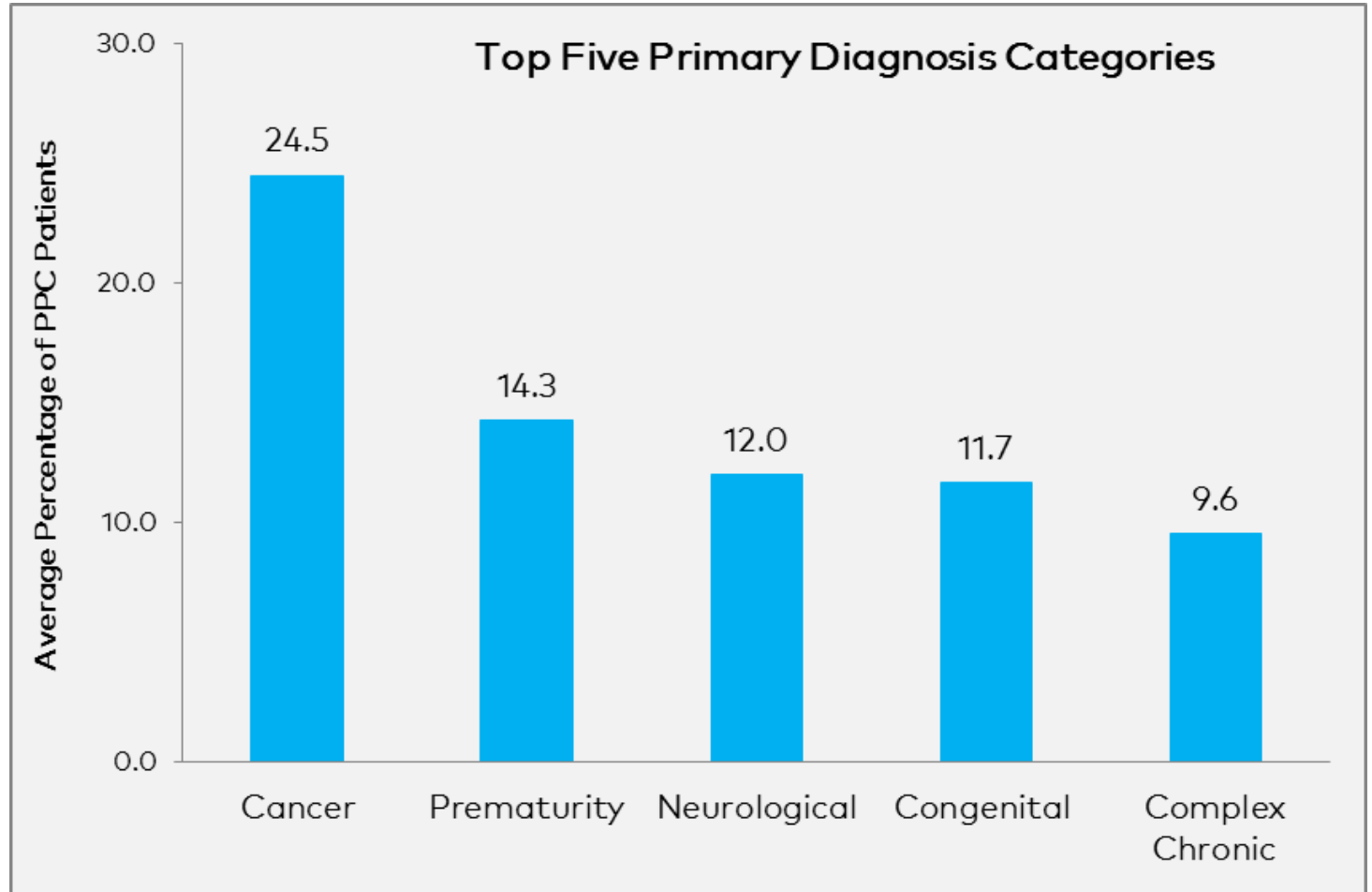


From CAPC: Spotlight on Pediatric Palliative Care: National Landscape of Hospital-Based Programs, 2015-16

