

GRAND ROUNDS

Michelle Mims, PGY-III
November 25, 2015

INTRODUCTION

Chief complaint: “seizure-like activity, vomiting, diarrhea”

HPI:

20 month old M with hx of complex congenital heart disease

One episode of seizure-like activity

- <1 minute, unresponsive, arms stiffening, eyes fixed ahead, perioral & facial cyanosis
- Self-resolved
- Fussy and drowsy following episode
- No previous Sz history

2 days of vomiting, diarrhea, decreased PO, afebrile

EMS → OSH

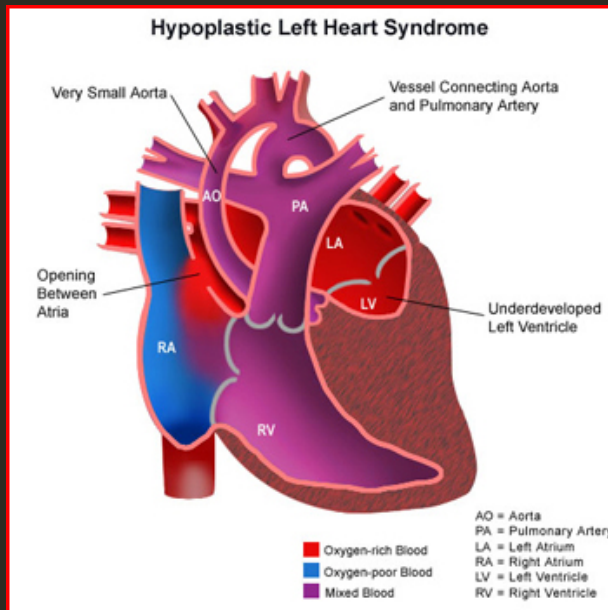
- Infectious w/u: Blood Cx, CBC w/ diff, Viral Panel → normal
- Baseline Mental Status

CHNOLA: vital signs stable, Oxygen sat's at baseline (75-85% on 2 LPM)

INTRODUCTION

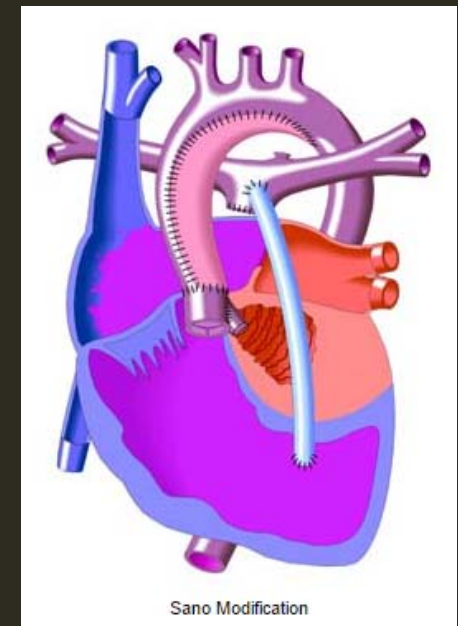
Past Med Hx:

- HLHS with intact ASD and Shone's Complex*, mitral stenosis, severe pulmonary HTN
- s/p Norwood and Sano
- On 2 L O2 at home, multiple medications for pulmonary HTN and CHF



* Shone's Complex:

Ao Stenosis, parachute MV, supra-valvular mitral membrane, Coarct of Ao



INTRODUCTION

Hospital Course:

- Placed on telemetry, continued on home medications, IVF for dehydration
- Vomiting & diarrhea resolved after admission
- Hospital day 2: No further seizure-like episodes, alert and active, no change in O2 requirement
- IVF discontinued on rounds, PO intake monitored → discharge ?

Paged: patient began to have another “seizure-like episode”

INTRODUCTION

At bedside...

- Crying, agitated
- ↓ alertness and difficulty holding head up
- No extremity jerking or posturing
- Vital signs and O₂ sat's at baseline (80%)

1-2 minutes later...

- Emesis 1x
- Perioral & facial cyanosis → O₂ sat's to low 70%'s
- BP unreadable
- Brachial/femoral pulses palpable, HR ~100

INTRODUCTION

Code Blue

- Crying and agitated in response to examiner
- Grunting
- Intubated, O₂ sat's improved
- HR ↓ to 40 bpm with poor perfusion, CPR initiated
- Multiple doses of epinephrine and sodium bicarbonate given
- iNO given via ETT
- CPR continued

Patient too unstable to be transported to PICU

INTRODUCTION

- Parents at bedside
- Taken aside, told patient would likely not survive
- Parents asked that resuscitation efforts be stopped
- Time of death called ~45 minutes after code

Autopsy report:

Cause of death likely an acute decompensation of complex CHD with CHF and severe pulmonary HTN, with inciting event of crying episode in the setting of gastroenteritis



