THE CHANGING NATURE OF
PALLIATIVE NURSING
IN ONCOLOGY

Where We’ve Been & A Path Forward

BILLY ROSA, PHD, MBE, ACHPN, FAANP, FAAN
PSYCHO-ONCOLOGY POSTDOCTORAL RESEARCH FELLOW
NEW YORK, USA
JUNE 14, 2021
OBJECTIVES

- Reflect on how moral suffering has showed up in our practice environments

- Discuss relevant research on moral distress and implications for palliative care clinicians

- Identify tools to promote moral resilience and moral courage

- Use advocacy as a method for improved self-efficacy and palliative care integration
Taking Action Against Clinician Burnout: A Systems Approach to Professional Well-Being
-The National Academies (2019)
How Reframing Distress can Support Your Workforce & Heal Your Organization – Moral Injury of Healthcare (fixmoralinjury.org)

Moral Suffering

Stressors → Moral Distress → Moral Residue → Moral Injury → Burnout

Personal, family, health, substance, etc.
To define the ways the COVID-19 pandemic has impacted end of life care and approach to bereavement care in pediatric palliative care (PPC).
Background

Cumulative loss, isolation/disconnection, and uncertainty

Parental worry about seriously ill children

“Will I be able to be with my child?”

Limited accessibility of cultural rituals and celebrating a loved one’s life

Limited ability of health teams to best support patients/families navigating death of a child

Dissonance between need for community and safety of self/others
Results

• N=207 PPC team members from 80 cities within 39 states and D.C.
• 38 NE, 51 S, 58 MW, 34 W, 23 SW per Nat Geo criteria
• MDs, RNs, SWs, child life specialists, and psychologists
Moral Distress Associated with Care Provided

• Open-ended questions gave opportunities to describe differing types of distress

• Example questions:

  • Can you tell us about an experience you have had related to COVID-19 that you feel will stay with you, always?

  • What is something you have learned since COVID-19 that will impact your palliative care practice going forward?

  • What is something you wish you’d learned prior to the pandemic that might have impacted how you approached palliative care during COVID-19?
Moral-Constraint Distress: One is feeling distressed because they are constrained from doing what they think is the ethically appropriate action. 

N = 21

I will never forget telling a mama that her child would die, while the child’s dad looked helplessly on via facetime, because he had not been allowed on campus due to new Covid-19 restrictions. It was heartbreaking.

Caring for dying children right now is much more difficult and sad. … Trying to balance which patients to check on from home and which need to be seen in person has led to a great deal of conflict within the team. That conflict and difficulty will stay with me for a long time.

Have a mother crying and very upset about her dying infant and not being able to hug her. It will stick with me. I hated it.

I had a child abuse case, likely due to stress of COVID-19, that ended in redirection of care. It was a terrible case, and to top it off we couldn’t get mom the additional support she needed during EoL care for her daughter. Also had a re-direction of care where grandfather facetimes from the lobby to say goodbye because he was not allowed to come to the room.

I’ve learned how important touch is… especially during difficult conversations and at the end of life.

Moral-Observer Distress: Observing (potentially) traumatic events but institutional or public health constraints make it impossible for a different action to be taken.

N = 18

Some families have held drive by funerals for teenagers and stood in their yards while the teens drove by to send love. Heart breaking to imagine.

A young mother facing removal of LST (extubation) of her toddler with only one other family member able to visit with her and their priest performing a ritual from the hospital parking lot.

The despair of families who knew their child was approaching the end of their life and not be able to be all together as a family until the child was actively dying.

The trauma inflicted upon siblings that were not able to visit their sibling as they died.

How awful awful awful it is when a family is not whole, when only one parent can be with a child, how staggering the suffering is for all family members.

Moral-Uncertainty Distress: One is feeling distressed because they are uncertain about whether they are doing the right thing.

N = 6

I don’t know if it’s the larger grief and stress we are all facing, or the lack of my team members with me, or if people are making different choices than usual and deaths are clustering, or what the root of it is.

Decisions about furlough, salaries, hiring freezes will impact teams for years and are not easy ones to make. Even those, like myself who are experienced leaders find the uncertainty overwhelming at times.

