

Nurses Providing Palliative Care Amidst a Disaster



What is a Disaster?



- Definition:

“A disaster is a sudden, calamitous event that seriously disrupts the functioning of a community or society and causes human, material, and economic or environmental losses that exceed the community’s or society’s ability to cope using its own resources.”

International Federation of the Red Cross, 2020

- Types of Disasters

- Natural: Can be area-specific from a localized to large regions of countries; usually weather-related or geological events
- Man-made: Terrorist attacks, release of hazardous materials (chemical or bioterrorism); nuclear disasters; mass shootings
- Infectious Disease Pandemics

Historically, Nurses Have Led the Way During Disasters

- Historically flexible and creative during crises
- The most trusted health care professionals
- Strong advocates for ethical, quality care for patients, families, and communities
- Expert, compassionate clinicians focused on holistic care of patients and families



Goals of Disaster Response: They Include Palliative Care

- Provide a coordinated response to:
 - Maximize the number of lives saved
 - Minimize the suffering of those not expected to survive; palliative care skills are as essential as life-saving skills
 - Do not forget that other patients, with serious illness are in hospitals, long-term care facilities, and are at home during the disaster. They also need care!

Wilkinson & Matzo, 2015

Phases of Response to a Disaster

- Federal Emergency Management Agency (FEMA) Model
 - Mitigation- This first phase addresses preventing or reducing the effects of a disaster
 - Preparedness- Focuses on the education and training needed to respond to and recover from a disaster. This should include palliative care education for all healthcare workers.
 - Response- Instituting the Disaster Preparedness Plan
 - Recovery- This last phase focuses on restoration and return to normalcy or a new normal. The response period may have taken over 6 months in a pandemic and years in a devastating natural disaster like a tsunami or earthquake.

Alderman et al., 2019

Best Practices for Prevention & Mitigation of Disease-Spread in a Pandemic

- Example: Prevention & Mitigation During The COVID-19 Crisis (2020)
 - Recommendations/Restrictions for all: strict hand hygiene, surface decontamination; social-distancing of 2m or 6 feet; limit gatherings to no more than 10 people in a group, maintaining social distancing
 - Healthcare system recommendations: Patients presenting with symptoms- facemask on arrival; rapid triage; separate in well-ventilated space with 6 ft. distance until isolation room available
 - Recommendations for healthcare workers in contact with infected individuals: strict hand hygiene, surface decontamination; PPE: gown, gloves and N95 respirator plus a face shield/goggles or a powered, air-purifying respirator (PAPR)

Adams & Walls, 2020; CDC.gov/coronavirus

Best Practices for Disaster Response

Initiate the Disaster Preparedness Plan which should include:

- Plans to save lives and prevent further property damage (in a natural disaster); resource distribution, restoration of utilities, public services and clean-up

Adelman et al., 2019

- A healthcare triage system that is:
 - Transparent and ethically sound
 - Consistent across settings
 - Dynamic; flexible enough to adapt to changing situations
- Integration of palliative care into this triage system – for the patients suffering during the mass casualty event as well as for those patients with serious illness before, during, and after the disaster

Best Practices for Disaster Recovery

- This period lasts anywhere from approximately six months to a year (depending on the damage or extent of the pandemic). Emphasis is on rebuilding the infrastructure and long-range sustainability.
 - Praise the great work that was done during the prevention, mitigation, and response periods
 - Evaluate what went well and what should be changed in the Disaster Preparedness Plan for future disasters
 - Integrate the changes into the revised Disaster Preparedness Plan
 - Rebuild the supplies and equipment that have been drained
 - Consider additional education that would benefit healthcare workers in the future- are all healthcare workers prepared to provide primary palliative care during a disaster?