**WHEN A CHILD DIES:
THE CHALLENGE OF END-OF-LIFE CARE IN PEDIATRICS**

LEARNING OBJECTIVES

1. Discuss the unique challenges pediatric death presents to healthcare providers
2. Discuss how to tell a family member that their child has died or is dying
3. Review the responsibilities of a physician both during and after a pediatric patient's death
4. Discuss how to best help a patient's bereaved family and how to help each other after the loss of a child

BACKGROUND

- Children under 18 years old = ~ 30% total population
- < 2 % (48,000) of all deaths occur in this age range
- ~ 100 years ago...
 - 30% of all deaths occurred in children younger than 5 years old
- Children < 1 year old now account for only 1.9% of all general ED deaths



BACKGROUND

Pediatric death occurs in many contexts and settings:

- ED, PICU, NICU, inpatient service, hospice or skilled nursing facilities
- Acute unanticipated trauma or illness
- Stillbirth
- Extreme preterm birth
- Child declared dead on arrival
- Child with known life-span limiting condition presenting for end-of-life care

Statistically and culturally, child death is no longer an expected part of life



WHY IS PEDIATRIC DEATH SO CHALLENGING?

WHY IS PEDIATRIC DEATH SO CHALLENGING?

BEFORE PATIENT'S DEATH...

- **Painful** or **distressing** symptoms for patient & family
- Presence of family during resuscitation
- **Deciding** terminating resuscitative efforts or not to initiating resuscitation



WHY IS PEDIATRIC DEATH SO CHALLENGING?

FOLLOWING PATIENT'S DEATH...

- Caring for family during **the most distressing moment in their life**
- Cases in which **intentional** injury or **neglect** is possible
- **Personal feelings** of anger, sadness, inadequacy, or guilt
- Belief that **death is a failure** on the part of the medical system

PHYSICIAN RESPONSIBILITIES

- AAP's *Pediatrics* published a technical report in July 2014
- Built on 2002 joint statement of the AAP and the American College of Emergency Physicians (ACEP)
- Called for a **patient** and **family** centered, **team-oriented** approach to compassionate end-of-life care
 - Respecting social, spiritual, and cultural diversity
- Report defined the physician and medical staff's **responsibilities**

American Academy
of Pediatrics



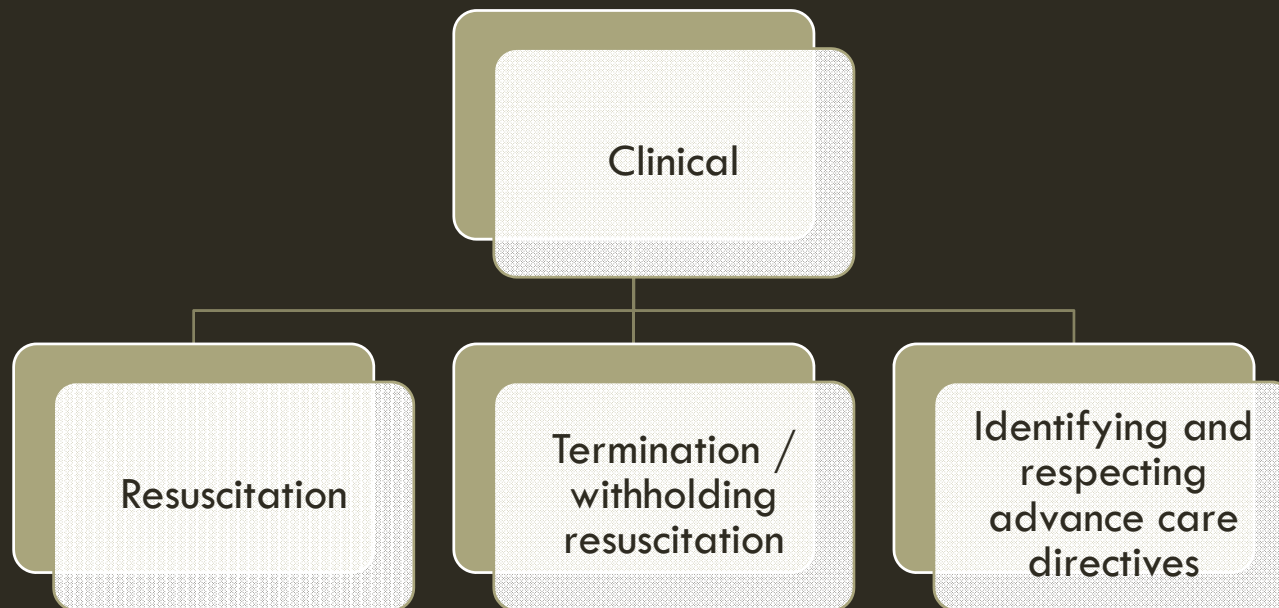
DEDICATED TO THE HEALTH OF ALL CHILDREN™

