Palliative Care Considerations in Disaster Situations

- Marianne Matzo, PhD, GNP-BC, FPCN, FAAN
- Tia Powell, M.D.
- Jon Surbeck, M.A. CFO, MIFireE, IC-2(t)
- Carma J. Erickson-Hurt, APRN, ACHPN

Panel Speakers

- Dr. Marianne Matzo is a Professor and Frances E. and A. Earl Ziegler Chair in Palliative Care Nursing, University of Oklahoma, College of Nursing.

- Dr. Tia Powell is Director of the Einstein-Cardozo Master of Science in Bioethics and Professor of Clinical Epidemiology at Albert Einstein College of Medicine in the Bronx, NY.

- Mr. Jon Surbeck is managing partner of OD Consulting, LLC and serves as Incident Commander on Colorado Teams 1 & 3. He works in the Greeley Colorado area..

- Mrs. Carma Erickson-Hurt resides in Oregon and is a retired Navy nurse who currently works for Project Hope in humanitarian assignments in Africa and Haiti.

Outline

- Marianne will provide an overview of what palliative care is, is "not", and provide a general overview of the palliative care capacity in the U.S.

- Tia will provide an overview of how palliative care fits into the Institute of Medicine (IOM) Crisis Standards of Care Committee Research and provide an ethical framework for palliative care in disaster situations.

- Jon will provide an overview of a palliative care disaster model he helped develop and use for a Colorado exercise and offer lessons learned from their after-action report.

- Carma will provide a first-hand perspective of the clinical implications of palliative care in disaster situations.

Palliative Care

MARIANNE MATZO, PHD, GNP-BC, FPCN, FAAN
PROFESSOR AND FRANCES E. AND A. EARL ZIEGLER CHAIR IN PALLIATIVE CARE NURSING
SOONER PALLIATIVE CARE INSTITUTE

The University of Oklahoma
HEALTH SCIENCES CENTER
College of Nursing

What Is Palliative Care?

- A specialty that focuses on relief of pain and other symptoms of serious illness with the goal of preventing and easing suffering and distress while offering patients and their families the best possible quality of life.

- APPROPRIATE AT ANY STAGE OF A SERIOUS OR LIFE-THREATENING ILLNESS AND IS NOT DEPENDENT ON PROGNOSIS

- **Provided at the same time as curative and life-prolonging treatment.**

- **Appropriate at any stage of a serious or life-threatening illness and is not dependent on prognosis.**

- **Provided at the same time as curative and life-prolonging treatment.**

- Focused on the relief of suffering and support for the best possible quality of life.

Palliative Care
Improves Health Care Quality

- Relief of pain and symptoms and emotional suffering for patients and families
- Enhanced patient/health care practitioner/family communication and decision-making
- Improved coordination of care across multiple healthcare settings

Palliative Care: Capacity

- 60 % of U.S. hospitals with more than 50 beds (CAPC 2010; Goldsmith et al. 2008) have palliative care services (1,500 U.S. hospitals).
- These programs affect approximately 1.5 percent of all discharges and is estimated to save $1.2 billion per year under the current penetration of services.
- This figure would increase to approximately $4 billion per year if capacity were expanded to meet the needs of 6% of hospital discharges at 90% of all U.S. hospitals with more than fifty beds (Morrison, Meier, and Carlson 2011; Morrison et al. 2008; Siu et al. 2009).

