



City of Hope  
End of Life Symposium  
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# *Relationship-Centered Approach to Pediatric Hospice & Palliative Care*

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I have no conflicts to disclose

“How can you do this job?”





## References

*Liben, Stephen, Papadatou, Danai, **Self-Care: The Foundation of Care Giving**, from Wolfe, Joanne, et. al., *Textbook of Interdisciplinary Pediatric Palliative Care*, 2011*

*Katz, Renee, Johnson, Therese, ed., **When Professionals Weep - Emotional and Countertransference Responses in Palliative and End-of-Life Care**, 2<sup>nd</sup> Edition, 2016*

*Ostaseski, Frank, **The Five Invitations - Discovering What Death Can Teach Us About Living Fully**, 2017*

# Self Care

➤ Taking time for ourselves, taking vacations, eating well, exercising, getting adequate sleep, regular medical care is not enough

## ➤ Key Components of Self Care

- Relationship to self and self compassion
- Acknowledging care giver suffering
- Cultivating personal and team growth

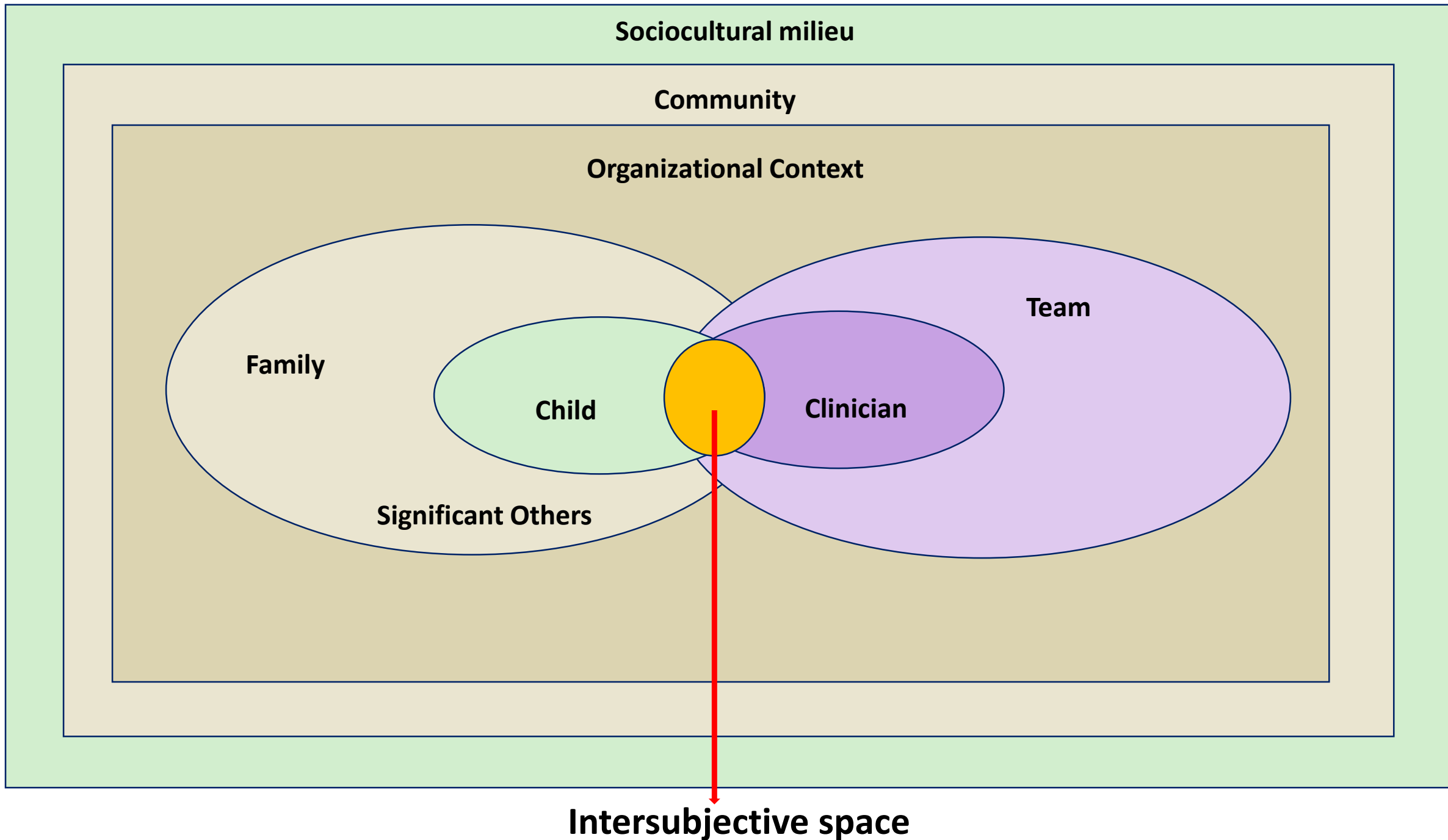
# Relationship to self and self compassion