FROM THE AMERICAN ACADEMY OF PEDIATRICS

TECHNICAL REPORT

Death of a Child in the Emergency Department

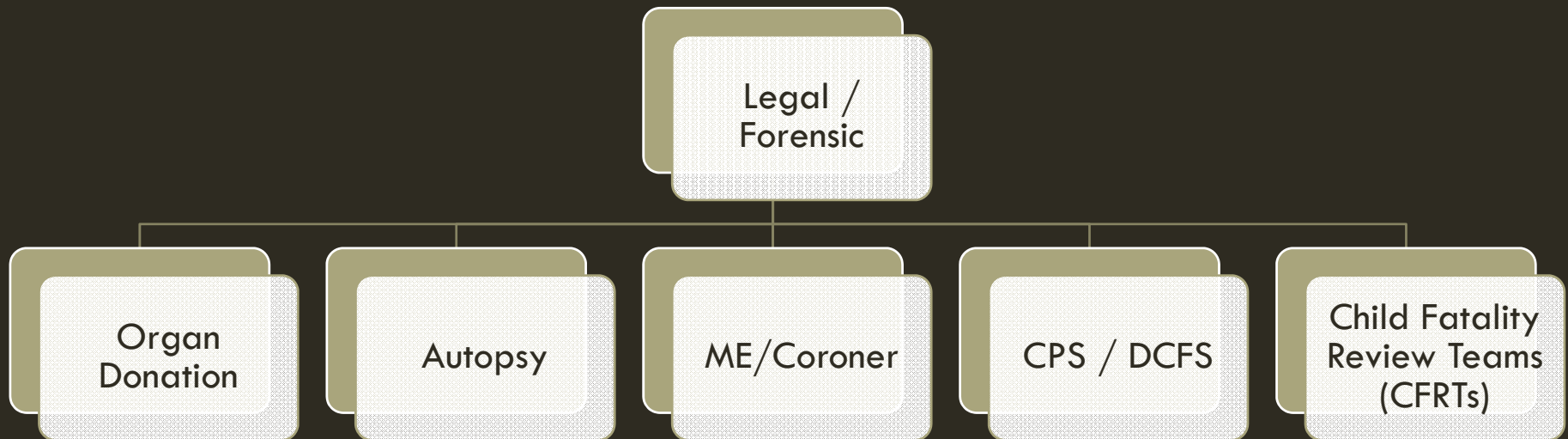
PHYSICIAN RESPONSIBILITIES: CLINICAL



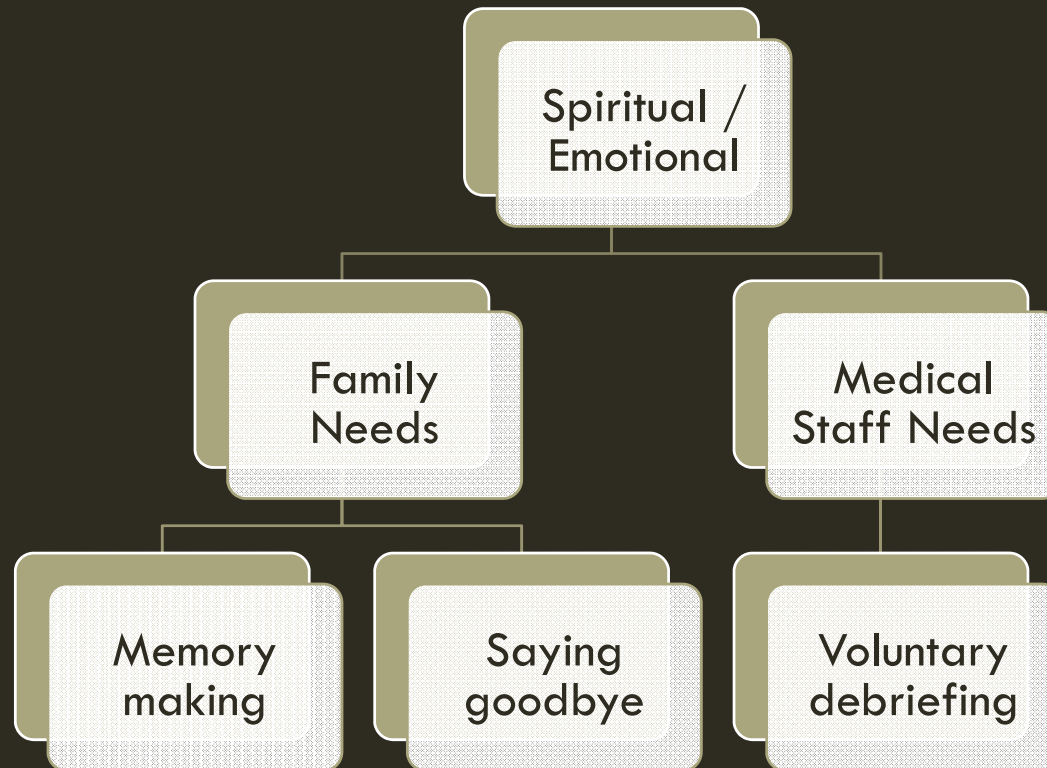
PHYSICIAN RESPONSIBILITIES: OPERATIONAL



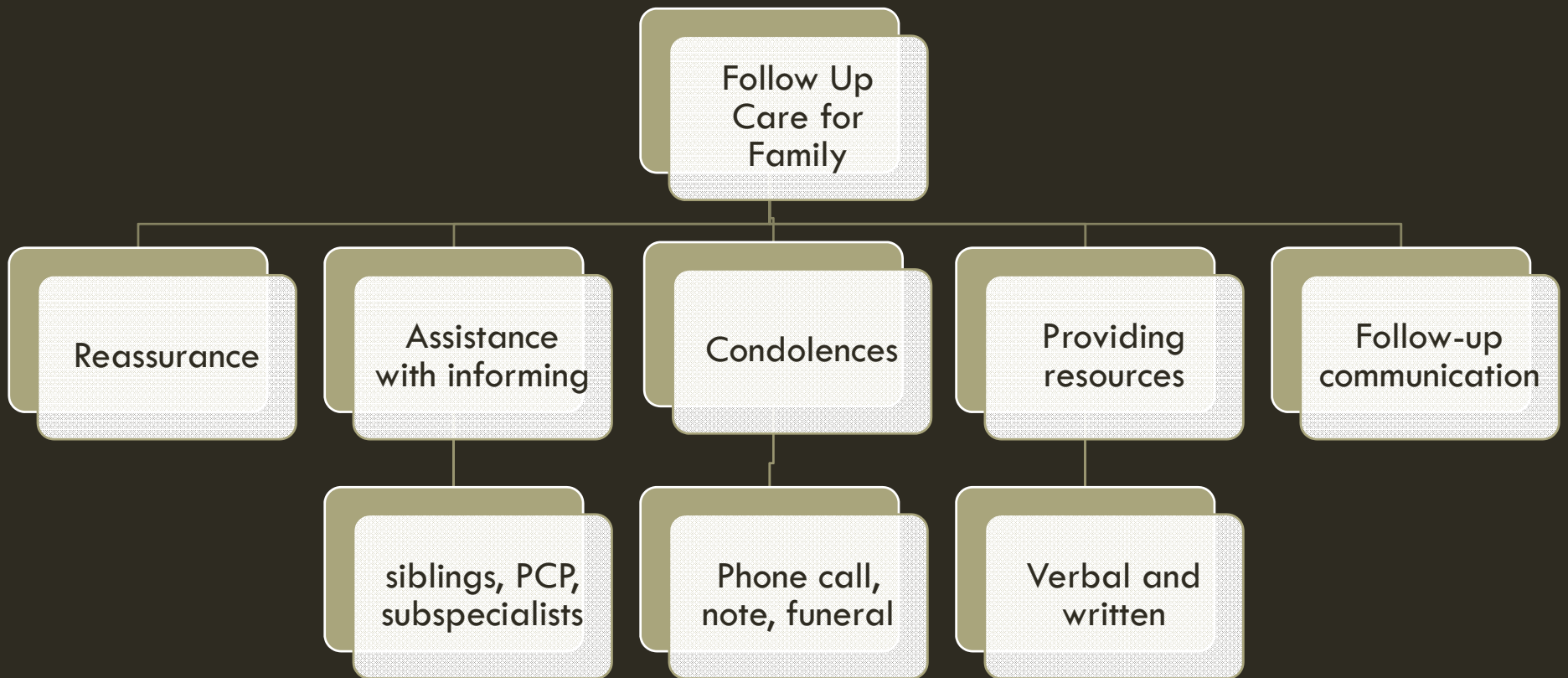
PHYSICIAN RESPONSIBILITIES: LEGAL/FORENSIC



PHYSICIAN RESPONSIBILITIES: SPIRITUAL & EMOTIONAL



PHYSICIAN RESPONSIBILITIES: FOLLOW UP CARE



OTHER PHYSICIAN RESPONSIBILITIES

Other physician responsibilities:

- Palliative care and comfort care
- Delivering the news



PEDIATRIC PALLIATIVE CARE

PEDIATRIC PALLIATIVE CARE

Seeks to improve **quality of life** in children and their families in cases of life-threatening conditions

3 goals of palliative care:

1. Relieve suffering
2. Address physical, psychosocial, and spiritual needs for child and family
3. Prepare families for later bereavement