Disaster-Related Challenges

- Provision of palliative care in the context of a mass casualty event is a new component of disaster response planning
- Palliative care, long-term care, and home care are already resource poor under conventional capacity, and will be further strained and under-resourced during mass casualty events
- There is a lack of understanding of the potential utility of incorporating community-based health care, mental health, and social service professionals into mass casualty event response planning efforts
- Significant lack of public awareness regarding the limitations of the health care system under austere circumstances

Palliative Care In Catastrophic Mass Casualty Events

- **Palliative Care is:**
  - … *Evidence-based medical treatment*
  - … *Vigorous care of pain and symptoms throughout illness*
  - … *Care that patients want*

- **Palliative Care is *not*:**
  - … *Abandonment*
  - … *The same as hospice*
  - … *Euthanasia*
  - … *Hastening death*

Under Disaster Conditions

- **Minimum Goal of Palliative Care**
  - ***Help patients die pain and symptom free***

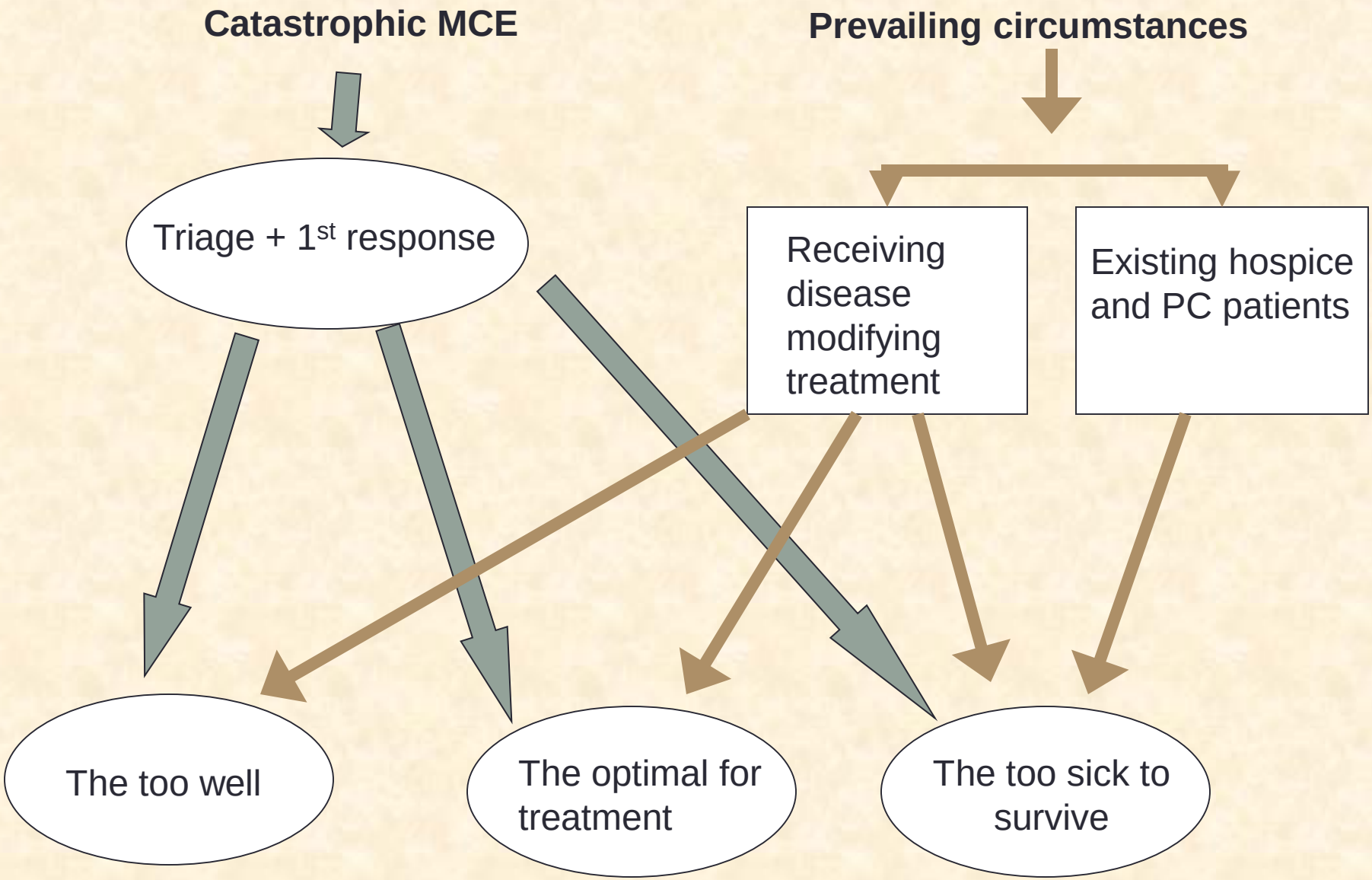
- **Basic Definition Minimum of Service of Palliative Care**
  - ***Effective, aggressive pain and symptom management***