Big increase in personal anxiety — fear of going to people’s homes, apartment buildings, etc. and worrying about bringing infection home to loved ones or other patients.
PERCEIVED SELF-EFFICACY OF PALLIATIVE CARE CLINICIANS

- How effective did you feel in meeting the psychosocial and spiritual needs of acute oncology inpatients using telehealth during the first COVID-19 surge?
- 11 clinicians across 6 disciplines (NP, PA, SW, PharmD, Chaplaincy, MD)
- One hour interviews
- Qualitative descriptive approach
“I don’t know what I was telling myself, I think I just told myself, ‘This is the normal. You just have to make it work. This is what we’re doing to keep everyone safe, and just figure out a way to make it work.’ You know, making multiple, multiple calls throughout the day to reassure myself that this is okay. Yeah. And you know, checking with the team. I got peer support from the team to say this was okay.

And that's how I kept going. But the cases still made you feel ... uncomfortable.” -P2, NP
“But there are just those moments and those particularly difficult cases where just the frustration sticks. You carry it with you and those are the patients that I remember. I'm sure I took care of a lot of happy patients that maybe weren't COVID positive or maybe they were but they were discharged. But of course, those are not the patients that I remember.”

-P3, MD
“One of the cases that haunts me is... this woman was COVID positive, her daughter was in the room. I called her daughter and... her daughter was really upset and crying and I was asking what's going on and she was like, ‘My mom isn't doing well, something's different.’ And I said, ‘Just take a deep breath, can you see if [your mom is] breathing?’ And her daughter paused and started freaking out because her mom wasn't breathing. Her mom had died. And so, it's like, being at home and being on the phone with somebody whose just lost a loved one and then telling that loved one, her daughter, to [ring] the call bell and have the nurse come in is so upsetting that I feel like I wasn't there to do my job. ... It was a lot of distress for me.” -P5, NP
Our ‘Total Moral Pain’

“We are trying to figure out how to [decipher the need for support] way before people get to the point where they are so distressed that it’s affecting them physically, emotionally, and spiritually.”

-Cynda Rushton, PhD, RN, FAAN

https://moraldistressproject.med.uky.edu
Define or Redefine Personal Moral Compass

Define Personal Code of Ethics

Work on Self-Awareness

Develop Self-Regulation

Seek Outside Assistance

https://healthyworkforceinstitute.com/1768-2/
The Role of Enhanced Transdisciplinary (TD) Models

- Transparent dialogue about +/- to TD philosophy
- Revisiting training & fellowship programs to unify frameworks
- Address & redesign research agenda to reflect TD science & care

MORAL COURAGE

“Every patient treated with a ventilator also needs palliative care. It is not an either-or clinical proposition, but rather a both-and moral imperative… Access to palliative care is a human right. Our inability to deliver it in the setting of COVID-19 and other serious illnesses is a human rights violation. Each of us is a stakeholder.”

Integration of Palliative Care Into All Serious Illness Care as A Human Right

William E. Rosa, PhD, APRN¹; Betty R. Ferrell, PhD, RN²; Diana J. Mason, PhD, RN³
ELNEC Support for Nurses During COVID-19

End-of-Life Nursing Education Consortium (ELNEC) project is a national and international education initiative to improve palliative care. Learn more. The ELNEC COVID-19 section is supported by grant funding from the Cambia Health Foundation and Pfizer.

Visit the ELNEC Materials tab for free modules including slides, recorded presentations, infographics, video vignettes, and more. Visit the Resources tabs for materials, websites, and webinars from our palliative care colleagues.

aacnnursing.org/ELNEC/COVID-19
Symptom Management - Infographics

Topics:
• Pain
• Dyspnea
• Cough
• Anxiety
• Delirium,
• Meditation/Mindfulness Apps
• Role of the Nurse

NURSING MANAGEMENT OF PAIN IN PEOPLE WITH COVID-19

PAIN SYNDROMES COMMONLY REPORTED DURING COVID-19

- Arthritis/myalgias due to infection, rigors, cough
- Chest/honococcal pain associated with persistent, severe cough
- Headache

PHARMACOLOGIC MANAGEMENT: ACETAMINOPHEN

Pharmacologic management at home: educate regarding acetaminophen content in many over-the-counter medications and the potential for overdose. Medications for a variety of conditions often contain acetaminophen.

