



INSTITUTE FOR INNOVATION
IN PALLIATIVE CARE

Interprofessional Webinar Series

Understanding Existential Distress and Meaning-Oriented Therapies in Patients with Advanced Illness

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Disclosure Slide

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Objectives

- Discuss existential distress and meaning in the context of advanced illness
- Review ways of recognizing existential distress in the context of other clinical manifestations
- Present evidence based meaning-oriented approaches for addressing existential distress in advanced illness

Existential Aspects of Palliative Care

- Part of the 5th domain: Spiritual, religious, and existential
- Spirituality as a fundamental component of care
- Honors personal beliefs, practices, and dignity
- Emphasis on exploring and communicating, not imposing
- Understanding hopes, values, fears, beliefs, meaning, and purpose
- Explore patient's sources of strength
- Spiritual and existential values may or may not overlap

Clinical Practice Guidelines for Quality Palliative Care, 2013

“Consciously or not, we are all on a quest for answers, trying to learn the lessons of life. We grapple with fear and guilt. We search for meaning, love, and power. We try to understand fear, loss, and time. We seek to discover who we are and how we can become truly happy.”

Elisabeth Kubler-Ross

Definition of Spirituality

“Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they express their connectedness to the moment, to self, to others, to nature, and/or to the significant or sacred.”

Puchalski, Ferrell, & Virani, 2009

Ramifications of Advanced Illness

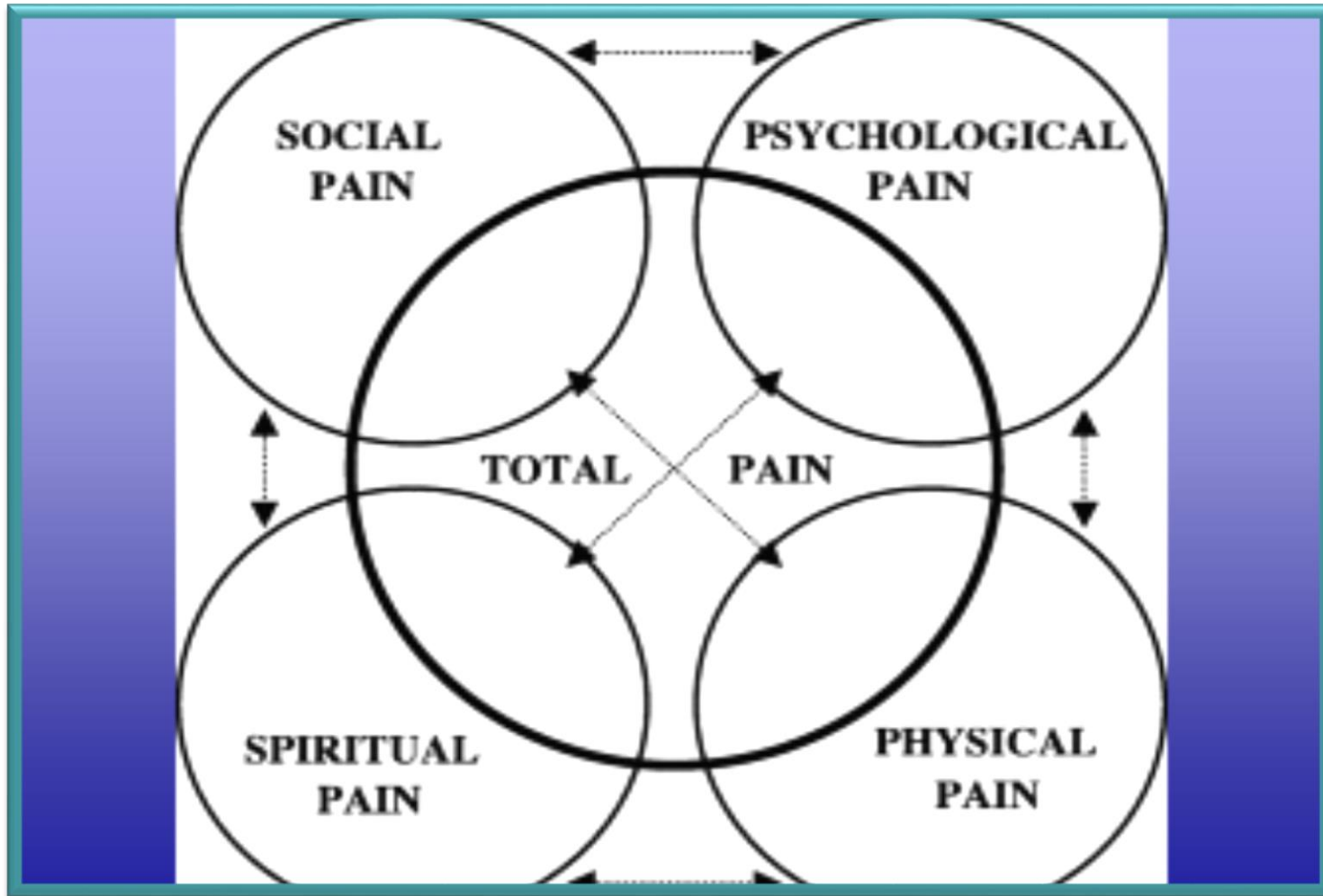
- Physical, emotional, social, spiritual
- Increased self-awareness and psychological growth
- Loss of meaning and purpose, demoralization, despair
- “Existential Plight” (Weisman and Worden, 1977)
- Appraisal of life threat associated with the disease
- Despair, hopelessness, and desire for hastened death in patients not clinically depressed
- Spirituality central construct in meaning-making