- **Good palliative care occurs wherever the patient is.**

- **The community should be prepared about the principles of palliative care in a disaster situation.**

- **Adequate and aggressive palliative care services should be available to everyone.**

Catastrophic MCE: Triage and Response



ETHICAL FRAMEWORK FOR PALLIATIVE CARE IN DISASTERS

Dr. Tia Powell is Director of the Einstein-Cardozo Master of Science in Bioethics and Professor of Clinical Epidemiology at Albert Einstein College of Medicine in the Bronx, NY.

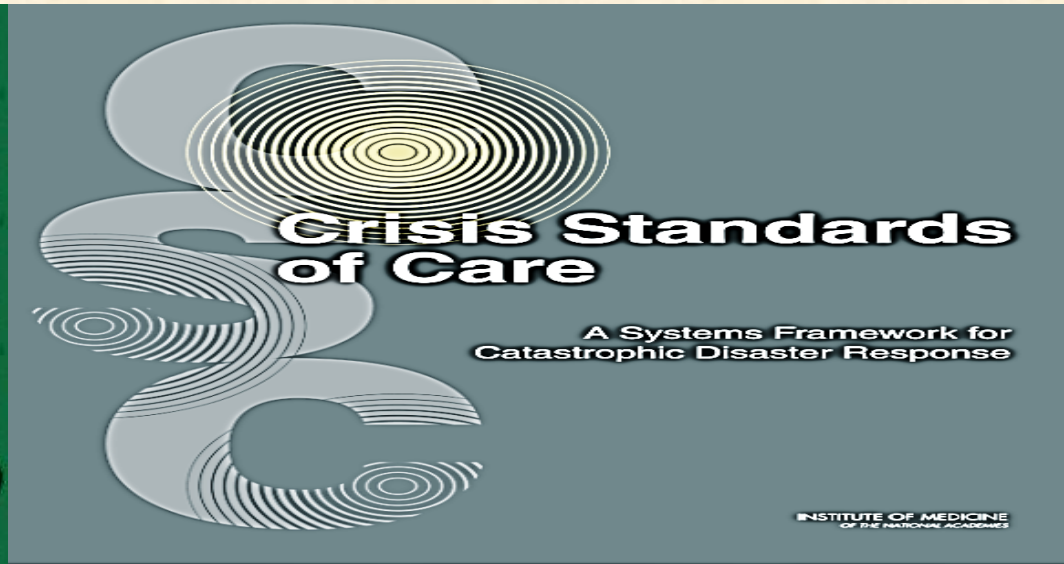
Montefiore
THE UNIVERSITY HOSPITAL

EINSTEIN
Albert Einstein College of Medicine
OF YESHIVA UNIVERSITY

THE TASK OF MEDICINE IS TO CURE SOMETIMES, TO RELIEVE OFTEN, AND TO COMFORT ALWAYS

Crisis Standards Of Care

- IOM Letter Report, 2009, Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations
- IOM 2012 Report, A Systems Framework for Catastrophic Disaster Response
- Delineate Standards that may shift in disaster setting
- Specify conduct that is ethically unacceptable irrespective of conditions
- Responsibilities of stakeholder groups



Legal Environment

- Provider concerns regarding liability
- IOM supports range of protections for providers acting in good faith, following established guidance
- IOM does not support protection for acts of gross negligence
- Most jurisdictions offer some form of liability for providers in disasters
- Controversy: some scholars deny liability concerns of providers and/or need to offer