PHARMACOLOGIC MANAGEMENT: NSAIDS

- NSAIDs are antiinflammatory, analgesic, and antiplatelet.
- The NIH COVID-19 Treatment Guidelines recommend that those with COVID-19 who are taking NSAIDs for a comorbid condition should continue therapy as previously directed by their physician.

PHARMACOLOGIC MANAGEMENT: OPIOIDS

- For moderate to severe pain (and anyone with moderate to severe illness with intractable pain where NSAIDs and acetaminophen are contraindicated)

Routinely helpful tips:
- Oral concentrated liquid (such as morphine or oxycodone) may be useful where dysphoria severe and swallowing tablets difficult.
- Transdermal fentanyl or buprenorphine - risk level with fewer due to rapid abscission, possible spontaneous respiratory depression.
- IV morphine, hydromorphone or fentanyl for inpatient/ICU use

PHARMACOLOGIC MANAGEMENT: OTHER AGENTS

- Gabapentinoids - typically reported with chronic kidney disease or worsening acute renal failure, common in COVID-19
- Ketamine - if patient already on gabapentin or pregabalin for existing pain, dose reduce if CO2 < 50 mmHg (no adjustments warranted)
- Duloxetine - dosing - if patient already on duloxetine, decrease dose if CO2 < 50, doubled up to 20 mg twice daily as needed
- Corticosteroids - for patients on oral corticosteroids therapy for other conditions (e.g. cancer pain) prior to COVID-19, these should not be discontinued

REFERENCES

Supported by funding to the ELNEC project by the Cambria Health Foundation. aacnnursing.org/ELNEC/COVID-19

NURSING MANAGEMENT OF DELIRIUM IN PEOPLE WITH COVID-19

DELIRIUM DURING COVID-19

Delirium is very common in sick, older patients. Although usually associated with trauma, many other conditions are common. In a study of COVID-19 patients referred to hospital consultation, 24% experienced delirium.

Types of delirium:
- Hyperactive - usually includes agitation
- Hypoactive - withdrawal behaviors more likely to be missed on assessment

CAUSALITY OF POTENTIALS OF SPECIFIC OR CONTRIBUTORS TO DELIRIUM

- Infection (pneumonia, urinary tract infection)
- Structural disease (primary or metastatic brain tumor, hypoxic-ischemic disease, stroke)
- Medications (sedatives, anticholinergics, corticosteroids, antihistamines, benzodiazepines)
- Metabolic abnormalities (hyperglycemia, hypokalemia)
- Nutritional (or vitamin deficiencies)
- Older age (> 75 years of age)
- Rapid withdrawal of medications (opioids, benzodiazepines) and/or alcohol, nicotine
- Renal, cardiac and/or hepatic failure
- Unrelated pain
- Urinary tract infection
- Use or withdrawal

ASSESSMENT

Several delirium assessment tools are available: select a tool based upon your setting and population. In many circumstances, delirium can be identified based upon a strong history and physical examination.

Conduct history and physical assessment:
- Review romantic signs including disturbed sleep/wake cycle, agitation, restlessness, morning, hallucinations, and delusional thoughts.
- Assess for signs of toxicity, dehydration, urinary retention or urinary tract infection, constipation, uncontrolled pain.
- Evaluate the medication list for possible causes or considerations; consider polypharmacy.
- Weigh the potential for possible delirium withdrawal from alcohol, nicotine, opioids, benzodiazepines, antihistamines, or other sedatives

PHARMACOLOGIC MANAGEMENT

Assessment:

When possible address potentially reversible etiologies such as fever (antipyretics/aspirin), hypoxemia (oxygenation, BP), dehydration (oral and IV fluids), urinary retention (anti-cholinergics), polypharmacy (discontinue unnecessary medications), metabolic abnormalities (correct electrolytes), and sleep deprivation (promote daytime sleep).

Benzodiazepines are generally not recommended in the treatment of delirium, except for midazolam given IV or SQ for palliative sedation.

