CLINICAL VIGNETTE

Preserving Legacy and Managing Existential Distress Through Dignity Therapy

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Case

A 30-year-old male with metastatic desmoplastic small round cell tumor presented to the emergency room after becoming unresponsive for 2 minutes. During the episode, his mother noted that he was drooling, and his eyes were open but "looking in different directions." She denied any tonic-clonic movements, tongue biting, or urinary incontinence. After 2 minutes, the patient regained consciousness but was confused and did not remember the event.

At the time of admission he was enrolled in a clinical trial involving trabectedin and nivolumab. Since his diagnosis in 2017, he had already completed 6 cycles of vincristine, doxorubicin, and cyclophosphamide (VDC), 6 cycles of ifosfamide and etoposide (IE), was kept on "maintenance therapy" with pazopanib, and underwent whole brain radiation for over 50 brain metastases. Other significant medical conditions included liver cirrhosis with recurrent ascites requiring periodic therapeutic paracentesis, and chronically poor oral intake.

Given his diffuse brain metastases and high clinical suspicion for seizures, he was started on levetiracetam 500 mg twice a day. His hospital course was complicated by a syncopal episode and volume overload. Near the end of his hospitalization, he began voicing desires of going home, particularly to his home in Tijuana, Mexico, to pass away. Palliative Care was consulted to further delineate his goals and assess for symptom needs.

In discussion with Palliative Care, he shared, "You know when you're tired, and it's time to go to sleep, but you stay up past that point, and then you're no longer able to go to sleep? I feel like that is what's happening, and I don't want to go past that point." He expressed a readiness to accept his mortality and a desire to rest from the struggles of his medical illness. While he acknowledged the presence of pain, his primary symptom was fatigue. He described his fatigue as looking back to see how far he has come and then looking ahead to see what is in front of him - God, peace, and light. Hospice was introduced as a service to provide him comfort and support in his transition from aggressive medical interventions to comfort care. He accepted these services in hopes that he could spend his remaining time comfortably with his family.

During his hospitalization, Dignity Therapy was used to help with his distress of lingering when he had already come to an acceptance of his mortality. Dignity Therapy interviews were conducted in the presence of his mother. During the read back session of his interview, he diligently looked over his generativity document with a renewed sense of energy to provide edits and add additional words of encouragement and gratitude. After the completion of Dignity Therapy, he was discharged home with hospice on a Monday and passed away peacefully in the presence of his family that following Friday. His mother expressed gratitude for the gift of Dignity Therapy as a way to cherish her son and hold on to his legacy.

Discussion

While significant progression has been made towards controlling physical symptoms associated with advanced disease, the psychosocial, emotional, and spiritual manifestations of a patient's illness are less obvious and remain challenging to many clinicians.[1] Dignity is a complex and multifactorial concept that involves aspects related to the patient's sense of self – physical independence, cognitive acuity, self-pride, and autonomy. In a basic sense, dignity is synonymous with terms such as self-esteem, self-worth, and self-respect.[2] Irreversible and life-limiting illnesses may lead to not only severe physical pain and significant symptoms but also loss of autonomy and challenging existential and spiritual experiences that can contribute to disintegration of a patient's sense of self and sometimes lead to a desire for a hastened death or suicidal ideation. Early studies suggest that among patients with terminal conditions, there is an association between the undermining of dignity and psychiatric symptoms related to anxiety and depression. These include feelings of worry and guilt and a sense of hopelessness and worthlessness. Loss of dignity, loss of a sense of meaning, feelings of burdening others, and spiritual distress were all found to correlate with patients' requests for hastened deaths.[3,4] As the disease worsens, and the end of a patient's life approaches, emotional suffering increases and the patient's sense of dignity becomes more fragile.[5]

The existential distress experienced by a dying patient can manifest as various cognitive, physical, and affective states and threaten their sense of meaning and personhood.[4,5] Such turmoil is typically associated with one of four existential domains: isolation or feeling disconnected from others; meaninglessness; loss of freedom, autonomy, or control; and mortality.[6,7] There is no single, agreed-upon definition of existential distress[8,9]; however, it an potentially be identified as a spectrum of psychological experiences, ranging from normal feelings of vulnerability, sadness, and fear to disabling depress-

sion, anxiety, panic, demoralization, social isolation, and existential crisis.[10] Existential distress can also manifest clinically as uncontrollable pain or other refractory physical symptoms. Importantly, both chronically and terminally ill patients who suffer existential distress have been shown to have an increased risk for poor health outcomes, high indices of pain and fatigue, and impaired daily functioning.[11] Existential distress can be successfully 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 also successfully alleviate existential suffering. In the case of our patient, Dignity Therapy was utilized to address his feelings of loneliness and isolation and his journey to accepting mortality.

Dignity therapy is a unique, non-invasive, and practical therapeutic tool for patients with end-stage illness. It is an evidence-based and clinically effective psychotherapeutic modality for patients with existential readiness and evidence of existential distress.[13] Perceiving that dignity depends on experiences of generativity and the pursuit of purpose and meaning, Dr. Harvey Chochinov proposed this psychotherapeutic intervention for people facing serious illness as a single (or multiple) session intervention constructed on principles of dignity (independence and control), as well as spiritual, psychosocial, and existential elements. Dignity Therapy uses a question protocol to guide the patient on dignity conservation tasks such as sharing words of love, settling relationships, and preparing legacies of memory and shared values. The session is recorded and transcribed into a generativity document as a form of legacy creation for the patient's loved ones to keep.[2] In a randomized trial comparing dignity therapy to standard palliative care and to client-centered care, dignity therapy resulted in significant improvements in patient quality of life and spiritual well-being as compared with the other arms, though it did not significantly impact levels of patient distress.[5]

For our 30-year-old patient, he was able to share and permanently record words of advice for his family and others. He has given permission to share his words to educate and guide future clinicians and healthcare providers. During his dignity therapy session he shared, *"Listen to your intention. There's something in life and inside of you that lets you know what the right path is. It's intuition, and I think it guides you to the best possible outcome in your life. Everything else is somebody else's opinion, which is not necessarily what your soul wants for you. But if you follow what your soul wants, without a doubt, there's no regrets in life…That wasn't how I've always lived my life, but the best moments of my life, I lived them that way. So that's your shortcut. Listen to yourself, and follow it without any doubt. No regrets. Sooner or later, you'll realize that it's the best thing you could have done."*

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