PALLIATIVE CARE CASE OF THE MONTH

"Identifying and Relieving Existential Suffering"

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Volume 21, No. 115 **June, 2021**

Case: Ms. D is a 72-year-old female with a past medical history of metastatic vulvar cancer who is admitted after a ground level fall at home, now status post a surgical repair of a pathological femur fracture; she desires no further cancer-directed therapy. Palliative care is following her for pain management.

She is in tears and is reporting intolerable pain, which has not improved with several different opioid and non-opioid pain regimens. Her oral morphine equivalent day-to-day seems sporadic without correlation to any pain relief.

When asked about her family, her crying intensifies. She shares she has not seen or spoken with her son in a year, and she does not want to discuss that relationship further. She repeats multiple times that her life is no longer worth living and she wishes she could just go to sleep and not wake up. She denies suicidality and other symptoms of depression.

Discussion: For patients with serious illness, existential suffering can exacerbate physical symptoms, sometimes preventing effective treatment and requiring first the recognition of other components of the patient's "total pain" – physical, mental, social, spiritual.

Although existential suffering is a widely recognized concept in palliative care, there is no consensus on its definition. Without a clear conceptualization, existential distress is difficult to identify and manage.[1] Furthermore, existential, psychological, and spiritual suffering have substantial overlap, making differentiation of those concepts challenging. Additionally, disciplines differ in how they define existential suffering: chaplains focus on the importance of guilt, palliative care physicians on impending death, and pain specialists on the pain associated with living.[2]

Existential issues in general are thought to include "concerns related to hopelessness, futility, meaninglessness, disappointment, remorse, death anxiety, and disruption of personal identity."[3] Existential suffering presents when a "condition robs individuals of their capacity for peace in their present state of being"[4] or when despair results from an inner realization that life is futile and without meaning.[5] Potential synonyms of existential suffering are "mental anguish" and "demoralization syndrome." While patients with existential suffering can develop psychiatric co-morbidities, they do not necessarily have clinical anxiety or depression.

Existential suffering may manifest in four domains: [2]

- Freedom – All humans make choices, and all choices have consequences, sometimes leading to guilt or unresolved conflict with others.
- Meaning – Questions arise on the purpose of one's life or illness.
- Isolation – Feeling of isolation from loved ones and/or higher being, particularly in relation to one's impending death.
- Mortality – Anxiety about dying and afterlife, including leaving loved ones.

When assessing existential distress, detailed assessment tools are available, such as the Patient Dignity Inventory, a validated 25-question survey to test sources of dignity-related distress among patients near the end of life.[6] More useful in everyday clinical practice may be the question, "Are you at peace?", with appropriate follow-up questions stemming from a place of curiosity.[7]

Risk factors for existential suffering include poor social support, poorly controlled symptoms, self-blame coping strategies or low sense of controllability, and low level of physical activity.[8] An important initial management strategy is to optimize treatment of physical, psychiatric, and spiritual symptoms and involve all pertinent disciplines including social work, chaplaincy, and psychology. Clinical providers should provide an empathetic presence by asking questions on topics that are potentially distressing emotionally, listening to responses, and providing reflective statements.

Questions for exploring existential distress may include:

- It sounds like you have a lot on your mind. What is causing you the most concern?
- Tell me a little about your life, particularly those parts you remember most, or think are the most important.
- What are the most important roles you have played in life? Why were they so important to you? What did you accomplish?
- Are there particular things that you feel you still need to say to your loved ones?
- How do you want to be remembered by your loved ones?

Additional interventions should focus on identifying meaning, building legacy, and creating connection. Some modalities to relieve existential suffering include:

- Reconnecting with aspects of life that bring significance, such as through sharing memories, spending time with loved ones, or visiting a special place[1]
- Dignity therapy aimed at strengthening self-esteem and feeling of self-worth by helping patients record aspects of their life that they would most want remembered[6,9]
- Strategies to focus on the present moment, such as music, meditation, or art[10]
- Individualized or group meaning centered psychotherapy to identify meaning in the illness experience[11]
- Supportive expressive group therapy to validate and normalize the traumatic aspects of a terminal illness[12]
- Positive affirmation in everyday clinical encounters, of the person's individuality and accomplishments, which will emphasize their internal resilience and strength[5]

Palliative sedation has been used for existential suffering when all other interventions have failed; however, its use is controversial.

Return to Case: Ms. D's physical cancer pain was negatively impacted by her social situation – being estranged from her son. She was experiencing existential suffering in the freedom and isolation domains. We provided an empathetic presence, exploring her prior roles in life. She shared that she was most proud of being a grandmother, and that she found meaning in her interactions with her grandson. We recommended legacy building activities, in the form of writing letters to him to open on future milestones, such as birthdays or graduations. We additionally prioritized her ability to visit with her grandson when helping to identify her disposition plan. Subsequently, her physical pain was also more responsive to interventions.

Included information modified from a Fast Fact and Concepts #319, #320

References:

1. Boston P, Bruce A, Schreiber R. Existential Suffering in the Palliative Care Setting: An Integrated Literature Review. Journal of Pain and Symptom Management. 2011. 41(3): 604-618.
2. Strang P, Strang S, Hultborn R, Arner S. Existential Pain – An Entity, a Provocation, or a Challenge? Journal of Pain and Symptom Management. 2004; 27(3): 241-250.
3. Blinderman CD, Cherny NI. Existential issues do not necessarily result in existential suffering: lessons from cancer patients in Israel. Palliat Med 2005;19:371e380.
4. Williams B. Dying young, dying poor: a sociological examination of existential suffering among low socio-economic status patients. J Palliat Med 2004;7: 27e37.
5. Kissane, DW: Demoralization: A life-preserving diagnosis to make for the severely medically ill. Journal of Palliative Care. 2014; 30(4):255-8.
6. Chochinov HM, Kristjanson LJ, Breitbart W, et al: The effect of dignity therapy on distress and end-of-life experience in terminally ill patients: A randomized controlled trial. Lancet Oncology. 2011 Aug;12(8):753-62.
7. Steinhauser KE, Voils CI, Clipp EC, et al: Are you at peace? Archives of Internal Medicine. 2009 Jan 9;166:101-5.
8. Robinson S, Kissane DW, Brooker J, et al. A systematic review of the demoralization syndrome in individuals with progressive disease and cancer: a decade of research. Journal of Pain and Symptoms Management. 2015; 49(3): 595-610.
9. Fitchett G, Emanuel L, Handzo G et al: Care of the human spirit and the role of dignity therapy: A systematic review of dignity therapy research. BMC Palliative Care. 2015 May 14(8): 1-12.
10. Mount BM, Boston P, Cohen R. Healing connections: on moving from suffering to a sense of wellbeing. J Pain Symptom Manage 2007;33:372e388.
11. Breitbart W, Rosenfield B, Pessin H, et al: Meaning-centered group psychotherapy: An effective intervention for improving psychological well-being in patients with advanced cancer. Journal of Clinical Oncology. 2015 Mar;33(7):749-54.
12. Kissane DW, Grabsch B, Clarke DM, et al: Supportive-expressive group therapy: The transformation of existential ambivalence into creative living while enhancing adherence to anticancer therapies. Psycho-Oncology. 2004 Mar;13:755-768.