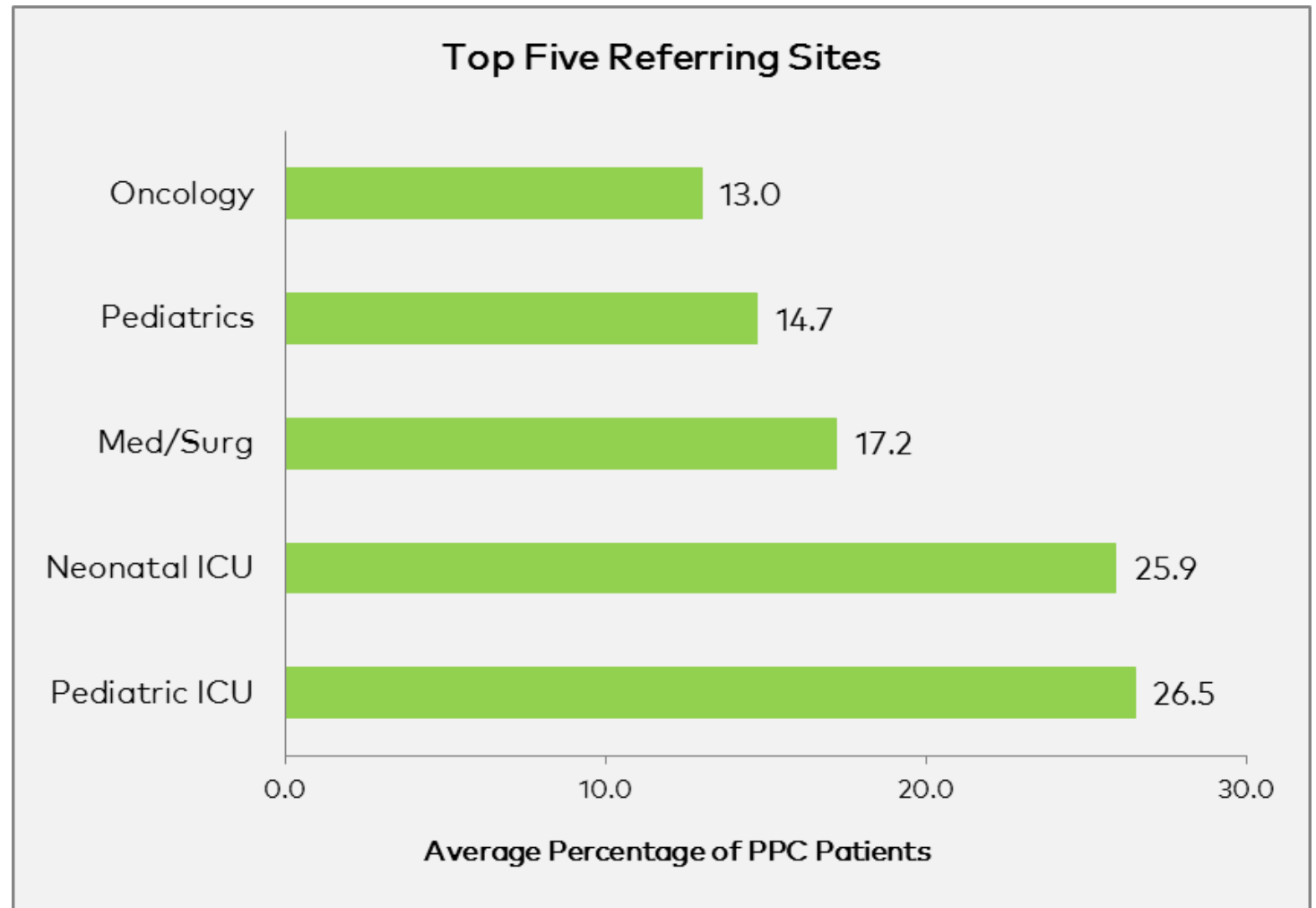
<https://www.capc.org/blog/palliative-pulse-palliative-pulse-july-2017-spotlight-pediatric-palliative-care-national-landscape-hospital-based-programs-2015-2016/>

Pediatric palliative care programs treat patients with diverse primary diagnoses.