Supported by funding to the ELNEC project by the Cambria Health Foundation. aacnnursing.org/ELNEC/COVID-19

NURSING MANAGEMENT OF VITAL SIGNS IN PEOPLE WITH COVID-19

VITAL SIGNS COMMONLY REPORTED DURING COVID-19

- Fever
- Hypotension
- Tachycardia
- Tachypnea
- Altered mentation

PHARMACOLOGIC MANAGEMENT: VITAL SIGNS

- Antipyretics
- Antivirals
- Corticosteroids
- Antiepileptics

REFERENCES

Supported by funding to the ELNEC project by the Cambria Health Foundation. aacnnursing.org/ELNEC/COVID-19
NURSING MANAGEMENT OF DYSPEA IN PEOPLE WITH COVID-19

DYSPEA DURING COVID-19
- Usually starts between day 4 and 8 of Admission.
- Also reported later in the course.
- Common causes: non-productive cough
- Also associated with pneumonia.
- 40% of patients with COVID-19 experience dyspepsia.
- In a study of 101 patients with COVID-19 admitted to palliative care, 66% experienced dyspepsia.
- Worsened with anxiety, even speaking on the phone.
- May experience very low blood oxygen saturation (less than 90%) without hypoxemia (called silent hypoxia).
- Assessment should be conducted using a self-report; some can use a 0-10 scale (0-no breathlessness, 10-severe breathlessness).
- Don’t forget other causes of dyspepsia, especially in people with comorbid serious illness.
- Advanced AIDs, cancer, obesity, heart failure, pulmonary embolism, ankylosing spondylitis.

PHARMACOLOGIC PALLIATIVE MANAGEMENT: OPIOIDS
Opioids are the foundation for management of dyspepsia for palliative care patients.
- Morphine PO 5 mg every 3-4 hours pm (2.5 mg for children or elderly).
- Oxycodone PO 2.5 mg every 3-4 hours pm.
- Hydromorphone PO 2-4 mg every 3-4 hours pm.
- Trazodone (25-50 mg) every 1 hour pm.
- Naloxone (0.4-0.8 mg) IV every 1 hour pm.
- Monitoring: increase frequency if dose does not provide relief but is not sustained.
- Every hour for oral administration.
- Every 15 minutes for IV administration.
- For patients intolerant to opioids, higher doses may be needed — use equivalent table to calculate IV dose and administer 10-20% increase.

Routes — helpful tips:
- Oral: concentrated liquid (such as morphine or oxycodone) may be useful when dyspepsia is severe and swallowing tablets difficult, onset of effect similar to oral tablets.
- Intravenous or subcutaneous opioid administration may be used during episodes of severe dyspepsia requiring faster onset and more rapid titration, or if patient unable to swallow.

Nonpharmacologic Management:
- Assessment: include history and physical exam to help differentiate possible causes of dyspepsia.

References:

Supported by funding to the ELNEC project by the Cambia Health Foundation atacaremaeleneacarematncaremaELNEC/COVID-19.

NURSING MANAGEMENT OF ANXIETY IN PEOPLE WITH COVID-19

ANXIETY DURING COVID-19
- Anxiety is often a sign of fear, worry, stress, or discomfort. It can be caused by many things, including the COVID-19 pandemic.
- Anxiety can affect your body and mind, and it can make it harder to focus, think clearly, and make decisions.
- Anxiety can also make it difficult to sleep, eat, and take care of yourself.
- It’s important to try to manage your anxiety and find ways to cope with it.

PHARMACOLOGIC MANAGEMENT
- Use self-report, including words such as “worried” or “concerned”.
- Assess for other responses such as restlessness, irritability, sleeplessness, or malaise due to anxiety.
- Determine if there have been prior episodes of anxiety, depression, schizophrenia, OCD, PTSD, or substance use disorder.
- Assess for and manage other symptoms such as pain and dyspepsia.

Consider metabolic causes:
- Hypercapnia, hypoxia, hypoglycemia, hypernatremia, serotonin syndrome.
- Evaluate psychosocial and spiritual needs.
- Review medications for drugs that can contribute to anxiety.