Stefanek et a., 2005; Lavery & O’Hea, 2010

Existential Concerns in Advanced Illness

- Important for patients with advanced illness
- Meaning of life
- Hope in advanced illness
- Meaning of death
- Freedom and control in advanced illness/dignity
- Belonging/alienation
- Support from spiritual/religious beliefs
- Finding comfort without religious beliefs

Morita et al., 2004; Murray et al., 2004; Milstein, 2008; Puchalski et al, 2009; 2010



Mehta and Chan, 2008

“The realization that life is likely to end soon may well stimulate a desire to put first things first and to reach out to what is seen as true and valuable – and to give rise to feelings of being unable or unworthy to do so.

There may be bitter anger at the unfairness of what is happening, and much of what had gone before, and above all a desolate feeling of meaninglessness.”

Saunders, 1988

Evolution of Existential Concepts

- Existential Philosophy
 - Exploration of life's limitations and overcoming them
 - Life lacks inherent meaning; authenticity, freedom, death, aloneness
 - Kierkegaard, Schopenhauer, Nietzsche, Heidegger
 - Camus, Sartre, Rilke, Dostoyevsky

Evolution of Existential Concepts (Cont'd)

- Existential Psychology and Psychotherapy
 - Binswanger, Rollo May, Victor Frankl, Yalom
 - Creating meaning in suffering
 - Understanding the patient's way of "being in the world"
 - Authentic and deep connection
 - Living fully in absence of obvious meaning

The Meaning-Making Model

- Global meaning
 - Ways of perceiving themselves and the world, global beliefs, goals
- Situational Meaning
 - Impact of stressful encounters, e.g., cancer diagnosis
- **Stress** → from discrepancy between global and situational meaning
- Meanings Made: Change in global or situational meaning

Leventhal et al., 2008; Park, 2010; Park & Folkman, 1997; Thomson & Janigian, 1988; Lazarus & Folkman, 1984

Logotherapy: A Framework for Meaning

- **Ultimate Meaning**

- Order, God, life, nature,...
- What I do matters
- Cannot be proved or disproved
- Live “as if” it existed
- It cannot ever be reached or captured
- Like the horizon, the closer we get, the farther it recedes

Frankl, 1946, 1985

Logotherapy: A Framework for Meaning (Cont'd)

- **Meaning of the moment**

- A meaningful life is a trajectory composed of infinite points of meaning realizing the unique meaning of each moment
- Practical
- Vital decisions at crucial moments
- Meaning as a “choice”

“For the meaning of life differs from man to man, from day to day and from hour to hour. What matters, therefore, is not the meaning of life in general but rather the specific meaning of a person's life at a given moment....”