On average, nearly one-quarter of all pediatric palliative care patients had a primary diagnosis of cancer. This was followed by prematurity (14.3%)



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- **Pediatric palliative care programs receive referrals from throughout the hospital, but the majority come from the ICU.**



PPC referral criteria

From UNIPAC 7/UK charity Together for Short Lives

4 broad PPC categories

1. **Life-threatening conditions for which curative treatment may be feasible but can fail**
 - cancer, irreversible organ failure, complex congenital heart disease, trauma, sudden severe illness, extreme prematurity
2. **Life-limiting conditions for which there is no realistic chance of cure**
 - cystic fibrosis, progressive neuromuscular disorders such as muscular dystrophy and spinal muscular atrophy, HIV/AIDS, severe short gut syndrome
3. **Progressive conditions without curative treatment options for which treatment is exclusively palliative**
 - Mucopolysaccharidoses, severe mitochondrial disease, Batten disease
4. **Severe, irreversible neurologic disability that may be stable (non-progressive) but may cause weakness and susceptibility to health complications**
 - Medical fragility caused by severe multiple disabilities following brain or spinal malformations or injuries, including severe cerebral palsy, Trisomy 13 and 18, or birth injury

Pediatric Palliative Care Team

- Doctor, nurse practitioner, nurse coordinator, social worker, child life specialist
- May also include: pharmacists, art and music therapists, chaplains, psychologists, rehabilitation therapists, dietitians and more

Child Life Specialists



- Help children understand their illness. They use play, dialogue, art, music writing exercises and other approaches.
- Often, they become the child’s “safe harbor” and closest source of support.
- Provide children in the medical setting with age- appropriate opportunities to engage in play and creative arts, encouraging normal development and a sense of FUN, even under difficult circumstances
- Prepare children for medical procedures or treatment using language they can understand, and introduce coping strategies to reduce their anxiety,
- Promote family-centered care by providing information, advocacy and support for parents, siblings and other family members
- Offer a variety of support services for children and families, which may include planning special events, entertainment, and gift drives, conducting pre-admission hospital tours and consultations, and leading support groups

Introducing palliative care

- PC should be introduced as close to the diagnosis of a life-threatening condition as possible.
- Vocab is impt: life-threatening and life-limiting less frightening than terminal when describing medical conditions appropriate for palliative services
- Supportive care or palliative care may be more acceptable than hospice as they accurately express the concept that intensive palliative interventions always will be provided to ensure comfort regardless of other interventions
- Informing families that PC is part of the care of any patient with serious illness removes the burden on families to agree to involve a service about which they are not properly informed

Differences between adult and PPC

- Diagnoses
 - CSHCN = children with special health care needs
 - CCC = chronic complex condition
 - LLL = life-limiting condition
 - LTC = life-threatening condition
- Prognostic uncertainty
 - Children are resilient, therefore unpredictable
- Providing developmentally-appropriate palliative care
 - Lack of patient reported outcomes (until PediQUEST study, a study of patient reported outcomes in children with cancer, helped understand the symptom burden)
- Autonomy/Consent/Assent
 - Delicate balance between autonomy and parental protection

Decision making with minors

- Assent

- Considered a child's agreement to a treatment decision without having the legal capacity to consent
- Goal is to create a supportive environment to allow decisions that are made cooperatively between the older child, physicians, and parents
- Process of respect for the emerging, autonomous adults they will become and the emotional investment they have in their current values
- Support can be given to the adolescent's preferences and decisions, with the parents providing guidance in their roles as educators, challengers, and shared decision makers
- In general, children older than 14 years are viewed as having the ability to reason as well as a competent adult, but children as young as 9 years have been found to express reasonable preferences regarding treatment that render them capable of participating in decisions about their own health.

Decision making with minors

- Assent

Practical Aspects of Assent by Pediatric Patients for Medical Decision-Making

• Help the patient achieve a developmentally appropriate awareness of the nature of his or her condition
• Tell the patient what he or she can expect with tests and treatments
• Make a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy)
• Solicit an expression of the patient's willingness to accept the proposed care

COMMITTEE ON BIOETHICS, Aviva L. Katz, Robert C. Macauley, Mark R. Mercurio, Margaret R. Moon, Alexander L. Okun, Douglas J. Opel, Mindy B. Statter; Informed Consent in Decision-Making in Pediatric Practice. *Pediatrics* August 2016; 138 (2): e20161484.