PEDIATRIC PALLIATIVE CARE

- A Palliative Care (PC) team is an **interdisciplinary** collaboration to address all the care needs of the child & family
 - **Physical needs**
 - **Psychosocial needs**
 - **Emotional needs**
 - **Spiritual needs**
- Establishing **goals of care** is critical

PROVIDING COMFORT CARE

Acute & Subacute symptoms:

Symptoms	Treatment
Pain	Treat Underlying cause Non-pharmacological: hot/cold therapy, PT, OT, guided imagery Pharmacological: Opioids
Dyspnea	When other identifiable causes ruled out, Opioids (Morphine 0.1 mg/kg PO q3-4 hrs/PRN) Cooled air, supplemental O ₂
Nausea, Vomiting	Treat underlying cause d/c meds causing N/V Alternating types of opioids
Seizure	May require AED treatment
Anemia, bleeding	blood products if symptomatic (PRBCs, Plts)

PROVIDING COMFORT CARE

Chronic symptoms:

Symptoms	Treatment
Depression, anxiety	SSRI, +/- benzo's CBT, Psychology
Anorexia, weight loss	Appetite stimulants Enteral Nutrition
Delirium	Antipsychotics

PEDIATRIC PALLIATIVE CARE

Studies have shown that only a small percentage of pediatric patients who died in a hospital received palliative care (<4%)

- Even less if **neonate** or patient with a **circulatory / cardiac disease**
- Higher percentage if patient with **neurological** disorders

Patients receiving PC were ...

- Less likely to have **invasive** procedures
- Likely to have **fewer medications** given
- Less likely to die in an **ICU** setting
- More likely to have a **shorter** hospital stay and **lower** cost of hospitalization

PEDIATRIC PALLIATIVE CARE

IPPC (Initiative for Pediatric Palliative Care)



<http://ippcweb.org/index.htm>

ADVANCE DIRECTIVES

Advance directive: legal document allowing families to communicate preferences for end-of-life care for their child with a chronic or life-limiting condition

- Rare for pediatric patients to have an Advance Directive
- Studies have shown that parents have found it **helpful** to be involved in **shared decisions**
- Some have said that it helps in the **grieving** process

ADVANCE DIRECTIVES



Important for physician to ...

- **Initiate** these discussions early when caring for patients with chronic/life-limiting conditions
- Be **supportive** in parent's decision making



FAMILY PRESENCE DURING RESUSCITATION



FAMILY PRESENCE DURING RESUSCITATION AND INVASIVE PROCEDURES IN PEDIATRIC CRITICAL CARE: A SYSTEMATIC REVIEW

By Sarah Smith McAlvin, RN, MSN, CPNP, CCRN, CPEN, and Aimee Carew-Lyons,
RN, MSN, CPNP, CCRN, NEBC, CPHQ

FAMILY PRESENCE DURING RESUSCITATION

Review from the American Journal of Critical Care (2014) covered:

- Parents' **thoughts** about being present
- **Satisfaction** with the care their child was given
- How their presence affected their **coping** process

Barriers to family presence during the resuscitation due to fear of

- Family members **critiquing** performance
- Increasing medical staff overall **stress**
- Causing **distractions** and / or impairing **patient care**
- Promoting **litigation**
- May **traumatize** parents

FAMILY PRESENCE DURING RESUSCITATION

Fewer than 50% of nurses and physicians surveyed supported parent presence during resuscitation.

Parents reported their responses to resuscitation in 3 categories:

1. Being present
2. Satisfaction
3. Coping

FAMILY PRESENCE DURING RESUSCITATION

Being Present

- Parents reported need to be the one to **decide** to be present
- Felt that their presence was **helpful** to their child
- **55%** who were not present for resuscitation said they wished they had been

Satisfaction

- **94%** of parents surveyed would choose to be present again for invasive procedures
- **100%** would choose to be present again for resuscitation.
- **76%** **would not change anything** about their experience when present
- Parents report presence enabled them to comprehend the **severity** of their child's illness

FAMILY PRESENCE DURING RESUSCITATION

Coping

- Being present helped them "make **sense** of the situation"
- **Less anxiety** of the unknown
- No additional **trauma** from witnessing the resuscitation itself
- Most successful coping: when parents were able to leave and return
- 83% parents wished to be present if they thought their child might die

FAMILY PRESENCE DURING RESUSCITATION

Research has led a movement in creating **parental presence policies**.

- **Offer** parents to be present, allow them to step out and return
- **Liaison** between the patient's family and the medical team
 - Experienced and trained in family support skills
 - No direct involvement in the patient's care
 - Remain with the patient's family during the entire resuscitation
- **Know** your resources

WITHHOLDING AND TERMINATING RESUSCITATIVE ATTEMPTS: WHEN TO SAY WHEN?

WHEN TO SAY WHEN?