7 Key Ethical Features

- Fairness
  - Transparency
  - Consistency
  - Proportionality
- Duty to Care
- Duty to Steward Resources
- Accountability

Fairness

- Mass casualty event means scarce resources
- Not all can receive all they need
- Allocation reflects ethical system
- No Patient abandoned
- Palliative care a crucial element of fairness

Transparency

- System of allocating scarce resources:
  - Developed in advance
  - Communicated openly
  - Responsive to community values
  - Includes review of palliative plans

Consistency

- All patients will <u>not</u> receive same treatment
- Similar patients have similar treatment
  - When system overwhelmed, may need lottery, first-come first-served for similar patients
- Different patients are treated differently for appropriate reasons
  - First responders
  - Greater risk

Proportionality

- Negative impact of public health plan in proportion to hoped for benefit
- Protection of civil liberties
- Minimization of lost income from work
- Minimize impact of limits to treatment
  - Palliative Care

Duty To Provide Palliative Care

- Part of duty to care
- Not all will recover
  - Dying because of disaster
  - Dying before disaster
- All must be treated with dignity, compassion
- Appropriate palliative care planning part of disaster care obligation

Palliative Care Planning

- Part of overall ethical obligation
- Few disaster plans incorporate
- Palliative care surge planning includes:
  - Educating staff
  - Stockpiling meds for symptom control
  - Training in counseling
  - Symptom management protocols

Stewardship Of Palliative Resources

- Use of supplies
  - Pain medications not only for survivors
  - Water, food
- Use of personnel
  - Trained v volunteers
  - Basic care: cleanliness, comfort
- Use of space
  - Promote privacy, comfort vs. technology

Accountability

- For planning
- For medical decisions
- For care of patients not expected to survive
- Palliative care crucial for :
  - Resilience
  - Responsiveness

Role of Family

- **Benefit:**
  - Comfort for both patient and family
  - Performing non-technical tasks helps surge
  - Promotes transparency
- **Liability:**
  - Potential risk to staff with limits to care
  - May increase differential for most vulnerable
  - Volunteers may impede effective treatment

WE Smith, Tomoko In Her Bath

A MODEL
FOR DISASTER PALLIATIVE AND HOSPICE CARE

MR. JON SURBECK IS MANAGING PARTNER OF OD CONSULTING, LLC AND SERVES AS INCIDENT COMMANDER ON COLORADO TEAMS 1& 3.

The Thought Process

- This is a difficult subject – it's better to have these conversations now!

- Do not compromise a patient's respect and dignity

- Plan for the worst case scenario – you can always scale back

Assumptions

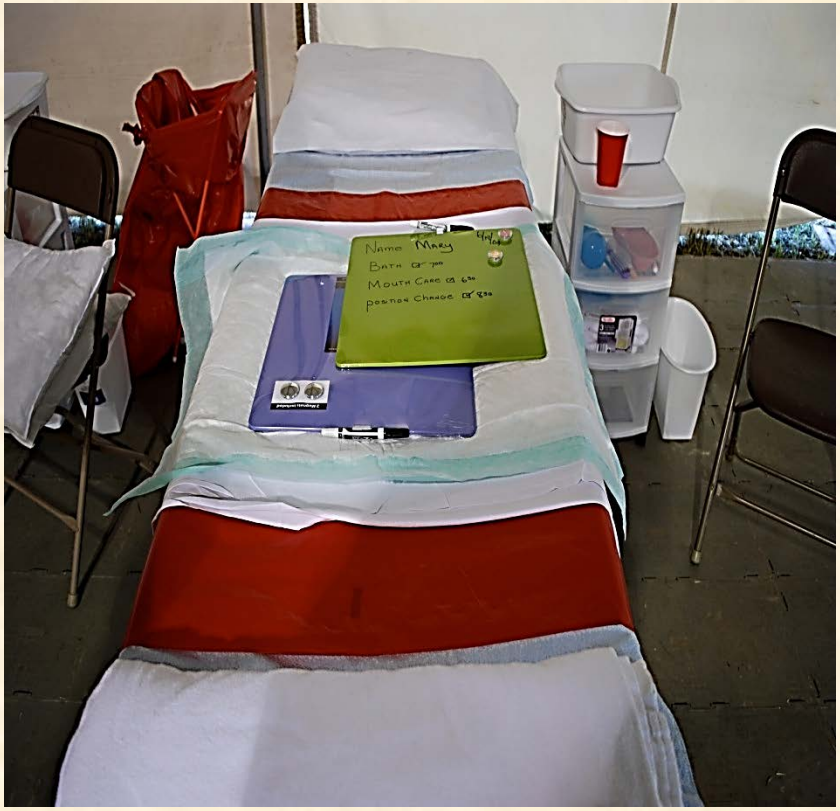
- Medical Surge will expand out as needed
- "Surging in Place" happens first
- Surging to Alternate Care Facilities happens next
- Surging to 'specialized' alternate care facilities may be the last expansion – such as a palliative and hospice alternate care facility

