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October 18–21 octobre 2022  
Palais des Congrès de Montréal

**Care and Feeding of Rare Birds:  
Sustaining Pediatric Palliative Care  
Specialists**

Stacy S. Remke, LICSW, APHSW-C




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**CONFLICTS OF INTEREST  
DECLARATION**

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None to declare



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**LEARNING OBJECTIVES**

At the conclusion of this presentation, participants will be able to:

- Describe 3 unique challenges for pediatric palliative care (PPC) practitioners
- Acknowledge 3 sources of personal stress as a PPC practitioner
- Develop a multidimensional plan to promote resilience and preservation of PPC experts



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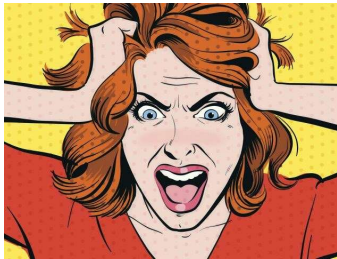
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**CanMEDS COMPETENCY  
FRAMEWORK**

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- Leader
- Communicator
- Health Advocate
- Collaborator
- Professional

“Self Care”?? !!



Care and Feeding of  
Rare Birds: Sustaining  
Pediatric Palliative Care Specialists

Stacy S. Remke, LICSW, APHSW-C  
Montreal, CA  
October 19, 2022

### WHO-5 Well-Being Index

Let's see how we are all doing...



	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1. I have felt cheerful and in good spirits	5	4	3	2	1	0
2. I have felt calm and relaxed	5	4	3	2	1	0
3. I have felt active and vigorous	5	4	3	2	1	0
4. I woke up feeling fresh and rested	5	4	3	2	1	0
5. My daily life has been filled with things that interest me	5	4	3	2	1	0



### Why do we need to be concerned?

- Staff recruitment and retention: turnover is expensive
- Lost expertise: work force shortages, etc.
- Health effects: obesity, heart and acute illnesses
- Mental health effects: depression, anxiety, vicarious trauma
- Team dysfunction
- Poor quality of services

*And then there's the Suffering...*



This is suffering.



*Blankets by J. Wipf 1993*

### Challenges inherent in PPC

- Exposure to suffering of others
- Evolving science and frontiers of medicine
- Inherent uncertainty and decisions in context of uncertainty
- Cultural denial of death: Death as a medical problem and a medical failure
- Marginalized field within health care, within society
- Inadequate resources to meet demands
- Lack of understanding of the practice: referrals too, little too late



Exposure to pain and suffering in children is a particular risk factor

- Children's trauma are also especially provocative for caregivers --Figley, 1995
- Most frequently reported triggers of compassion fatigue were seeing painful procedures done to children, too much sadness, and too many deaths of children suffering with chronic illness --Maytum et al, 2004
- Secondary traumatization as "occupational hazard" --Beck, 2011
- Traumatic stress appears to 'infect' the entire system after first appearing in only one member -- Figley, 1995



## Vicarious Trauma or Secondary Traumatic Stress...

- An outgrowth of empathy for the person as well as professional's secondary experience of the traumatic material
- Is a result of helping or wanting to help the traumatized person



(Figley, 2004; Ting et al, 2005)

## What is vicarious trauma?

- " Vicarious trauma is the emotional residue of exposure that [practitioners] have from working with people as they are hearing their trauma stories and become witnesses to the pain, fear, and terror that trauma survivors have endured.
- It is important not to confuse vicarious trauma with "burnout". Burnout is generally something that happens over time, and as it builds up a change, such as time off or a new and sometimes different job, can take care of burnout or improve it. Vicarious trauma, however, is a state of tension and preoccupation of the stories/trauma experiences "

• American Counseling Association Fact Sheet on Vicarious Trauma  
<https://www.counseling.org/docs/trauma-disaster/fact-sheet-9---vicarious-trauma.pdf>

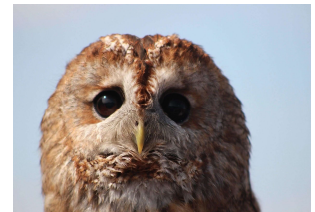
## VT/STS manifests as...

- Arousal:
  - Fight, flight or freeze
  - Fawn
  - Annihilation anxiety
- Intrusion:
  - Thoughts, images, memories
- Avoidance:
  - avoid talking or thinking about what the trauma effected client(s) have been talking about, been through: almost being numb to it



## Long Term Exposure Can Change...

- Thought (Neurological) processes
- Cognitive processes
- Emotional well being
- Personality
- Perceptions, world view



### 16 warning signs of trauma exposure / response

Adapted from L. van der Meert and C. Buih, 2020



- Feeling helpless, hopeless
- Sense one can't do enough
- Hypervigilance
- Diminished creativity
- Inability to embrace complexity
- Minimizing
- Chronic exhaustion, physical ailments
- Inability to listen, deliberate avoidance
- Dissociative moments, intrusive thoughts
- Sense of persecution
- Guilt
- Fear
- Anger and cynicism
- Inability to empathize, numbing
- Addictions
- Grandiosity: "only I..." or "there's no one else..."

