

# NHPCO Project ECHO 2023

*Equity Where It Matters*

**Topic: Mental Health Implications In Serious Illness and End Of Life Care**

**Date: May 04, 2023**

# NHPCO Project ECHO Team



## Program Director

Aparna Gupta – Vice President, Quality



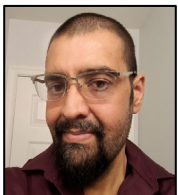
## Program Lead

Sarah Simmons – Director, Quality



## Program Coordinator

Karuna Tamrakar – Program Specialist, Quality



## IT Support

Tej Chana – Data Analyst, Quality



## Content Expert

India Harris-Jones – Manager, Health Equity and Diversity



## Content Expert

Rory Farrand – Vice President, Palliative & Advanced Care



## Curriculum Advisor

Nicole McCann-Davis – Communications Expert and Health Equity Advocate, External Consultant

# Disclosures

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## **Disclosure**

The faculty and planners for this educational event have no relevant financial relationship(s) with ineligible companies to disclose.

## **Data Collection**

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

## **Evaluation**

You will be receiving an email with a link to complete a short survey about this session. Please complete the survey within 48 hours. We ask all participants to take the survey as it will help us to improve future sessions.

# Ground Rules and Video Teleconferencing Etiquette

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- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

# Today's Agenda

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- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

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## Session Faculty



**Louise Knight, LCSW-C, OSW-C, FNAP**

Director, Harry J. Duffey Family, Patient and Family Services

Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, MD



**Aparna Gupta, DNP, FACHE, CPHQ**

Vice President Quality

National Hospice and Palliative Care Organization (NHPCO),  
VA

# Didactic Presentation

# Issues and Impact – Patients and communities

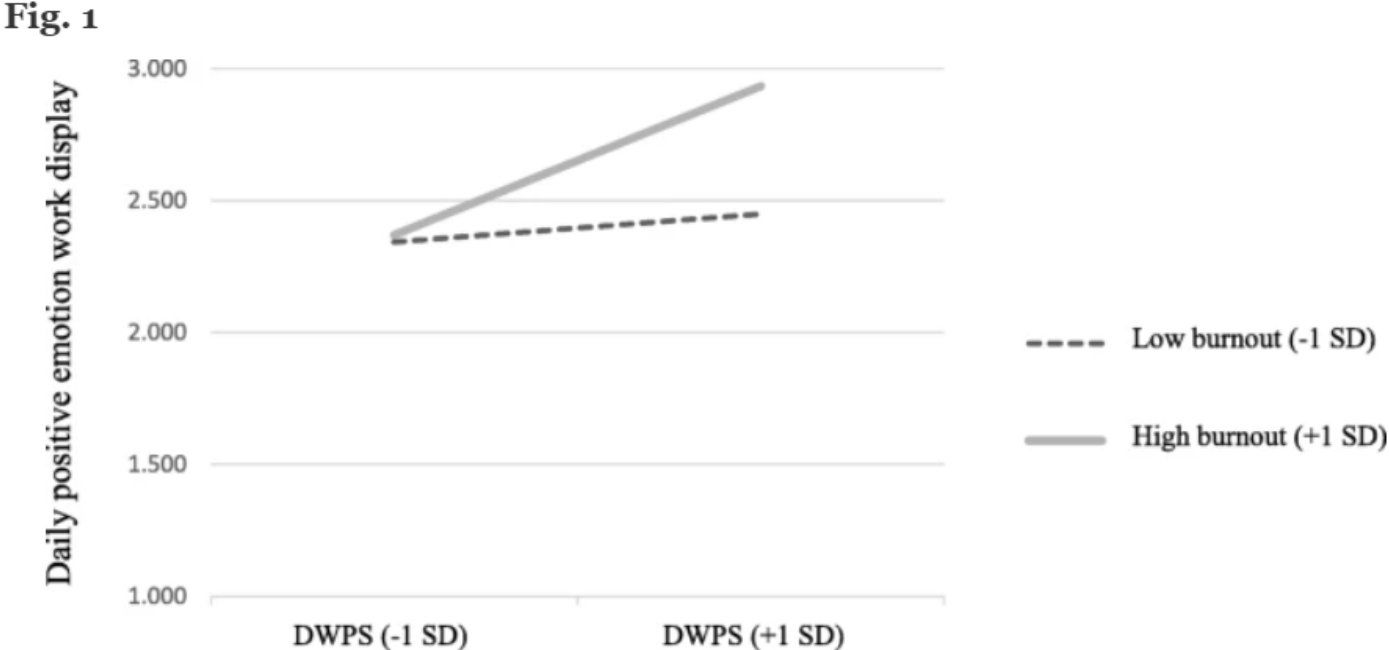
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- Physiological changes
- Anticipatory Grief
- Coping styles (females – higher problem-focused coping; males – higher emotion-focused and avoidant coping)
- Bereavement and complicated grief
- Experiencing (and coping with a range of emotions):
  - ✓ shock
  - ✓ fear
  - ✓ anger
  - ✓ resentment
  - ✓ denial
  - ✓ helplessness
  - ✓ sadness
  - ✓ frustration
  - ✓ relief
  - ✓ acceptance