REFERENCES:

Supported by funding to the ELNEC project by the Cambia Health Foundation atacaremaeleneacarematncaremaELNEC/COVID-19.
ELNEC Materials – Loss, Grief, and Bereavement

- ELNEC Loss, Grief & Bereavement in a Pandemic Module
  - Materials developed and presented by Polly Mazanec PhD, ACNP-C, AOCN, ACHPN, FPCN, FAAN
  - Supplemental Materials
  - Recorded Presentation
  - Slides (PDF)

- Complicated Grief and Loss: Uncharted Territory With COVID-19
  - Recorded Webinar and Blog

- Supporting Bereaved Staff
  - Developed by Billy Rosa, PhD, MBE, ACHPN, FAANP, FAAN
  - Nurse Coaching Process to Support Bereaved Staff - Infographic
  - A Clinical Leader’s Guide to Support Bereaved Staff During COVID-19
    - Slides (PDF)
    - Recorded Presentation
1. Start with your staff's agenda
2. Track both the emotional and cognitive data gleaned from staff
3. Stay with the staff, moving forward one step at a time
4. Articulate empathy explicitly

- What brings you joy in your work?
- What meaning or purpose do you find in your work?
- How have you dealt with recurrent loss during COVID-19?
- How do you cope with the grief you experience at work?
- What has gotten you through hard times in your life in the past?

5. Talk about what you can do before you talk about what you can’t do
6. Start with big-picture goals and processes before nitty gritty
7. Give staff your complete and undivided attention

Be flexible, open, and nonjudgmental as staff express evolving needs
Disease trajectory

- Diagnosis
- Disease-modifying
- Supportive and palliative care
- Bereavement care

Knaul et al. (2018)
Palliative Care in the COVID-19 Pandemic  
**Briefing Note**  
Palliative Care for LGBT+ People in the Time of COVID-19

**Authors**  
Harding R (Cicely Saunders Institute, King’s College London, UK), Ciruzzi MS (Hospital de Pediatría Samic Prof. Dr Juan P. Garrahan, Argentina), Downing J (ICPCN, UK/Uganda), Hunt J (Independent Social Worker, Zimbabwe), Morris C (WHPCA, UK), Rosa W (University of Pennsylvania, USA)

---

Palliative Care in the COVID-19 Pandemic  
**Briefing Note**  
Palliative Care for those Experiencing Homelessness in the Time of COVID-19

**Authors**  
Skinner E (Ottawa Inner City Health, Canada), Colclough A (St Luke’s Cheshire Hospice, UK), Downing J (ICPCN, UK/Uganda), Harding R (Cicely Saunders Institute, UK), Luyirika E (APCA, Uganda), Palat G (MNJ Institute of Oncology and Regional Cancer Centre, Hyderabad, India), Rosa W (University of Pennsylvania, USA).
The highest attainable standard of health for persons with disabilities

Draft resolution proposed by Argentina, Australia, Botswana, Brazil, Canada, Chile, Costa Rica, Ecuador, Israel, Mexico, Norway, Peru, United Kingdom of Great Britain and Northern Ireland, Uruguay and the Member States of the European Union

(PP23) Underscoring that the health needs of persons with disabilities need to be met across the life course, through comprehensive preventive, promotive, curative, rehabilitative services and palliative care and including psychosocial support;
Palliative Care Specialists Series
Featured Editors: Christopher A. Jones and Arif H. Kamal

Top Ten Tips Palliative Clinicians Should Know About Evidence-Based Advocacy

William E. Rosa, PhD, MBE, ACHPN, FAANP, FAAN, Katherine I. Pettus, PhD,
Liliana De Lima, MHA, Allison Silvers, MBA, Stacie Sinclair, MPP, and Lukas Radbruch, MD
“In any dark time, there is a tendency to veer toward fainting over how much is wrong or unmended in the world. Do not focus on that...

We are needed, that is all we can know...

One of the most calming and powerful actions you can take to intervene in a stormy world is to stand up and show your soul.

Soul on deck shines like gold in dark times...

When a great ship is in harbor and moored, it is safe, there can be no doubt. But that is not what great ships are built for.”

-Clarissa Pinkola Estés, PhD