Exceptions to Limitations on Adolescent Medical Decision-Making

- exceptions based on specific diagnostic/care categories
- the “mature minor” exception
- legal emancipation

COMMITTEE ON BIOETHICS, Aviva L. Katz, Robert C. Macauley, Mark R. Mercurio, Margaret R. Moon, Alexander L. Okun, Douglas J. Opel, Mindy B. Statter; Informed Consent in Decision-Making in Pediatric Practice. *Pediatrics* August 2016; 138 (2): e20161484.

- <https://vtethicsnetwork.org/presentation-recordings-ven-fall-2021-ethics-education-series>
- **Exceptions to the Rule: When Minors Get to Make Their Own Medical Decisions**
- Presented by: Bob Macauley, MD, FAAP, FAAHPM, HEC-C: Cambia Health Foundation Endowed Chair in Pediatric Palliative Care, Oregon Health and Science University
- While 18 is the “age of majority,” there are several situations where patients younger than that are authorized to make their own medical decisions. This session will explore the minor treatment statutes, emancipation, and the mature minor doctrine, as well as current challenges relating to vaccination of minors without their parents’ consent.
- Recorded Oct. 5th, 2021 via Zoom

Exceptions based on specific diagnostic/care categories

- The legal ability of adolescents to consent for health care needs related to **sexual activity, including treatment of sexually transmitted infections, contraceptive services, and prenatal care**, is recognized in all states*
- similar expansion regarding adolescents' access to **mental health and substance abuse** prevention and treatment services.
- These changes reflect a public health concern that adolescents will not access these services if parental consent is required.
- However, **state statutes** that permit adolescents to consent to these services **do not always protect their confidentiality**

TABLE 1. State-by-State Policies on the Ability for Minors to Consent for Medical Services

State	General Medical Care	Immunizations (see Figure 2)	Dental Care	Sexual Assault Evaluation	STI Testing and Treatment	HIV Testing and Treatment	Contraceptive Care	Prenatal Care	Substance Abuse Treatment	Mental Health Care
Florida	If 16 or older and emancipated, or married, homeless, or living apart and financially independent	No	16 or older and emancipated, or married, homeless, or living apart and financially independent	No explicit policy	Yes	Yes	Yes, if married, a parent, pregnant or ever pregnant	Yes	Yes	Yes, if 13 and older

From AAP- <https://publications.aap.org/pediatrics/article/149/6/e2021053458/187003/State-by-State-Variability-in-Adolescent-Privacy>

Sharko M, Jameson R, Ancker JS, et al. State-by- State Variability in Adolescent Privacy Laws. Pediatrics. 2022;149(6):e2021053458

Mature-minor doctrine

- The mature-minor doctrine recognizes that there is a subset of adolescents who have adequate maturity and intelligence to understand and appreciate an intervention's benefits, risks, likelihood of success, and alternatives and can reason and choose voluntarily.
- Many states recognize “mature minors” by criteria similar to emancipated-minor status.
- Not in Florida

Emancipated minor

- Emancipated minors are persons younger than 18 years who live independently from their parents; who have taken on the responsibilities of an adult, including financial independence, parenthood, or military service; or who are emancipated by court order.
- Emancipated minor laws vary from state to state.

Special ethical and legal issues

- Decision making conflicts
 - Bottom line:
 - children are the patients and their views must be taken into consideration
 - Physicians have a duty of fidelity to treat their child patient as primary; in reality, however, family-centered care and the fact that children rarely exist independently of the family system mean that a delicate balance must be struck between legal and ethical approaches to decision making
 - Families need good communication; realistic, factual information; and emotional support

Baby Doe Regulations

- The initial Baby Doe regulations, developed in 1982, stated that healthcare providers were at risk of losing federal funds for withholding treatment or nourishment from “handicapped” infants.
- Following the Baby Doe regulations, in 1984 an amendment to the Child Abuse Prevention and Treatment Act (CAPTA) changed the definition of child abuse to include failing to provide “medically indicated” treatment for life-threatening conditions.
- CAPTA permitted limiting or discontinuing life-sustaining medical treatment (LSMT) in 3 specific instances:
 - when a baby is chronically and irreversibly comatose
 - when providing treatment merely prolongs dying, would be futile in terms of survival, or would not be effective at correcting or ameliorating all of the infant’s life-threatening conditions
 - or when treatment would be ultimately futile and inhumane.