*Garg, R., Chauhan, V., & Sabreen, B. (2018). Coping styles and life satisfaction in palliative care. Indian journal of palliative care, 24(4), 491.*




# Issues and Impact – Burnout among hospice professionals



Cross-level interaction. Moderation of burnout in the relationship between watching patients suffering (DWPS) and daily positive emotion work display

Portoghese, I., Galletta, M., Larkin, P., Sardo, S., Campagna, M., Finco, G., & D'Aloja, E. (2020). Compassion fatigue, watching patients suffering and emotional display rules among hospice professionals: a daily diary study. *BMC palliative care*, 19, 1-7.



**Mental Health Implications  
In Serious Illness  
And  
End-Of-Life-Care**

# Definitions for Today

**Your Patient: There are always (5) indefinable patients.**

- ❖ The identified patient
- ❖ The family/caregiver
- ❖ The *Team*
- ❖ The agency/employer
- ❖ The larger community: local, state, federal

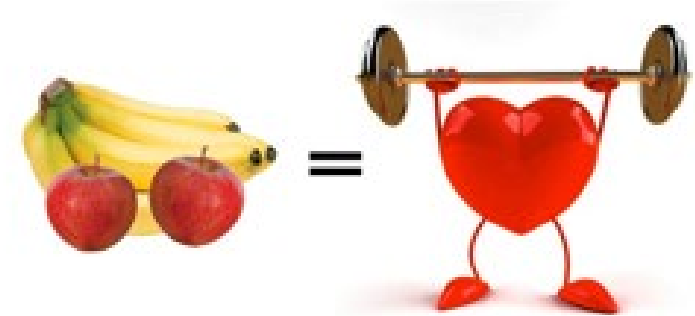
**Family Functioning: Today we will focus on**

- ❖ Flexibility
- ❖ Cohesion
- ❖ Communication

While we are going to focus our discussion around the patient and family, your job will be to identify when and how the other patients enter your care plan.

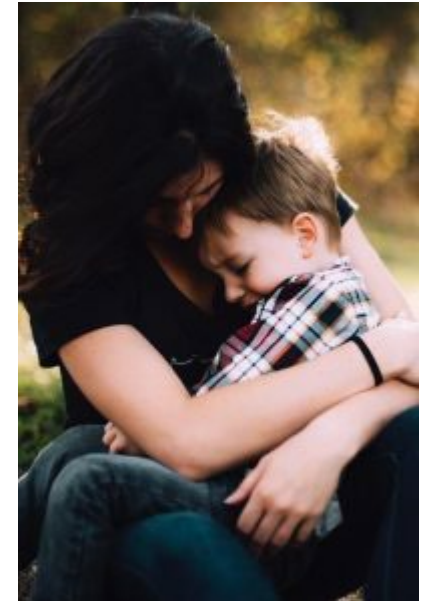
Let's start with language...

# Physical Health...What Comes to Mind???





# Mental Health...What Comes to Mind???



Implicit Bias

# Is there Stigma, Prejudice and Discrimination Against People with Behavioral Health Concerns?



- **Yes**, on the part of the public – a negative/discriminatory attitude and belief
- **Yes**, on the part of the person – a self-stigma, internalized shame

Language is important in the context of our work. Labels Stick...