Determining when to terminate resuscitative efforts and when not to initiate them is one of the most difficult tasks facing the health care team

- Lack of objective data on which to base guidelines for terminating pediatric resuscitation
- Factors in the decision
 - Waiting until family is present
 - Organ donation
 - Provider distress

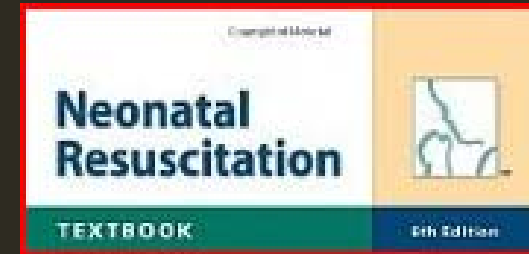
All of the above factors may lead to initiation or persistence in futile resuscitation attempts.

WHEN TO SAY WHEN?



- Pediatric-trained EM physicians twice as likely as adult EM physicians to terminate efforts if no ROSC **after 25 minutes of resuscitation**
- A 2008 systematic review stated that there is **not sufficient evidence** to base a recommendation for duration of resuscitation efforts in all situations
 - Most studies done on PICU patients who had undergone CPR followed by ECMO initiation
- 2010 Pediatric Advanced Life Support Guidelines (PALS) gave clinical variables **associated** with survival, not able to **predict** outcome:
 - Duration of CPR
 - Number of epinephrine doses given
 - If cardiac arrest witnessed versus unwitnessed
 - First and subsequent rhythms identified

WITHHOLDING RESUSCITATION: PREMATURE INFANTS



Determination of viability and decision to initiate resuscitation usually based on **weight** and **estimated gestational age**

- Cannot always accurately be determined

Neonatal Resuscitation Program (NRP) from the 2010 AAP/AHA guidelines suggest that no resuscitative efforts be initiated for:

1. Infants born at <23 WGA
2. <400g
3. Visible lethal anomalies (trisomy 13 / anencephaly)

NRP suggests termination of resuscitation if no spontaneous heartbeat after 10 minutes of effective resuscitative efforts.

WITHHOLDING RESUSCITATION: PREMATURE INFANTS

Cases where gestational age and weight **cannot be determined precisely**, some studies have suggested that:

- If physician and medical team agree that there is **no** chance of survival, resuscitation is **not indicated** and should not be initiated
- If physician & medical team believes that survival is **unlikely**, seek input from parents for decision
- If medical team believes that patient has **a good** outcome as reasonably likely, resuscitation should be initiated and its benefit should be frequently **re-assessed**

WITHHOLDING RESUSCITATION: PREMATURE INFANTS

Other factors affecting **viability**:

- Gender
- Antenatal steroids
- Multiple gestation



BREAKING THE NEWS

BREAKING THE NEWS

Tasks that family of deceased child need to complete

- **Understanding** of events leading up to child's death
- Having **control** over some aspects of situation
- Ability to **say goodbye** to their child in a meaningful way

First step to completing these tasks is **how the news is delivered**

BREAKING THE NEWS

Preparing to deliver the news

- Take a moment to **reflect** on your own feelings about situation
- Families report a greater sense of respect news is delivered by **attending** physician
- Speak of child using **child's name**
- Make sure right family members are **present**
- Have your contact information readily available

BREAKING THE NEWS

1. **Introduce** yourself and role, shake hands
2. Sit down with family at **eye level** in a quiet, private place
3. Ask “please tell me what you already known has happened to [child’s name]?”
4. After they are done answering, deliver news in a **direct manner using the word “die” or “death”**

“We did everything we possibly could, but [child’s name] has died.”

“I am so sorry to tell you this, but [child’s name] has died.”

5. Sit quietly and **allow the family to respond**
 - Resist temptation to “fill silence”
 - Allow family to speak first
 - Ask for any questions they may have about what has happened

BREAKING THE NEWS

6. **Reassure** family that child did not suffer
 - Parents may have natural feelings of **guilt**
7. Be prepared to **repeat** information multiple times as necessary
 - Re-construct or explain the events that happened
8. Explain **what** will happen next
9. Let them know you will inform PCP / specialists
10. Offer family **assistance** in helping inform other family members

Give families information they ask for at the pace that they require

NOTIFYING CORONER / MEDICAL EXAMINER

1. **Notify** local parish (county)'s coroner or medical examiner (ME) once patient has died
2. **Coroner or ME** will determine if patient falls under their jurisdiction
 - Unexpected deaths
 - Death due to accidents (MVA, burns)
 - Death in which non-accidental trauma or neglect is possible

Autopsy usually required in these situations



AUTOPSY

AUTOPSY

Why do we Autopsy?

