

CLINICAL VIGNETTE

The Complexities of Hope – Coping with Existential Distress at the End of Life

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Case Report

A 54-year-old woman presented to the hospital with worsening abdominal pain five-months ago with undifferentiated endometrial carcinoma, treated with surgical resection and adjunct carboplatin and paclitaxel. Recent imaging showed disease progression. She enrolled in a clinical trial and received the first dose of immunotherapy prior to hospitalization. Her medical history also included post-traumatic stress disorder and major depressive disorder in remission. Home medications were venlafaxine, gabapentin, extended release morphine, senna, polyethylene glycol, and docusate. She acknowledged several psychosocial stressors including the recent death of her brother due to drug overdose, estrangement from her sister whom she blamed for their brother's death, and her cancer diagnosis, which she had not disclosed to family or friends. Upon admission, she was found to have multiple malignant bowel obstructions and was determined to not be a candidate for surgical decompression. Palliative care was consulted to assist with management of persistent pain, nausea, and anxiety.

Over several discussions with the palliative care team, it became clear that the patient's physical symptoms were not the primary cause of her suffering but instead stemmed from despair associated with the loss of faith, meaning, and control. At the heart of her existential crisis was the irreconcilable conflict between her strong belief in a God that would not allow her die before achieving her artistic destiny and acknowledgment of her aggressive, incurable cancer. She was able to occasionally engage in discussions about her end of life goals, which included disclosing her diagnosis and saying goodbye to her family and friends, reconciling with her sister, and returning home. While viewed as "non-negotiable" priorities, she did not see them as applicable to her current situation. She introduced her "hope of being cured of cancer" into nearly every discussion with her medical providers as part of her coping mechanism. While she wanted to be fully informed about her condition and prognosis, she implored her treatment teams to not take away her hope of being cured. This unfortunately resulted in prognostic non-disclosure and collusion in false optimism.

During her prolonged hospitalization, she grew increasingly weak and frail. As her pain and nausea worsened, a venting gastrostomy was placed. She also received her second dose of immunotherapy but continued to have worsening pain and anxiety. While exploring her hopes, worries, and expectations for the future, the palliative care team engaged her in structured life review with active efforts to facilitate therapeutic reframing

to help alleviate her suffering. Through this process, she began to make amends with friends and family. Approximately one week after her second dose of immunotherapy, as she became increasingly somnolent with worsening and pain, the patient and her family decided to transition to comfort-focused care. She died comfortably the following day in the presence of her family and close friends.

Discussion

Existential distress is a multi-dimensional construct defining the state of psychological turmoil that can arise when one's fundamental sense of meaning, control, or identity is threatened, as is often the case in the setting of serious illness.¹ While the diagnosis of existential distress is supported by many organizations, there is no single, agreed-upon definition.^{2,3} Existential distress can be identified as a spectrum of experiences, typically associated with one of four existential domains: isolation or feeling disconnected from others; meaninglessness; loss of freedom, autonomy or control and mortality.^{4,5} Patients frequently interpret existential distress through psychological or spiritual frameworks.⁶ Existential distress can also manifest clinically as uncontrollable pain or other refractory physical symptoms. Both chronically and terminally ill patients who suffer existential distress have been shown to have increased risk for poor health outcomes, high indices of pain and fatigue, and impaired daily functioning.⁷

Most patients want to discuss their existential concerns with their medical teams but expect their clinicians to initiate these conversations. Yet studies show that clinicians typically avoid engaging patients in such discussions, often because they feel ill-equipped to manage patients' distress. Given the prevalence of existential suffering, the negative impact it can have on patients' quality of life, and the availability of effective methods to ameliorate it, clinicians have an ethical responsibility routinely screen for existential distress.

The question, "are you at peace?"⁸ has been suggested as a broad screening tool to assist health care providers in identifying existential suffering. This open-ended approach is widely applicable, allowing each patient the ability to respond based on his/her individual interpretation of the question. Further exploration of distress should occur for patients who screen positive.⁹ Examples of follow up questions include: "what's keeping you from being at peace?" and "what worries you the

most about your illness?" This exploration can clarify the appropriate intervention, such as referral to a chaplain or a mental health professional. It is important to remember that this screening tool will miss patients who feel at peace but are still struggling with existential suffering (e.g. feeling hopeless). Therefore, additional screening tools should be considered.

For a multi-dimensional approach to measuring distress, the Structured Interview Assessment of Symptoms and Concerns in Palliative Care was developed to measure various sources of distress or concerns that arise in the context of end-of-life care.¹⁰ This 13-item psychometric assessment not only evaluates physical aspects of the palliative experience (e.g. pain, nausea, dyspnea) but also areas of psychological and existential distress (e.g. loss of control or dignity, sense of burden, anxiety, depression, hopelessness). Another tool is the FACIT-Sp-12, a 12-item self-report measure designed to assess the nature and extent of spiritually-based distress or well-being.¹¹ It is comprised of two subscales: one measuring a sense of meaning and peace and the other assessing the role of faith.

After identifying the nature of a patient's existential concerns, a clinician is well-positioned to offer a supportive presence through skillful communication and to connect the patient with appropriate resources. Existential distress can be mitigated by strong social or spiritual support, implementation of effective coping and relational skills, timely palliative care interventions, or referral to a mental health provider or allied health professional.¹² A variety of psychotherapeutic interventions can successfully alleviate existential suffering. These include cognitive behavioral therapy, supportive expressive group therapy, dignity therapy, meaning-centered group or individual psychotherapy, and managing cancer and living meaningfully.

Caring for patients with existential distress often presents a challenge for clinicians, many of whom feel ill-equipped to manage these concerns. There are also times in which, despite clinicians' best efforts, patients' suffering cannot be alleviated. In such instances, clinicians may experience their own existential distress, as the sense of identity and meaning they derive from alleviating patients' suffering at the end of life is called into question. It is critical for clinicians to recognize and attend to their own feelings of sadness, isolation, inadequacy, powerlessness, or hopelessness that may be result from caring for seriously ill patients. It is important that those clinicians seek help from others in order to cope with their own existential distress and to assist with parallel processing.¹³

In this case, the supportive presence of the medical teams was perhaps the most significant intervention the patient experienced during her hospitalization. Through efforts to understand where she was in her process of accepting her mortality, her clinicians were able to identify an appropriate intervention—structured life review—to facilitate management of existential suffering. This case presented several challenges to the clinicians involved in her care by evoking feelings of frustration, powerlessness, impatience, anger, and grief among members of her medical team. Her case also provided her

clinicians an opportunity to reflect on these triggered emotions and to find productive ways of managing the associated distress. Importantly, the practice of frequent structured debriefings proved to be one of the most therapeutic interventions for many members of the team.

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