Coping Skills                      Anxious

Healthy vs Unhealthy            Adjustment

Adaptive vs Maladaptive        Anticipatory

**Adaptive vs. Maladaptive Coping Strategies**

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**Adaptive Coping** 

- Active: *problem-solving, reaching out for support*
- Accommodative: *changing expectations*
- Emotional: *regulating emotions*
- Behavioural: *taking actions to reduce stress*
- Cognitive: *changing how we think about the stressor*

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**Maladaptive Coping** 

- substance use
- rumination
- physical escape
- mental escape
- procrastination
- self-injury
- binge eating
- risk-taking
- self-criticism
- safety behaviours
- avoidance

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Noncompliant                      Depressed Mood

Poor historian                      Depression

Stress                                Demoralization

    Delirium

    Distress

# Family Functioning

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The Good - We can all recognize great family functioning. We often comment on how easy it is to work with them, they are open to difficult conversations and appreciate the needs of those in the family first. The Good family functioning uses problem-solving skills, open communication, role assignments for the members of the family and respect for others.

The Bad – Poor family functioning often includes high levels of conflict, lack of cohesion, they are disorganized without family roles and have overall poor communication. When they do communicate, the communication is personalized and without content.

The Ugly -



# David Olson, Circumplex Model <https://psychology.org.au/publications/inpsych/2011/february/sanders>

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The model suggests that:

- ✓ Balanced levels of cohesion and flexibility offer the healthiest family functioning
- ✓ Unbalanced levels of cohesion and extremes in flexibility describe problematic family functioning

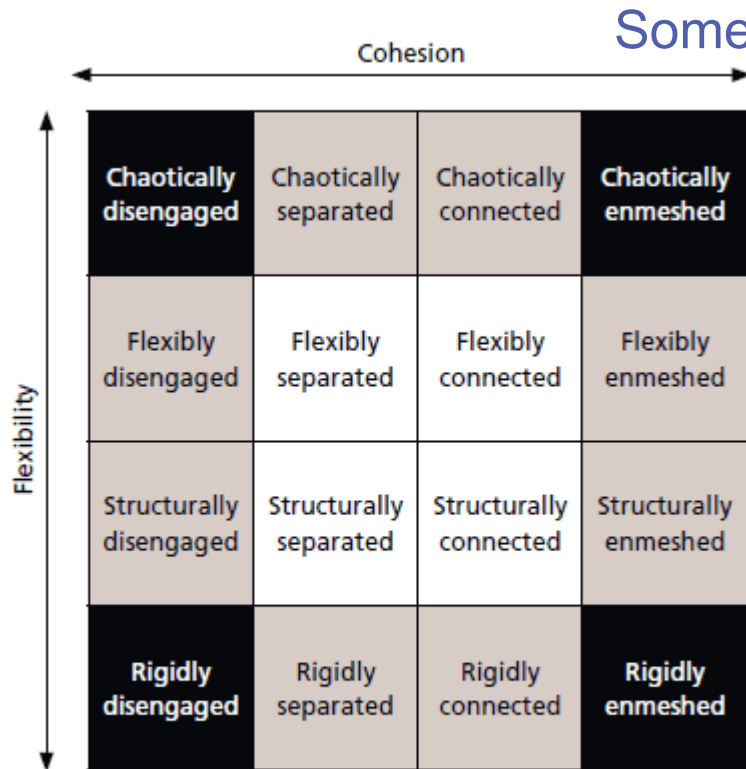
The Circumplex Model focuses on the three dimensions of family systems:

**Cohesion** – 4 levels: disengaged, separated, connected and enmeshed. The concept of balance when members are separate yet highly connected – a balance between person and group allows for highest functioning.

**Flexibility** – The amount of change in the relationships, in roles within the family and the rules of those relationships. The concepts of rigidity vs chaos.

**Communication** – Skills include listening, self-disclosure, respect and regard for others. Families that have balanced engagement and open flexibility tend to also have higher communication skills.





### Some assumptions:

- Families naturally progress through cycles of change
- Functional families understand change
- Balanced families flexibly transform
- Unbalanced families remain stuck in their patterns
- Interventions to improve communication skills can be highly effective

### Example of a chaotic enmeshed family:

Divorced couple that continues to fight.  
 Poor communication skills to resolve the changes in the family, even when living apart.

Figure 1. The Circumplex Model (after Olson, 2000)

### Example of a chaotic disengaged family member:

There are two adult children. One at the bedside for weeks, partner in the healthcare decisions. As mom is dying, the second child arrives, demanding to speak with providers, see the medical record and direct the care plan.