The Facility Staffing

- Medically trained personnel will be spread thin
- Medically trained personnel will be needed to provide care for those that have the best chances for survival
- Volunteers with little or no medical background may be called upon to provide palliative and hospice care
- These volunteers will need training

Just In Time Training

- ER Nurse provided training for basic hygiene and comfort care



Just In Time Training

- Hospice Chaplains provided training for:
  - What to expect as end of life nears
  - How to talk/not talk to the dying
  - How to deal with the caregiver's emotions

The Model - Logistics

- Scalable depending on the size of the community served – or the number of casualties

- Adaptable for varying conditions, locations and scenarios

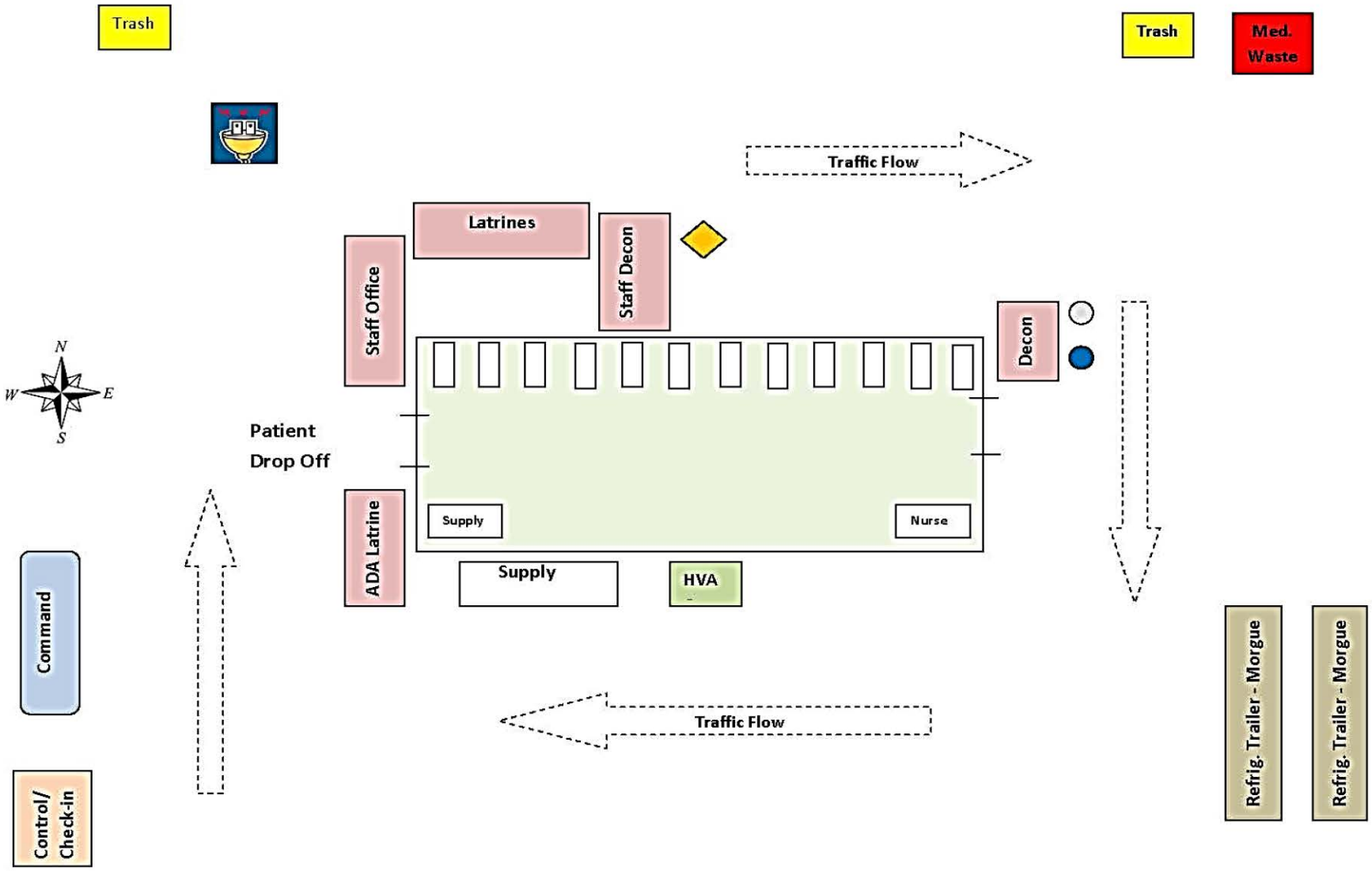
- Cover as many of the details as possible – make it comprehensive