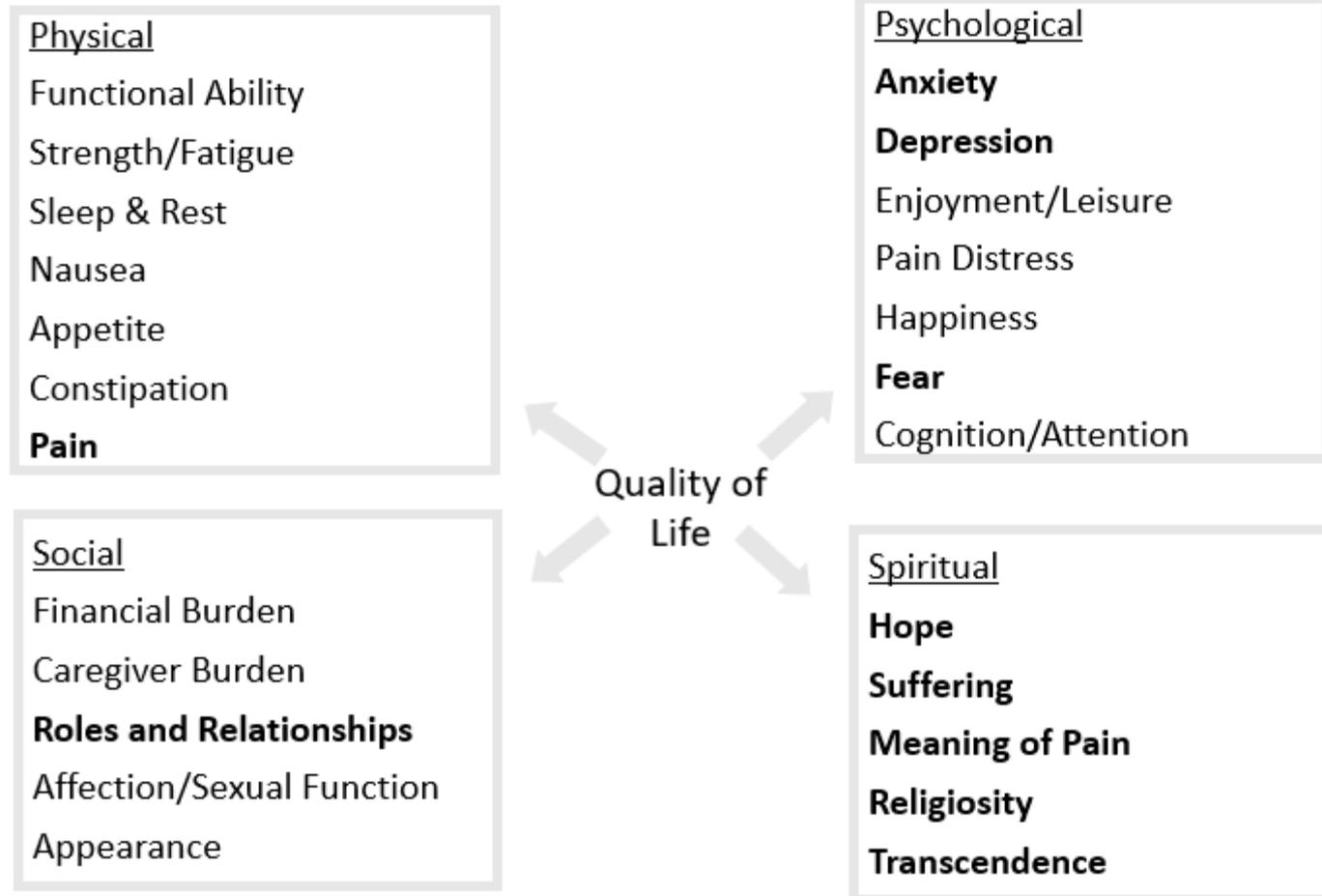
Adelman et al., 2019

Palliative Care is the Key to Address the Challenges

- Palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers.
- Palliative care must be part of disaster care. It is as important as focusing on saving lives. Attending to all components of quality of life is important, especially if survival is not expected. When deaths occur, provision of community bereavement services to family must be provided.

NCP, 2018

Quality-of-Life Model



<http://prc.coh.org>

Critical Components of Palliative Care Needed During a Disaster

- Communication skills
- Pain and symptom management expertise
- Care during the final hours/days of life
- Attention to loss, grief and bereavement- for patients, families and healthcare workers.

