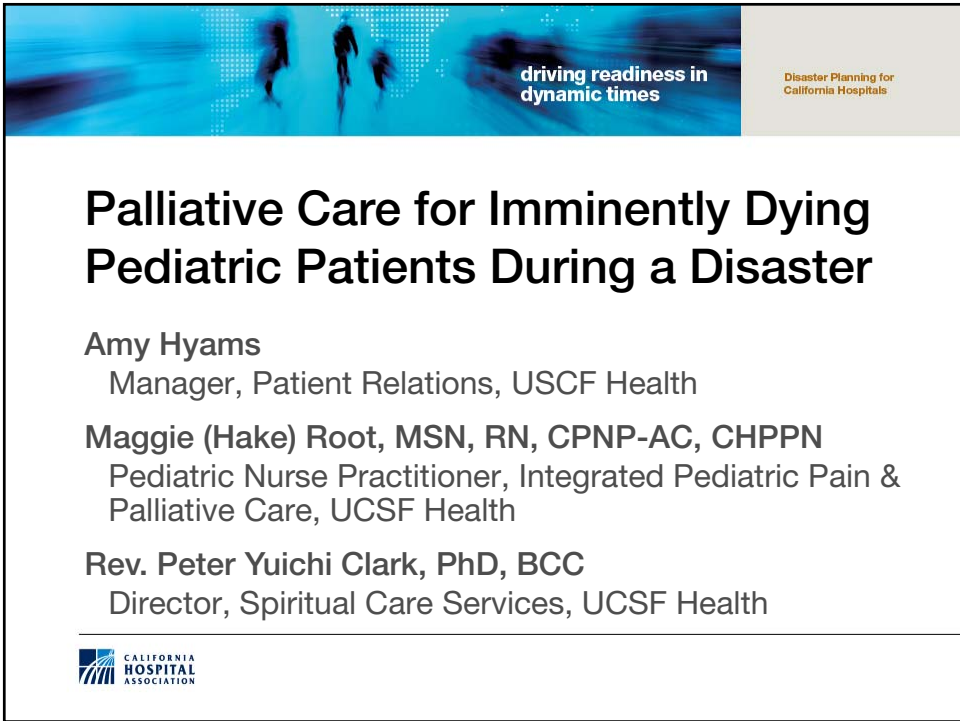


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Palliative Care for Imminently Dying Pediatric Patients During a Disaster

Amy Hyams

Manager, Patient Relations, UCSF Health

Maggie (Hake) Root, MSN, RN, CPNP-AC, CHPPN

Pediatric Nurse Practitioner, Integrated Pediatric Pain & Palliative Care, UCSF Health

Rev. Peter Yuichi Clark, PhD, BCC

Director, Spiritual Care Services, UCSF Health



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Integrated Pediatric Pain & Palliative Care

Rev. Peter Yuichi Clark, MDiv, PhD, BCC
Spiritual Care Services

Warning Shot:

An opportunity to check our emotions



“Disaster gave me two things: a moment to react and a decision to overcome.”

~ Michael Dooley

Introductions

Amy Hyams, Manager

- UCSF Medical Center / UCSF Benioff Children's Hospital, Patient Relations / Decedent Affairs
- Member, UCSF Emergency Management Committee



Introductions (cont.)

Maggie (Hake) Root, Pediatric Nurse Practitioner

- Integrated Pediatric Pain & Palliative Care, UCSF Benioff Children's Hospital – San Francisco
- Pediatric Nurse Practitioner – Acute Care
 - Specialty certification in Pediatric Hospice and Palliative Care
- Previous bedside nurse in pediatric oncology and bone marrow transplant at two major academic medical centers
- Previous National Disaster Volunteer, American Red Cross
 - Hurricane Katrina



Introductions (cont.)

Rev. Peter Yuichi Clark, Director

- Spiritual Care Services, UCSF Medical Center / UCSF Benioff Children's Hospitals
- Member, UCSF Emergency Management Committee
- Seminary professor (Graduate Theological Union, Berkeley) and volunteer clinical faculty for UCSF School of Medicine
- Chaplaincy experience in acute care hospitals, psychiatric hospitals, geriatric settings and the U.S. Air Force



Objective I

Describe the process of developing a guideline for pediatric patients designated as imminently dying, or “expectant,” in a disaster.