- Autopsy considered gold standard to **assure appropriateness of care**
- **Confirms** major and minor diagnoses
- **Detects** unknown conditions
 - Produces new major diagnoses that would have been relevant treatment plan of a child in 20-50% cases
- Determining **response to treatment**
 - Quality improvement (QI)
 - Research

DISCUSSING AUTOPSY

When autopsy is not required, the option can be **recommended** and **discussed**. In these cases, **consent** is required

- Private area
- Consent obtained from child's next of kin

Proper consent defined by

- Transparent and thorough discussion of what autopsy exam is
- Proper consent forms including details of procedure should be used
- Should include any intent to retain certain organs or tissues

FAMILIES AND AUTOPSY

ARTICLES

Bereaved Parents' Perceptions of the Autopsy
Examination of Their Child

Voluntary survey of 53 parents whose had child died and undergone autopsy (2011)

FAMILIES AND AUTOPSY

- Initial discussion < 3 hours of the child's death
- Discussion initiated by a doctor (69%)
- Discussion of report occurred within 1-2 months
- The statement with the highest positive response rate (90%):
"I needed to know why my child died"
- 69% of parents did not regret their child had undergone autopsy

TABLE 6 Parents' Grief and Autopsy

Question	Strongly Agree, %	Agree, %	Unsure, %	Disagree, %	Strongly Disagree, %
The autopsy examination of my child has helped me with my grief (<i>N</i> = 52) ^a	15.5	23	25.5	17	19
I feel comforted by knowing that through the autopsy examination of my child medical knowledge is increased (<i>N</i> = 52) ^a	44	33	11	6	6
The results of the autopsy examination made it possible for me to plan for the future (<i>N</i> = 51) ^a	10	17.5	25.5	21.5	25.5
I needed to know why my child died (<i>N</i> = 53) ^a	60	30	4	2	4
The results of the autopsy examination helped me grieve for my child (<i>N</i> = 53) ^a	7.5	28	24.5	19	21
Being able to help others through my child's autopsy examination was important to me (<i>N</i> = 52) ^a	31	33	21	7.5	7.5
The autopsy examination of my child assisted me to have a feeling of "finality," (<i>N</i> = 49) ^a	14	22.5	22.5	27	14
The autopsy examination of my child assisted me to have a feeling of "closure," (<i>N</i> = 51) ^a	10	27	20	25	18
The autopsy examination of my child assisted me to have a feeling of "acceptance," (<i>N</i> = 50) ^a	14	20	20	22	16
Knowing my child had an autopsy examination has added to my grief (<i>N</i> = 52) ^a	17	25	14	21	23
The results of the autopsy examination of my child increased "feelings of guilt," (<i>N</i> = 52) ^a	0.5	23	9.5	29	29
The autopsy examination of my child left unanswered the question "why did my child die," (<i>N</i> = 52) ^a	12	23	14	22	29
The autopsy examination of my child helps me to live with my loss (<i>N</i> = 51) ^a	2	39	14	27	18
Looking back, I now regret that my child had an autopsy examination (<i>N</i> = 52) ^a	4	4	23	25	44
The autopsy examination of my child reassures me that "everything that could have been done was done," (<i>N</i> = 51) ^a	31	14	25.5	17.5	12
The autopsy examination of my child gives me comfort (<i>N</i> = 50) ^a	6	24	26	26	18

^a *N* = the number of parents who responded to the questionnaire item.

FAMILIES AND AUTOPSY



Conclusion: parents' responses towards their child's autopsy remain very **complex**

- Autopsy has more **informational** and **altruistic** value
- Keep discussion **open** and **realistic**



ORGAN AND TISSUE DONATION

ORGAN AND TISSUE DONATION

Inform state **Organ Procurement Organization (OPO)** as soon as possible if...

- Patient has just died
- Patient's death is imminent
- Patient has been declared brain dead



www.lopa.org 1-800-521-4483

Federal regulations require that a trained, designated worker (LOPA) approach families to discuss and request organ and tissue donation

ORGAN AND TISSUE DONATION

Higher consent rates and greater parental satisfaction when:

- **De-coupling** of informing the family of patient's death and the request of organ donation
 - By time and place
- OPO worker makes the request
- Request in a **quiet, private** place

NOTIFYING PCP

- **Prompt** notification of PCP, subspecialists, and other members of medical home (ST/PT/OT)
- Family members should not have to perform this task
- Allows PCP to **reach out**
- Can allow for **follow up meeting**



FAMILY BEREAVEMENT



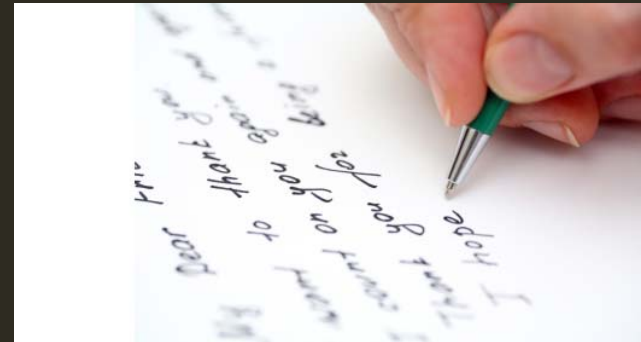
Child's death leads to a **distinct type of bereavement**:

- Against expected **order** of events
- Parental need to **protect** their child
- Witnessing child **suffering**
- May sense a loss **of identity** as a parent
- **Siblings**: social isolation and withdrawal

FAMILY BEREAVEMENT

Bereavement **follow-up** is essential

- Provide families with information about local **support** groups
- Give family contact information for **grief therapists**
- Stay in touch
- Condolence **note** from physician helps in healing
- **Funeral** attendance



RESOURCES FOR GRIEVING FAMILIES



<https://www.compassionatefriends.org>

1-877-969-0010



<https://kidsaid.com>

IMPORTANCE OF DEBRIEFING



Informal and formal debriefings help healthcare providers with:

- Promote **self-efficacy** and **functioning**
- **Lessen** feelings of uncertainty, insecurity, and hopelessness
- Reinststate sense of **purpose**

Debriefings allow each team member to ask questions & offer comments

Helps assess strengths and weaknesses of a resuscitation (**Quality Improvement**)

- Reinforcing positive actions
- Allows review of negative actions

RESIDENTS AND PEDIATRIC DEATH

ARTICLE

Pediatric Residents' Clinical and Educational Experiences With End-of-Life Care

Megan E. McCabe, MD^a, Elizabeth A. Hunt, MD, MPH^{b,c}, Janet R. Serwint, MD^c

RESIDENTS AND PEDIATRIC DEATH

Internet-based **survey** of 80 peds residents at Johns Hopkins Children's Center

Study found that...

- Residents present for a mean of **4.7** patient deaths
- >50% had participated in..
 - Discussions of withdrawal or limitation of life-sustaining therapy
 - Managing symptoms of dying
 - Completed a death certificate

Residents overall strongly agreed that they found it valuable to care for dying children

RESIDENTS AND PEDIATRIC DEATH



Using Likert scale, **majority** of residents did not feel adequately trained in:

- Holding discussions of withdrawal or limitation of life-sustaining therapy
- Declaring death
- Discussing autopsy
- Completing death certificate
- Follow-up communication with families

RESIDENTS AND PEDIATRIC DEATH

Other findings:

- Majority of deaths residents encountered in **PICU** and **NICU**
- Residents spent **15%** training time in ICU setting
- **Limitations** of ICU time from ACGME curriculum guidelines → low exposure rate to end of life care

Possible solutions: Seminar series ?

- Johns Hopkins
- University of Arizona

RESIDENTS AND PEDIATRIC DEATH

TABLE 1. Seminar Series Overview

Session	Topics Covered	Facilitators or Guests
1	Defining death in medical and legal terms, declaring death, documentation of death, arranging organ donation, discussing autopsy	Series co-coordinators
2	Symptom management Pain, anxiety, fluids/nutrition, seizures, bowel/bladder, respiratory symptoms	Hospice director, former intensive care unit nurse, MD with expertise in complementary and alternative medicine
3	Roundtable discussion Giving bad news, discussing "do not resuscitate," interacting with families at the time of death and thereafter	General pediatrician, pediatric intensivist, pediatric oncologist, pediatric pulmonologist
4	Caring for patients from varying ethnic and cultural backgrounds	Anthropologist
5	Death in the context of the family	Parent of deceased child, community-based social workers
6	Impact of death of pediatric patients on physicians and their partners	Spouses/significant others, psychologist

THE “GOOD DEATH”

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of Pediatrics
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FROM THE AMERICAN ACADEMY OF PEDIATRICS

TECHNICAL REPORT

Death of a Child in the Emergency Department

3 components of a “good death”:

1. Best resuscitation practices
2. Caring for family in a way that allows them to:
 - Understand events leading up to patient’s death
 - Have some control over situation
 - Say goodbye to their child in a way that is meaningful to them
3. Medical staff caring for each other

“THE CODE”

"Often we keep [these] feelings to ourselves, rarely giving voice to them as we proceeded through far more challenging situations during our clerkships - a 2 year old with an inoperable and therefore fatal brain tumor, a young man with quadriplegia from diving into shallow water. We discussed the medical management in detail and with intense care, but we could not give voice to the feelings these events evoked, often reducing them to a single word, 'unfortunate.'

We learned the trick of silencing the parts of our brain that didn't really want to be this close to death. We learned to put those feelings away. The question, of course, is how to avoid losing them altogether, and how to come back to them later, when we have time to think about them."

- Dr. Katharine Treadway, NEJM 2007

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THANK YOU!