Victor Frankl

Existential Distress and Depression

- ***Demoralization***
- Inability to cope
- Subjective incompetence vs. Anhedonia
- Helplessness, Hopelessness, Meaninglessness
- May respond to existential/meaning focused psychotherapy
- Clinical depression limits patient's ability to engage in existential exploration

Frank, 1968; Clarke & Kissane, 2002; Strada, 2009; Vehling & Mehnert, 2014

Meaning-Oriented Therapies

- Developed for patients with cancer
 - Flexibility
-
- Meaning-Making Intervention (MMI) – Lee et al., 2006
 - CALM Therapy – Hales et al., 2006
 - Meaning-Centered Psychotherapy – Breitbart et al., 2004
 - Dignity Therapy – Chochinov et al., 2005

Meaning-Making Intervention

- Derived from cognitive-processing model of reaction to trauma and influenced by Frankl's work on meaning
- Diagnosis of cancer is a traumatic event that threatens a person's "life schemas"
- 4 sessions of 2 hours and 3 phases
 1. Rapport, safety, and control; transitions and grief
 2. Challenges and coping; past and future meaning
 3. Commitment to life
- Improved self-esteem; sense of meaning in life in breast, colorectal cancer, and ovarian cancer

Lee, 2004; Lee et al. 2006; Henry et al., 2010

CALM Therapy

- Managing Cancer and Living Meaningfully (CALM)
- Supportive expressive/Cognitive/Existential/Meaning
- Facilitates affect regulation, problems solving, and exploration of challenging issues
- Six individual sessions over 3- to 6-month period
 - Symptom management and communication with HCP
 - Change in Self and relationships with others
 - Sense of meaning and purpose
 - Future and mortality
- Reduction in depressive symptoms and death anxiety over time; improvement in spiritual well-being over time

Hales et al., 2010; Lo et al., 2014; Hales et al., 2015

Meaning-Centered Psychotherapy

- Inspired by Victor Frankl's work on meaning
- Reconnect with and enhance sense of meaning
- Sources of meaning:
 - *Creativity, Experience, Attitude, History*
- Enhanced spiritual well-being, faith, quality of life, meaning
- Decreased hopelessness, desire for hastened death, and symptom distress

Breibart et al. 2002; 2004; 2006, 2012

Meaning-Centered Psychotherapy

- Group format (MCGP): 8-week intervention
- Individual (IMCP): 7-week intervention
 - Concepts and sources of meaning
 - Cancer and meaning
 - Historical sources of meaning
 - Historical sources of meaning
 - Attitudinal sources of meaning
 - Creative sources of meaning
 - Experiential sources of meaning
 - Transitions: Reflections and hopes for the future

Dignity Therapy

- Dignity: The quality or state of being worthy, honored, or esteemed
- Loss of dignity is associated with feelings of degradation, shame, depression, hopelessness, and desire for death
- Loss of dignity is a central concern in patients requesting physician-assisted suicide and euthanasia
- Patient Dignity Inventory (PDI)
- Dignity Model
 - Dignity-related concerns
 - Dignity-conserving repertoire
 - Social dignity

Chochinov et al. 2002; 2005; 2007; 2008; 2011

Dignity Therapy

- Ameliorate distress and enhance dignity
- Dignity therapy question protocol designed to invoke a sense of meaning and purpose, bolster self-worth
- Typed transcript provides “generativity” document
- Beneficial for patients and bereaved caregivers
- Improved depression and anxiety compared to standard PC

Case example: Connie

- 55-year-old woman with advanced pancreatic cancer
- Her husband was killed by a drunk driver 1 year ago
- Lost her 5-year-old child in a car accident 6 years ago
- She was an atheist and often felt discriminated against
- She stated: “*The issue of meaning has no meaning for me*” and would become very irritated at any attempt at exploring personal values, or spiritual issues. She explained: “*The only question that matters to me is: Can you show up for me? Can you be with me through my despair without trying to change it?*”
- Therapeutic stance with Connie: Authenticity, openness, honoring the uniqueness of each moment; “Give me absolute presence.”
- Use of hypnosis to mitigate the impact of memories and rumination and achieve “equilibrium.” Did not like the word “peace.” Making tea together; exploring the texture of flowers. Mindfulness.

*“Acceptance should not be mistaken for a happy stage.
It is almost void of feelings.”*

Elisabeth Kubler-Ross

Conclusion

- Existential and spiritual needs must be considered in all patients with advanced illness
- Existential distress is primarily related to loss of a sense of meaning and purpose in life
- Psychotherapy interventions that enhance connection with a sense of meaning and purpose can improve quality of life and promote existential well-being
- Clinicians should refrain from imposing any “existential agenda”, but should honor the uniqueness of each patient

Understanding Existential Distress and Meaning-Oriented Therapies in Advanced Illness

Q/A