Baby Doe Regulations

- There has been considerable debate about the way that the language of CAPTA should be interpreted in clinical practice, with neonatologists and ethicists differing on their interpretation of when it is ethically permissible to forgo life-sustaining treatments.
- In recent years, the AAP has shifted their stance away from supporting the language of CAPTA to emphasize the role of shared decision-making when applying the best-interest standard to ensure compassionate and individualized end-of-life care for children.

Research and assent

- Before taking part in a [clinical trial](#), children are asked for their assent.
- Unlike informed consent, assent is not always required by law, though [IRBs](#) may require it.
- They may also dissent
- To take part in the [assent process](#), your child must be mature enough to understand the trial and what they are required to do. Some children as young as 7 years old may be able to take part. But this age varies depending on the child and the group running the trial.
- It may take several sessions before the research team feels that your child has a clear understanding of what the trial involves. At that point, your child is asked to show assent or dissent.

Discontinuation of nutrition and hydration

UNIPAC 7 pg 46 & 102

- Issues surrounding the provision and removal of food and fluids take on particular significance in the pediatric population because infants and young children are dependent on adults to feed them and because of the emotional power of feeding as a basic element of the care of children
- Ethics committee involvement is indicated if any controversial dimensions to the case or any stakeholders who disagree with the decision
- Currently, evidence to support lack of suffering or even improved comfort in patients for whom nutrition and hydration are withheld is restricted to adults

- When artificial nutrition and hydration no longer meet therapeutic goals, the family may benefit from gentle exploration of their beliefs and wishes about forgoing or discontinuing artificial hydration or nutrition
- Physicians should provide information about the effects of either administering or forgoing artificial nutrition or hydration in terms of their effects on a patient's comfort

Refractory pain and other symptoms

Sedation at the end of life

UNIPAC 7 pg 46 & 105

- In PPC, palliative sedation in its strictest sense is rarely practiced, although the true frequency is unknown
- Before pain or other sx considered refractory, a physician with expertise in peds and PC should review all preceding interventions and their outcomes and suggest additional maneuvers that can be attempted within a reasonable time frame
- Begin preparing the patient and family early through compassionate, recurring discussions of tx options
- Team meeting to achieve consensus about the intervention options and goc before the family's involvement
- Share information with family

Palliative sedation

- Caregivers and family members should understand the following:
 - The child cannot be kept both awake and in a relative state of comfort.
 - Sedation at the end of life is the only effective means of providing comfort at this stage.
 - Such sedation will likely result in loss of consciousness.
 - The aim of sedation is the relief of suffering, not the shortening of life.
 - Family members and staff should feel free to voice any concerns at any time; concerns should be fully addressed with compassion.
 - If sedation at the end of life is chosen, all involved staff members must understand the principles involved and follow established guidelines.

FLORIDA CHILD CUSTODY: WHO GETS TO MAKE MEDICAL DECISIONS

- state of Florida presumes that both parents are fit and able to make decisions for the minor children which means the parents would share parental responsibility for the minor children.
- If parents are unable to agree upon what is in the children's best interests, they might agree that one parent has decision making authority over certain issues or the court may determine one parent has decision making authority to avoid additional court intervention
- If a parent is designated as having decision making authority over certain issues, that parent is still required to confer and discuss with the other parent his or her requests and ideas. It is not a blank check to simply veto the other parent's input
- At times, sole parental responsibility is awarded to a parent. This is very unusual and only happens when one parent is incapable of assisting in the decision-making process and his or her absence from the process is detrimental for the minor children.

Communicating with children

- Many benefits to discussing death with the child and giving the child an active role in end-of-life decision making
 - Children feel less isolated, experience a greater sense of control and less anxiety, their long-term emotional and social adjustment is enhanced, better able to participate in decisions
- What happens when a child asks, “Am I going to die?”
 - important to understand what the child is really asking.
 - What is he or she really worried about; it may not be as anxiety-provoking (or as “deep”) as you think.
 - The best response when anyone asks, “Am I going to die?” is “Tell me more” or “What’s on your mind?”