The Partners

- Public Health and Emergency Management
- Physicians and Nurses
- Hospitals
- Mental Health
- Palliative and Hospice Care
- Law Enforcement and Coroner
- EMS
- Private Business
- Volunteers/Civilians
- Various Public Information Officers

The Layout

- Start with nothing – a vacant field
- Build what you need – where you need it
- OR – use existing structures



Palliative Care Facility Layout

Other Model Considerations

- Patient triage
- Patient transport
- Intake information
- Facility ambience
- Pain Management
- Comfort care
- Spiritual and emotional care

Lessons Learned

- Considerations for families
- Public information and messaging
- Temporary Morgue
- Stress management for facility staff
- And much more….

Clinical Implications of Palliative Care in Disaster Situations

A First-hand Perspective

MRS. CARMA ERICKSON-HURT RESIDES IN OREGON AND IS A RETIRED NAVY NURSE WHO CURRENTLY WORKS FOR PROJECT HOPE IN HUMANITARIAN ASSIGNMENTS IN AFRICA AND HAITI.

Why Is Palliative Care Important?

- Expert pain and symptom management
- Interdisciplinary team approach
- Bereavement
- Ethics
- Autonomous nursing care
- Care for *Carer's*
- Experts at end-of-life care

Pain And Symptom Management

- Chronic pain
- Pain syndromes
- Understand the holistic nature of pain not only physical