- Getting Started
- Definitions
- Stakeholders
- Process



How We Got Started and Why?

Identifying a Gap – September 2015

- In a disaster, what do we hang on to above all?
 - *UCSF Health* Mission – Caring, Healing, Teaching, Discovering
 - Goal of relief for those suffering
 - The tools to do good for the greatest number

Thanks to Henry Newhall Mayo Hospital for the inspiration (CHA 2015)

Definitions

Palliative Care

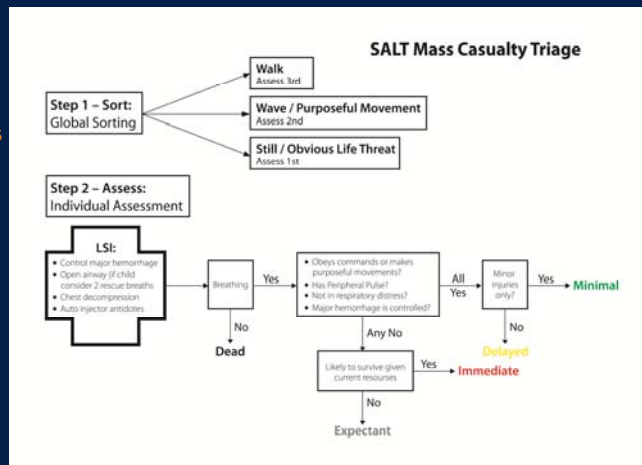
- “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”
- Helping children with serious illness/injury live as well as possible, for as long as possible

World Health Organization; www.who.int/cancer/palliative/definition/en/

Definitions (cont.)

SALT Triage

Sort
Assess
Lifesaving Interventions
Treatment/Transport



Definitions (cont.)

Expectant or Imminent Patient

- Injuries that overwhelm current medical resources at the expense of treating salvageable patients
- Should not be abandoned
- Should be cared for in separate area
- Require staff members who are capable of monitoring and providing comfort measures

Definitions (cont.)

Psychological First Aid

- An evidence-informed approach for assisting children, adolescents, adults and families in the aftermath of disaster and terrorism



Stakeholders



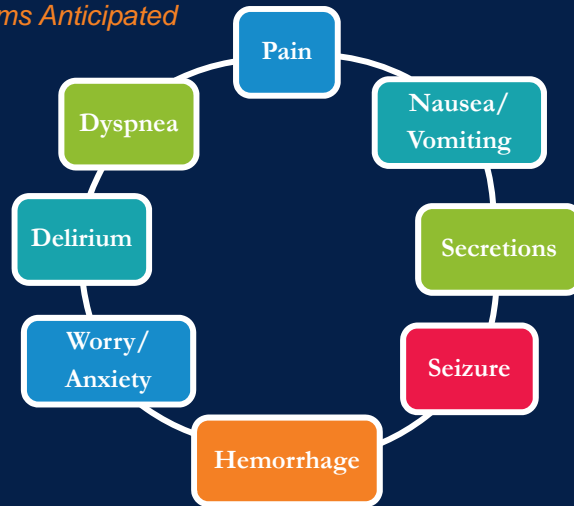
Objective II

Identify clinical and ethical considerations specific to pediatric patients who are identified as imminently dying

- Clinical Considerations
- Ethical Considerations

Clinical Considerations

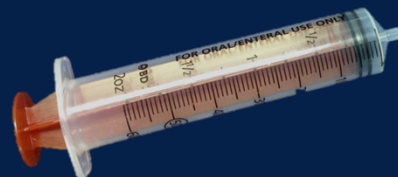
Symptoms Anticipated



Clinical Considerations (cont.)

Medication

- Administration routes
 - Oral, intranasal preferred in children
- Dosing
 - Weight-based in pediatrics
 - Guidelines are internet-based
- Concentrations
- Compounding
- Current inventory



Clinical Considerations (cont.)

Logistics

- Location of care
 - Two campuses
 - Few stairs, low likelihood of being moved
 - Medication availability
 - Level of nursing comfort
 - Proximity to suction, emergency power
- Staff training/preparedness



Clinical Considerations (cont.)