### What have you experienced...?



- Sources of stress
  - on self, others
- Helpful behaviors, interactions?
- Team dynamics:
  - facilitators, detractors?

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### PPC: Reframing Self Care

Risk and opportunities  
Complexity and suffering  
Relational Practice  
Factors beyond our control  
Involves multiple levels of system of care



### The Cordelia Syndrome: *Boundaries are OK!*



## 5 Resilience Functions



C. Figley, SWHPN New Orleans, LA (2013)

## Resilience:

*"The capacity to regain one's energy after adversity has drained it"* -- Pauline Bos



## Role of Recognition: PPC as a "marginalized" practice



- Self reflection: what's going on with me?
- Peers, Colleagues: do they understand, appreciate what we do?
- Patients and Families: do I experience appreciation and thanks?
- System: does administration / organization understand work and provide adequate resources?
- Society: denial of death and avoidance as prevailing

Vachon and Guite-Verret (2020)

## Teamwork...

- Relationships
- Boundaries
- Collaboration
- Sharing
- Resources
- Advocacy

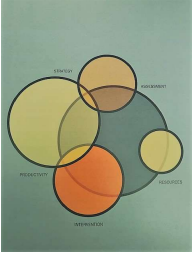


Attributes of Healthy Teams
• Well-defined program mission, vision, and goals
• Roles clearly delineated for each clinician/discipline, with acceptance that aspects of palliative care are shared across disciplines
• Shared team values that are consistently articulated
• Established lines of staff accountability, reporting, and supervision
• Clear work and productivity expectations
• Constructive and routine staff evaluation process
• Established routine team health activities
• Demonstrated respect and appreciation for individual team members and team as a whole
• Open communication among staff members to resolve conflicts, promote trust, and work to achieve common goals
• Strong leadership skills of palliative care program leader(s)

Factors/Behaviors That Impair Team Function <sup>10-12</sup>
• Absence of trust among team members
• Fear of conflict within the team
• Lack of commitment to the team/program
• Avoidance of staff accountability
• Inattention to desired team outcomes/results
• Wanting team-based results without constructing a team-based structure
• Overestimating the importance of the task focus and underestimating process and relationship
• A team culture that discourages collaboration and cooperation
• Neglecting the talent pool that resides in a team
• Insufficient training prior to launching the team's work

## Protective Practices



- Administrative Support
- Resources match expectations
- Exercises to address VT
  - Schwartz style rounds: focus on impact of the work
  - Writing exercises: process recording, "morning pages"
  - Clinical supervision: use of self in work
  - Structured Team debriefs
  - Meditation, mindfulness
  - Team skills and structure: CAPC Monograph (2013)

### n.i.c.e analysis

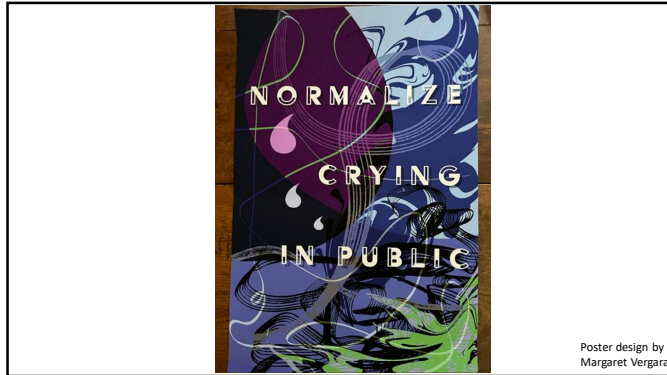
<b>Needs</b> Staff development/ training Capacity Development Staff Support resources: time, expertise Clarity of roles/ boundaries	<b>Interests</b> Staff coping Capacity development Recruitment and retention Team effectiveness/ efficiency Excellence
<b>Concerns</b> Staff coping with stressful work Team experience of losses, stress Cost containment/ productivity Staff retention Team Morale	<b>Expectations</b> Productive work habits Effective team collaboration Excellent client/ family care Adequate resources available Open communication

Eisenbach, Christie, and Runkin. Palliative Care. 2010

### Self Care is not enough...



but it is something we can control



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Let's Talk!

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