Interdisciplinary Team Approach

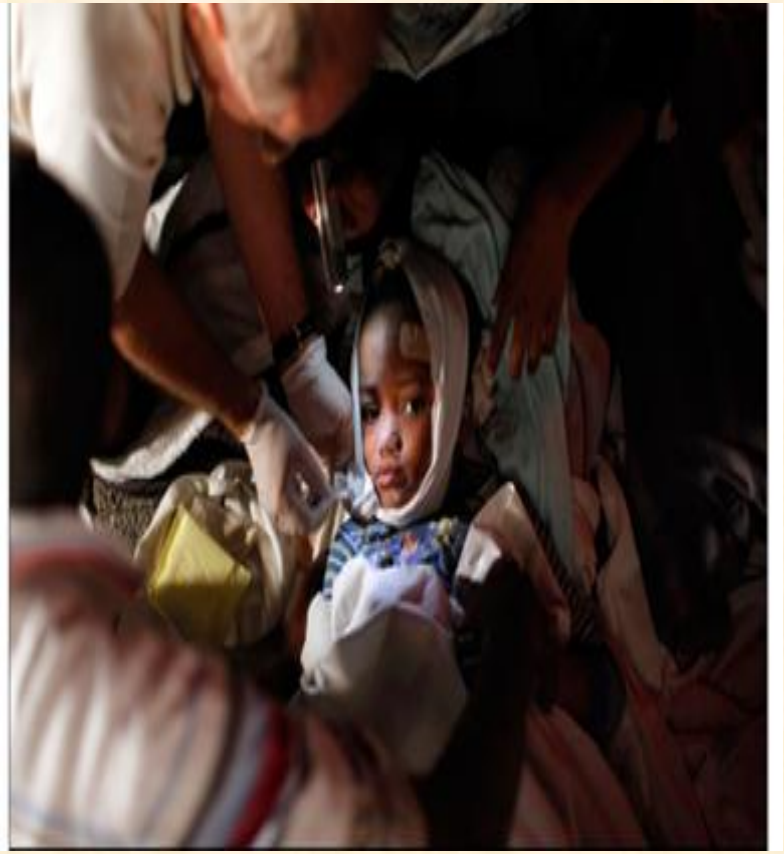
- Physicians
- Nurses
- Social workers
- Chaplains
- Psychologists
- Home health aides
- Volunteers

Bereavement

- Communication experts at difficult conversations
- For patients, community, and staff

Ethics

- Indonesia
- Haiti
- Consults/teams
- Relief of suffering
- Staff ethical concerns:
  - Patient ratios
  - Rationalization
  - Standards of care



Palliative Care

Autonomous Nursing Care

- Used to working in the home environment
- Minimal supplies/equipment
- Making due
- Charting and supplies

Care For The *Carer's*

- **Standards of practice - --*Traumatizing***
- **All team, not just health care provider's**

End Of Life Care

- Indonesia
- Haiti earthquake (need psych/sw/chaplain at beside)
- Haiti cholera outbreak
- Comfort care

Incorporate Palliative Care in Your Community Disaster Planning

- Care for the chronically ill must continue
- Care for the dying should continue
- Involve local hospice/palliative care professionals in disaster planning
- Use paraprofessionals and volunteers
- Expectation management in crucial

PANEL RE-CAP

Marianne Matzo, PhD, GNP-BC, FPCN, FAAN

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- ***Palliative Care Considerations in Disaster Situations is a Journey of Consensus Building***

- **Let's review the panel highlights on the next slide.**

Major Points

Incorporate Palliative Care into Disaster Planning

- Incorporate community-based care, long-term care and palliative care providers in all phases of preparedness, response, and recovery

- Integrate specific planning for those likely not to live long in all threat scenarios ("all-hazards approach")

- Include pediatric–specific palliative care issues in planning

Triage and Treatment

- Work with first responder personnel and local/regional disaster planners to identify and develop clear guidelines and protocols to address:
  - Triage
  - Alternative care sites for palliative care
  - What levels of care are to be delivered in what settings and by whom
  - Lines of authority and clear identification of responsible personnel

Training

- Creating specialized rapid response teams made up of palliative care professionals and lay volunteers recruited and trained to serve as providers, to include "just-in-time" training curriculum.

- Providing community and family members training regarding individuals response actions and personal protection, while caring for dying patients.

Medical Supplies and Equipment

- Stockpile palliative care medications in each community for disaster response

- Plan for the need of individuals chronically dependent on dialysis, ventilators, or other specialized supplies/equipment