Communication

- Patient/family expectations during a disaster:
 - Take time to listen to fears
 - Be honest
 - Keep family and patient informed when possible
 - Communicate with the team

Dahlin & Wittenberg, 2019



Supportive Communication for Those Who Are Not Expected to Survive

- Be honest: Use words such as “death” and “dying”
- Ask what is most important to the patient at this time- it may be to not die alone, to have pain addressed, to get a message to family, or to honor cultural or spiritual rituals (i.e. prayer, facing the patient towards Mecca, receiving a sacrament). Try to honor their wishes whenever possible.
- Think of ways to reminisce about their family/life- to create a family presence and bring comforting memories to the forefront
- Consider using technology to connect patient/family if technology is available, or record a message on your smart phone to give family at a later time

Communicating with Family Members of Those Seriously Injured or Ill from a Disaster

- If family members can be reached, and patient is unable to respond, determine if the family is aware of any advance directives.
- If no AD exist, medical decisions fall to the next of kin. Help family identify what the patient would want, if they could speak for themselves. The decision is not about what the family member would want. Ask, “Was there ever a time when the patient shared if they would want to be kept alive on machines, if the prognosis was poor- for example after a family member or friend’s death.”

Communicating with Family Members of Those Seriously Injured or Ill from a Disaster (continued)

- Family want to be updated and kept informed, especially if they are unable to see/visit their loved one. Set up a schedule for updates via phone calls and commit to that promise.
- If family members are seeking help to locate a loved one during a disaster, nurses should direct them to contact the Red Cross, domestically, and the Red Crescent across international borders:
<https://www.redcross.org/about-us/our-work/international-services/reconnecting-families.html>

Pain & Symptom Management

- Palliative care emphasizes aggressive pain and symptom management
 - Be knowledgeable about symptoms common during a disaster (i.e. dyspnea in an influenza pandemic, pain associated with catastrophic injury) and advocate for aggressive management
 - Create protocols and standard order sheets before a disaster
 - Ensure there is a stockpile of medications at your facility that can treat common symptoms:
 - Opioids for pain and dyspnea
 - Haloperidol for nausea or delirium
 - Scopolamine for secretions
 - Intravenous supplies
 - Drug delivery pumps

Care During Final Hours/Days

- Ensure pain and symptom management is addressed
- Attend to the patient's quality of life- for however long that life might be: especially emotional needs and spiritual well-being
- If possible, connect the patient and family (technology may help)
- Respect the sacred time of dying: honor cultural considerations that are important to a patient. Ask if they have any rituals of significance that you might be able to initiate.
- **Try to stay with the dying patient, no one should die alone**

Open, Honest Communication During Final Hours

- Patients often have an awareness of dying
- Convey caring, sensitivity, and compassion
- Provide information in simple, honest terms
- Maintain presence – some things cannot be fixed-
However, you can give your patients the most important gift of all- the gift of presence

Care and Respect of the Body



- Reflects importance and value of each patient
- When possible, make the body presentable in case family members are permitted to view the body – remember this may be their last image of their loved one
- Family members who are allowed to see their loved ones in a disaster morgue should never go without a nurse or counselor for support
- It will be very hard for families who cannot have access to their loved one's body immediately after death, as is the case during a pandemic, and for families whose loved one's body may never be recovered (i.e., after a natural disaster like a tornado or earthquake). They will need bereavement support to deal with complicated grief.

Berry & Griffie, 2019

Attention to Loss, Grief & Bereavement

- There will be multiple losses during a disaster (i.e. patient deaths, property loss in natural disasters, etc.)
- There is little time to grieve those losses, which can accumulate and result in compassion fatigue/burnout
- For families, the grief experience will be complicated
- Disasters create sudden, unexpected death, an inability to say goodbye, an inability to hold funerals or cultural rituals that provide support



Dealing with Multiple Deaths During a Disaster

- Honor and respect the person who has died by taking a moment to remember; this will also help you with your own experience of cumulative loss during this crisis. Watch this short video, “The Pause”, which highlights the importance of integrating this brief but essential intervention during a disaster, after a patient has died.