Supplies

- Oral syringes
- IV syringes (luer lock)
- Saline flushes
- IV start kits
- Subcutaneous infusion start kits
- Ice packs
- Heat packs
- Fans/handheld fans
- Peppermint oil



Ethical Considerations

Where will moral distress exist? And what will we do in response?

- Identification of physical space for pediatric patients
- Communicating triage status
 - Spiritual care, security, ethics
- Families triaged differently
- Giving “the last dose”
- Reframe “do everything”
- Body processing / medical examiner

Objective III

Illustrate the role and importance of grief and loss support for pediatric patients, their families and the medical care team in the midst of the disaster

- Identifying and addressing moral distress in staff
- Allocating resources
- Providing on-the-spot education on developmentally appropriate stages of loss / grief to staff members and families

Defining and Describing Grief ...

Grief is the normal but bewildering cluster of ordinary human emotions arising in response to a significant loss, **intensified** and **complicated** by the relationship to the [lost] person or object (Mitchell and Anderson 1983: 54), as well as the level of **expectation/anticipation** of the loss

Common elements include:

- **Numbness**
- **Emptiness, loneliness** and **isolation**
- **Fear** and **anxiety**
- **Guilt** and **shame**
- **Anger**
- **Sadness** and **despair**
- **Somatization**



A Pictorial Interpretation ...

1. **The child's reactions and grief** (as mediated by her/his developmental maturity)
2. **Family members' reactions and grief**
3. **Caregivers' reactions and grief** (including moral distress)

— influenced and supported by a “table” of varying familial, sociocultural, religious/spiritual and other values, norms, convictions *and* connections to communities ...

... until situational uncertainty enters the picture ...



Some Implications for Parents and Families

- A child's spirituality is often family-centered
- Watching a child fall sick and die is a **crisis of meaning** for all families
- "Often what children and families want is support as they struggle to make meaning out of what is happening to them. The most basic invitation of all is to say, '**Tell me about it.**'" (Barnes et al. 2000)
- A single family may be "**multicultural**" as members respond to the crisis
- Parents want to be listened to, want to be recognized as experts about their children and want to receive **clear, accurate and timely information**

Some Implications for Caregivers

- A **potential crisis of meaning** for caregivers, as much as it is for families
- Pediatric palliative care can seem **inherently unnatural** in U.S. caregivers' minds
- **High potential for moral distress**
→ increased need for staff support and diligence in self-care practices
- Listening **care-fully** to their stories, even amid the triage



(inspired by Geertz 1966)

Two Risks:



1) *being overwhelmed and too deeply touched by the psycho-spiritual power of the pain of death and loss*

or else

2) *becoming closed, untouched, spiritually numbed and beyond vulnerability*

Tasks of Grieving and Caring Responses

Tasks Faced by Grievers (* = not likely to occur in immediate aftermath of disaster)	How Caregivers Can Respond
Ensure physical safety	Concrete help, logistical assistance
Recognize and accept the reality of the loss (shock, numbness, denial)	Listen care-fully to grievers' stories (content, feelings and meanings) and normalize their responses
Re-collect and re-experience the pain of loss (fear, anger, sadness)	Compassionate presence while resisting the temptation to offer "fixes"
* Cope with the changes (adjust to an environment in which the deceased child is missing)	Facilitate reality testing, gently and gradually
* Place the loss within a wider context of meaning	Foster spiritual growth and emotional coping responses
* Reach out to others and re-invest in relationships	Enable and encourage outreach

(Worden 1982; Lester 1987; Rando 1993; NCTSN and NCPTSD 2006; NYDIS 2007; WHO 2011; Nefstead 2013; National Disaster Interfaiths Network, n.d.)


A Final Word From a Modern Sage:



“Anything that’s human is mentionable, and **anything that is mentionable can be more manageable.**”

When we can talk about our feelings, they become less overwhelming, less upsetting and less scary. The people we trust with that important talk can help us know that we are not alone.”


~ attributed to Fred Rogers



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Questions?



CALIFORNIA HOSPITAL ASSOCIATION



Thank You!

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