Development of the Child's Concept of Death

Age	Developmental Stage (Piaget)	Perception or Concern	Anticipated Response
< 2 years	Sensorimotor	Sense separation and the emotions of others	Withdrawal Irritability
2 – 6 years	Preoperational	Dead = “Not Alive” Death as Temporary	Wonder about what the dead “do” Magical thinking
6 – 10 years	Concrete operational	Morbid interest in death Others die ==> I die	Exaggerated behavioral reactions to the idea of death and dead things
Adolescence	Formal operational	Adult concepts Existential implications	“But not me” Death as an adversary

<https://downloads.aap.org/AAP/PDF/Understanding%20Grief%20and%20Loss%20in%20Children%20Discussion%20Guide.pdf>

Supporting siblings

- Siblings seem to cope best with the loss of their ill brother or sister if they are involved in their care, see them often, and are fully informed about their status, even when the child is near death.
- Longer-term follow-up of these bereaved children suggests that they have fewer psychologic problems when they have been informed and involved.
- Guidelines from several pediatric cancer organizations encourage involvement and contact of siblings with their dying sister or brother.

Supporting siblings

- Need outlets to explore their experiences and feelings which can have a positive impact later on sibling bereavement
- Can be supported through their losses via community resources available through palliative care and hospice programs, mental health specialists with experience in this area, and bereavement programs
- Research has shown that changes in family life when one child has a life-threatening condition can provide opportunities for personal growth in siblings.
- In studies, children most appreciated the support and understanding they received, the freedom to express themselves, a **diminished sense of isolation**, and the **normalization of their emotions**.
- Children felt they benefited from talking to a non-family member

Perinatal palliative care

UNIPAC 7

- Cases of life-limiting conditions that could impact the transition from life inside the womb to life after separation from utero-placental circulation upon birth. absolute prognostic capability may be elusive regarding specific organ system function or impairment, as well as the length of time that the newborn may survive with or without intensive care.
- These cases are addressed by interdisciplinary obstetric, neonatal, and palliative clinicians

Common Clinical Scenarios in PPC:

- **The Tiny Baby**- The birth of extremely early gestations results in issues a/w periviability - that is a determination based on gestational ages less than 25 completed weeks of pregnancy, or birth weights less than 600 grams, for whom resuscitative efforts and the initiation of neonatal intensive care may not secure their future health and well being
- **The Baby with Congenital Anomalies** - Many congenital anomalies may be recognizable syndromes, some due to chromosomal aneuploidy (trisomy 13 or 18, triploidy) or major deletions (5p-, cri-du-chat, 4p-, Wolf Hirschhorn syndrome), and others may have seemingly unique characteristics with genetic roots that confer conditions incompatible with long term survival unless interventions are offered.
- **The NICU Patient Who Is Suffering**- infants who may not progress toward independent life and remain dependent on medical technology (tracheostomy/ ventilator, dialysis), infants who decline in their health status before ever reaching a point for safe discharge to home, perhaps suffering overwhelming sepsis or necrotizing enterocolitis, infants who experience repeated and continued life-threatening events, such as severe hypoxic-ischemic encephalopathy or multiple organ system failure.

Assessing pain in children

- Two main categories – assessment through self report and observational assessment
- Assessment that utilizes reporting and rating of pain must be appropriate to the child's cognitive level
- Understanding of the child's functional level should be sought from parents and care providers and is often indicated as a developmental age.
- Clinicians should use a validated pain-rating system appropriate for the level of the child's intellectual function.

QUESTT model

- The challenges of assessing pain in children gave rise to the QUESTT model, which includes evaluating the results of an intervention.

Includes the following steps:

- Question the child, if verbal, and the parent or guardian of both verbal and nonverbal children
- Use pain-rating scales
- Evaluate behavior and physiological change
- Secure parental involvement
- Take the cause of pain into account
- Take action and evaluate results.