<https://www.youtube.com/watch?v=HVXM2YhZ2A>

The Grieving Process

- Grief work is never completely finished
- Healing occurs when the pain is less
- Letting go- the ability to move forward into a new “normal”



Legal and Ethical Considerations During Disasters

- During disasters, nurses are faced with the difficult decision of responding to the call for nurses
- Nurses may struggle with:
 - The fear of putting oneself in harm's way (i.e. risk of injury during a hurricane or contracting a contagious illness)
 - Worries about placing one's family at risk (family care issues during prolonged work shifts; spreading a contagious disease)
 - Standard of care concerns
 - Legal and professional protection/liability

ANA Code of Ethics with Interpretive Statements (2015)

- “Nurses’ primary commitment is to the patient”
- But this must be balanced with the recognition that “the nurse owes the same duties to self as to others”
- The 2017 ANA Issue Brief on disaster response noted that nurses have a responsibility to help care for and protect patients while also protecting their own right to self-preservation and self-care

ANA 2015; ANA 2017



What are Some of the Ethical Challenges Associated with Disaster?

- During the crisis, we have an obligation to provide good symptom management to all, including those who may not survive
 - Some may be denied potentially life-saving therapies in a triage system
 - Families may lose the opportunity to be involved in decision-making
 - Patients may be forced to die alone
- A mass casualty event stresses the frontline healthcare workers
 - Workers are often asked to work in unfamiliar areas
 - Workloads attending to those injured or ill may exceed normal limits
 - Resources and supplies are limited

Downar & Seccareccia, 2010

Potential Ethical Issues During a Disaster

- Protection of the public from harm- Families may not be allowed to be with their loved ones due to danger of injury or contagion
- Equity/Justice- hoarding of equipment, supplies, etc. can create an ethical dilemma when large areas of the country are involved in the disaster
- Autonomy -under the triage system, patients who have a limited chance of survival may not receive certain medical treatments (i.e. mechanical ventilation) even if they desire them, as a result of limited supplies/equipment
- Vulnerability- those who are disabled or elderly and cannot reach out for help may suffer; there may be a bias against meeting their needs over those most likely to survive the disaster

Moral Distress

- Moral distress is the result of having to act in a way that is in opposition with our own values & beliefs
 - Providing care in unfamiliar workplaces with different cultures/practices
 - Witnessing unrelieved pain or suffering
 - Witnessing inefficient healthcare systems
 - Struggling with limited availability of equipment, ICU and hospital beds, staff & hospice care during the crisis- and having to improvise in ways that do not meet the usual standard of care



Cultivating Moral Resilience During a Disaster

- Foster self-awareness
- Develop self-regulatory capacities
- Develop ethical competence
- Speak up with clarity and confidence
- Find meaning in the midst of despair
- Contribute to a culture of ethical practice
- Engage with colleagues for support

Rushton, 2017

Attending to Self-Care Needs During a Disaster

- Maintain positive, pro-active self-care
 - Take breaks
 - Balanced, healthy nutrition
 - Realistic exercise plan
 - Quality sleep
 - Engage in activities that give you meaning
- Pay attention to your body's signals & respond to needs
- Create positive emotions:
 - At the end of the day write down 3 things that went well during the day & an affirmation (an intention, "I" statement using action-oriented verbs)
 - Find and express gratitude



Kravits, 2019

Every Nurse Should Be Prepared for a Disaster

- Develop a personal disaster plan for yourself and your family and include:
 - Information: how will information be received?
 - Communication: best communication plan; cell phone alternative.
 - Contact list
 - Shelter or meeting place: set a planned location and an alternative
 - Specific needs of the household:
 - Have a “to go” box that include food & water, special dietary needs, medications, hygiene products, and pet food.
 - Keep flashlights, batteries, & blankets readily accessible
 - Additional necessary items are listed on:
<https://www.ready.gov/kit>

American Red Cross, 2017; Casey, 2017

Additional Resources

- American Red Cross: How to make an emergency plan.
<https://www.redcross.org/get-help/how-to-prepare-for-emergencies/make-a-plan.html>
- American Red Cross: Types of emergencies.
<https://www.redcross.org/get-help/how-to-prepare-for-emergencies/types-of-emergencies.html>
- Center to Advance Palliative Care (CAPC) COVID-19 Response Resources: <https://www.capc.org/toolkits/covid-19-response-resources/>
- Center for Disease Control & Prevention (CDC): COVID-19 Resources for healthcare professionals and healthcare facilities: <https://www.cdc.gov/coronavirus/2019-ncov/index.html>
- Center for Disease Control & Prevention (CDC): Natural Disasters & Severe Weather: <https://www.cdc.gov/disasters/index.html>

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<http://elnec.academy.reliaslearning.com>
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