- **How do I cope with the life-threatening illness or death of child?**
- **How do I think about my own mortality, vulnerabilities and imperfections with compassion?**
- **How do I manage relationships with the children and the families under my care?**





# Relationship-Centered Approach to Care



**Sociocultural milieu**

**Community**

**Organizational Context**

**Family**

**Child**

**Clinician**

**Team**

**Significant Others**

**Intersubjective space**



# Intersubjective Space

- Domain of feelings, thoughts, and knowledge that two (or more) people share about the nature of their current relationship *D. Stern*
- When clinicians and the patient or parent are open to each other and to their respective worlds, the intersubjective space is enlarged to include a rich partnership, a fruitful collaboration and the co-creation of new narratives
- Creates opportunities for increased self-awareness, new learning, positive changes and personal growth in the midst of uncertainty and hope for children, families and clinicians



# Mistaken Beliefs of Clinicians

- **Suffering affects only our patients and their families: clinicians do not and should not experience suffering**
- **Effective care is ensured through clinical skills, rational thinking and objectivity – emotions are subjective and lead to biases and mistaken clinical judgements**
- **Clinicians must adopt an attitude of detached concern that involves an intellectual interest, concern and understanding of others, along with emotional detachment that protects us from burnout and compassion fatigue**





# Clinician Self Awareness

- **As clinicians, knowing oneself is equally important to knowing your patient and family**
- **This approach leads to a committed and authentic relationship with the child and family in which we strive to remain fully present and open to their experiences, no matter how bad things get**

# Vulnerability

- **Openness is associated with vulnerability**
- ~~Highly Vulnerable~~
- ~~Invulnerable~~
- **Vulnerable Enough**



# Clinician Suffering

- **Suffering that leads to impairment**
  - *Burnout*
  - *Compassion Fatigue*
  
- **Suffering that is unavoidable**

# Rewards in Palliative Care

- **Growth associated with perception of self**
- **Growth associated with perception of and connection to children, families and colleagues**
- **Growth associated with life perspective**

# Resilience Tools and Methodologies

## ➤ **Whole Person (Child) Care**

- *Curing vs Healing*
- *Wounded Healer*

## ➤ **Countertransference**

## ➤ **Mindfulness**

# Whole Child Care

**Whole Child Care means while we will do everything to fix what can be fixed, we will also foster a caring relationship with children & their families as the unique & valuable whole people that they are now & be ready to support them in the journey of healing that may be necessary as they learn how to live with their illness**

*Tom Hutchinson*



# Curing

***Curing* is treatment aimed at eradicating disease or correcting an injury where the goal is survival & the avoidance of change**

# Healing

***Healing* is the process by which a person comes to terms with their chronic, serious or terminal illness, redefining their sense of self, recognizing the possibilities for joy, meaning and gratitude in their illness experience**

# Wounded Healer Paradigm

- **We are all wounded**
- **Bi-directional relationship**
- **Equal partners on the journey**

*Tom Hutchinson, Whole Person Care, 2017*

# Countertransference

- **First described by Freud (1910) as an unconscious process involving the arousal of the analyst's unresolved conflicts and problems**
- **Current definition extends to include the totality of feelings experienced by the clinician toward the patient – whether conscious or unconscious or whether prompted by the patient's dynamics or by issues or events in the clinician's own life**



# Countertransference

- **Now regarded as a natural, appropriate and inevitable emotional response, and a crucial source of information about the patient**
- **A positive and important therapeutic tool**
- **The basis for empathy, compassion and a deeper understanding of both the patient's and clinician's own processes**

# Mindfulness

*“Being Present”*

# Loving Kindness Practice

“All I want is what is in your  
mind and in your heart”

*David Tasma to Cicely Saunders*



*If you want others to be happy, practice compassion.*

*If you want to be happy, practice compassion.*

*His Holiness the 14th Dalai Lama*