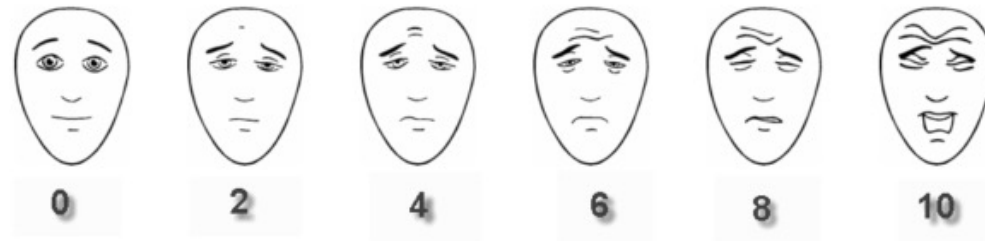
Observational Scales- for infants, children less than 3 yrs old, and developmentally disabled patients.

- **CRIES**, Neonatal Infant Pain Scale (**NIPS**); Face, Legs, Activity, Cry, Consolability scale (**FLACC**); Children's Hospital of Eastern Ontario Pain Scale (**CHEOPS**)
- Commonly used and validated pain scales for use with neonates:
 - **CRIES**- 10-point scale with 5 parameters scored 0 to 2. Parameters include crying, oxygen requirement, vital signs, facial expression, and sleeplessness; **COMFORT**; Premature Infant Pain Profile (**PIPP**); Children's and Infants' Postoperative Pain Scale (**CHIPPS**), Neonatal Pain, Agitation and Sedation Scale (**N-PASS**)

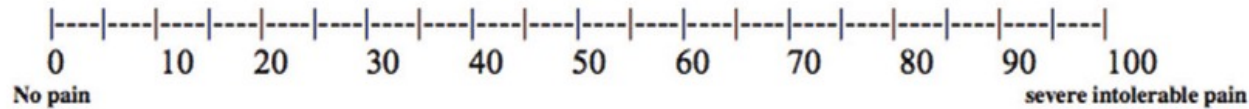
Self report- Children 3 years of age and older

- FACES pain scale-revised (FPS-R), Visual analog scale (VAS), Numerical rating scale (NRS), Pieces of Hurt tool (also known as Poker Chip Tool), Oucher photographic scale

Faces Pain Scale - Revised



Visual Analogue Scale (VAS)



Assessing pain in children

AAHPM

- 2 y/o – children often gain the ability to report that they have pain using words and nonverbal indicators
- b/w 3 and 4 - gradually gain the ability to differentiate upwards of four levels of pain, but their self-report remains unreliable as they answer questions about pain inconsistently (for instance, by choosing only the top or the bottom of a pain scale, treating pain as dichotomous).
- children 4 to 6 years old are developing the ability to create a series in order of size but only through trial and error
- between 5 and 6 years, children gain the ability to distinguish upwards of six categories of pain intensity such as those on the common faces scales.
- children 7 to 10 years old can generally use tools to quantify pain such as a visual analog scale
- As young as age 8 years, a child may have the ability to use a numerical rating scale, such as a 0-to-10 scale, to rate pain without any visual tool being present

FYI

- Moderate to severe pain in neonates, infants, and children can be well controlled with opioids, and the risks associated with treatment are not greater than those seen with adult patients.

Symptom support in neurologically impaired children

AAHPM

- Retching can be 2/2 dysregulation of central control of vomiting, visceral hyperalgesia, or dysautonomia
 - Cyproheptadine blocks multiple receptors in the vomiting center - can be initiated if central dysregulation of the vomiting center is suspected.
- Causes of somatic pain include UTIs, renal stones, pancreatitis, spasticity, GERD, constipation, problems with hip joint, dental issues
 - For pediatric patients who experience distress due to GERD, the optimal medical therapy is an 8-12 week course of a PPI such as omeprazole.
 - Spasticity is very common - Baclofen crosses the blood-brain barrier and acts as a gamma-aminobutyric acid (GABA) agonist and is frequently effective in addressing spasticity. Other medications that may be effective in treating spasticity include benzodiazepines, dantrolene, and alpha-2 adrenergic agonists. For localized spasticity, intramuscular injections of botulinum neurotoxin can be used.
- Visceral hyperalgesia is common. Administering feeds often precipitates pain in children with visceral hyperalgesia. Administering feeds at a slower rate over a longer period typically is better tolerated than bolus feeds, in which a large volume is administered over a short period of time. Gabapentin is the treatment of choice for visceral hyperalgesia.