# Didactic Presentation Q&A

# Who is my Patient?

## The Case of the Lost Patient Voice.



JJ, is our identified patient.

He is a 79-year-old widower living in a single-family home on the Eastern Shore of Maryland. Last year, his wife died and his adult daughter, AB, age 55 moved in with him.

He has a long list of comorbidities to include uncontrolled hypertension and diabetes.

He has a primary care provider (PCP), but rarely keeps appointments and instead uses the Emergency Department (ED) as a source of healthcare.

He has had a number of falls at home, some with injury over the past 2 years.

Recently he has had severe back pain and swollen lower extremities making it difficult to walk.

On a recent ED encounter, advance prostate cancer with extensive localized disease, bone and liver involvement was diagnosed.

# Situation

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- While JJ was once a fiercely independent man with a strong voice, over the years he became dependent upon his wife for all decisions; to include finances, household operations and daily living.
- Upon the death of his wife, AB moved in and assumed this role.
- JJ spends most of his time at home, but his energy has been very low.
- AB made an appointment with an oncologist and is insistent that JJ have treatment.
- Treatment includes daily radiation which has exhausted JJ.
- His pain has increased along with other new symptoms which he shared with AB.

# Background

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- JJ presents to the ED and is hospitalized with acute renal failure, increased bone pain and worsening liver function. Goals of care discussion is needed.
- His daughter has been staying in the hospital with her father since admission 5 days ago.
- When the team attempts to speak directly to the patient, his daughter answers for him.
- She shifts the discussion away from prognosis, saying “we don’t need to hear that...we are not here for bad news, we are here to get well”.
- Nursing reports the same. When asking the patient about his physical symptoms, she will answer, ask for changes in medications or minimize what is being said.
- She often shifts the conversation away from her dad and onto her own health issues; asking what do you think of this...

# Assessment

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- Who is your patient?
  - How many do you have?
- How would you assess and describe..
  - The relationship between them
  - The family flexibility, cohesion, communication
- How do you balance JJ's needs from AB's – are they different or similar?
- What techniques have you used when faced with a similar family system?

# Discussion and Recommendations

# References

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- Garg, R., Chauhan, V., & Sabreen, B. (2018). Coping styles and life satisfaction in palliative care. *Indian journal of palliative care*, 24(4), 491.
- Portoghese, I., Galletta, M., Larkin, P., Sardo, S., Campagna, M., Finco, G., & D'Aloja, E. (2020). Compassion fatigue, watching patients suffering and emotional display rules among hospice professionals: a daily diary study. *BMC palliative care*, 19, 1-7.
- <https://www.sciencedirect.com/topics/psychology/circumplex-model#:~:text=The%20Circumplex%20model%20has%20two,levels%20for%20all%20the%20people>
- <https://psychology.org.au/publications/inpsych/2011/february/sanders>



# Session Evaluation and Certificate of Completion

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- Your feedback is valuable as we plan upcoming sessions!
  - Please complete the [Project ECHO Session Evaluation](#)
- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for each session. To receive confirmation of completion, please complete the following within 10 days of each session using the links found on the Project ECHO webpage.
  - *Project ECHO Session Evaluation*
  - *Project ECHO Post-Session Knowledge Check*

# NHPCO Health Equity Certificate

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- Would you like to demonstrate your commitment to delivering culturally competent care across the continuum of serious illness in an equitable, inclusive, and person-centered manner?
  - NHPCO is pleased to offer a Health Equity Certificate for individuals who participate in at least 17 sessions in the *Equity Where It Matters* series
- To receive participate in the Health Equity Certificate, please complete the following within 10 days of each session using the links found on the Project ECHO webpage.
  - *Project ECHO Session Evaluation*
  - *Project ECHO Post-Session Knowledge Check*

# Upcoming Sessions

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Date: May 18, 2023

Topic: Supporting Chinese Patients in Serious Illness and at the End of Life

Date: June 1, 2023

Topic: Supporting LGBTQ Patients and Communities

# Additional Information

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NHPCO Project ECHO webpage:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/>

NHPCO Project ECHO session recordings and Key Takeaways:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/2023-project-echo-session-recordings/>

NHPCO Project ECHO Registration Link:

<https://nhpc.zoom.us/meeting/register/tZEsfu-trz4oGtQeKfw41UEIYNwjSli8QCBF>

For more information:

[innovation@nhpc.org](mailto:innovation@nhpc.org)