

# Attending to the Existential Experience in Oncology: Dignity and Meaning Amid Awareness of Death

William E. Rosa, PhD, MBE, NP<sup>1</sup>; Harvey M. Chochinov, MD, PhD<sup>2,3</sup>; Nessa Coyle, PhD, RN<sup>4</sup>; Rachel A. Hadler, MD<sup>5</sup>; and William S. Breitbart, MD<sup>1</sup>

The COVID-19 pandemic has deeply challenged the integrity of the human spirit. Health systems worldwide have seen a marked escalation in health-related suffering and uncertainty about the future. Beyond these broader collective concerns, patients with cancer continue to confront treatment disruptions and increased isolation from support systems. Moral distress and burnout are leading to clinical staff exhaustion and depletion across settings. As cancer clinicians adapt to a rapidly changing world characterized by viral variants and global inequities, we call for a widespread commitment to recognize and prioritize the existential experience of all persons with cancer as a moral standard of care.

By *existential experience*, we mean the patient's fluctuating state of awareness related to their own mortality and death.<sup>1</sup> This existential experience may shift between *existential suffering* (disturbance of soul and spirit) and *existential health* (wholeness and connectedness with self and others).<sup>1</sup> Many cancer clinicians have witnessed firsthand the sting of the existential slap—a patient's emerging, yet sometimes sudden, awareness that death is an inevitability.<sup>2</sup> Once acknowledged, they cannot unknow the fragile limits of their human form and distress often ensues. The ever-present threat of loss to personhood, health, relationships, and, ultimately, life is omnipresent in the cancer experience; acknowledging these existential concerns can support coping, autonomy, and existential health.<sup>3</sup> Providing consistent existential care through humanistic responses to the patient's existential experience may help alleviate internal angst as one encounters disease transitions that increase proximity to death.

Interventions designed to enhance meaning and purpose have been empirically shown to decrease anxiety, depression, demoralization, and a desire for hastened death for patients with cancer-related existential suffering.<sup>4</sup> By drawing on sources of meaning from the patient's narrative, we know that patients with life-threatening cancer possess the innate capacity to actively create their legacy and engage with life regardless of prognosis. Dignity enhancing approaches foster meaning making and generativity (eg, investment in

loved ones who will be left behind) in relation to an individual's life, relationships, and values.<sup>5</sup>


Despite evidence that meaning-making improves the existential experience, it is unclear who owns the provision of existential care. The existential experience is typically underemphasized or entirely absent as a clinical priority. If included at all, medical and nursing curricula commonly address existential care under the umbrella of broader psychosocial phenomena without distinct attention to developing literacies in understanding and specifically addressing the existential experience. However—by way of contrast—existential issues are innately personal and foundational to the cancer experience, hence underscoring a moral obligation that they be acknowledged and addressed.

Existential care is a core component of palliative care, and integrated palliative care is foundational to high-quality oncologic care.<sup>6,7</sup> As palliative care models seek to relieve cancer-related suffering, how will oncology clinicians and systems prioritize existential literacy moving forward? Person-centered care is an illusion if frontline clinicians cannot or will not embed existential care principles throughout the relational aspects of cancer care. The very experience of living sees us all—patients and clinicians alike—grapple with existential issues. If clinicians are incapable of coming to terms with their own existential experience, being fully available to the existential experiences of patients is impossible. A common misnomer is that existential suffering is limited to end-of-life settings, but existential suffering may arise at any point along the cancer trajectory. Investments are needed to cultivate clinicians capable of forging human conversations and connections with patients and to approach the human dilemma of living and dying with compassion.<sup>8</sup> Table 1 provides pragmatic approaches to promote existential literacy throughout oncology culture.

The pandemic has led to cumulative loss and mass bereavement on a global scale, heightening the public's collective death salience and existential terror and informing the need for existential maturity to mitigate mortality-related fears.<sup>9</sup> When experiencing existential terror, humans may become more polarized and have

Author affiliations and support information (if applicable) appear at the end of this article.

Accepted on February 1, 2022 and published at [ascopubs.org/journal/go](https://ascopubs.org/journal/go) on March 14, 2022; DOI <https://doi.org/10.1200/GO.22.00038>

Licensed under the Creative Commons Attribution 4.0 License 

**TABLE 1.** Recommendations to Promote Existential Literacy and Humanize Oncology Care

<p>Integrate stand-alone didactic existential care knowledge throughout health curricula to prepare future cancer care clinicians with the language and awareness relevant to existential experiences</p> <p>Embed existential literacy into cancer residencies, fellowships, and professional development as a core component of ensuring holistic, person-centered care</p> <p>Advance quality improvement initiatives and research projects aimed at understanding and attending to the existential experiences of patients on the continuum from suffering to health</p> <p>Prioritize existential care as a fundamental component of oncology and palliative care to anticipate and alleviate distress and enhance quality of life</p> <p>Shift institutional and system-level cultures to recognize the existential experience as a barometer for quality, integrity, and humanity of health services</p> <p>Design, implement, and evaluate existential communication skills training to strengthen authentic presence and empathic clinician-patient relationships</p>	<p>Include existential assessments into initial and ongoing clinical evaluations to acknowledge and understand the patient's current and evolving existential state</p> <p>Understand the characteristics of existential suffering and existential health to provide appropriate and holistic support and seek specialist input as needed</p> <p>Develop generalist competencies in meaning-centered and dignity therapy interventions to foster existential health and transparency regarding the patient's existential state</p> <p>Normalize and validate existential experiences of patients to build trust, enhance patient satisfaction, and recenter cancer care planning on their unique needs, preferences, and values</p> <p>Foster clinician self-awareness and self-development related to existential experiences to promote clinician resilience and capacity in being with the existential experiences of patients</p> <p>Attend to the patients' need for legacy building, advance care planning, and pathways for generativity that can support meaning and purpose</p>
--	--

diminished capacity for empathy.<sup>10</sup> However, the hope inherent to existential care is one of creating a future in the face of uncertainty and the courage to do the hard work of living in the face of death.

Cancer treatment is a microcosm of the COVID-19 crisis: victories, losses, hopes, fears, uncertainty, and the potential for healing and cure. The pandemic has sparked

urgency for all clinicians to build capacities to recognize and respond to the existential experiences of patients and to partner with patients in preserving the essence of who they are amid the unpredictability of cancer. Patients' existential concerns are ubiquitous and deserving of our attention. Indeed, it is time we call those concerns by name.

### AFFILIATIONS

<sup>1</sup>Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, NY

<sup>2</sup>Department of Psychiatry, Max Rady College of Medicine, University of Manitoba, Manitoba, Canada

<sup>3</sup>CancerCare Manitoba Research Institute, Manitoba, Canada

<sup>4</sup>Ethics Committee, Memorial Sloan Kettering Cancer Center, New York, NY

<sup>5</sup>Department of Anesthesiology, University of Iowa Hospitals and Health Clinics, Iowa City, IA, USA

### CORRESPONDING AUTHOR

William E. Rosa, PhD, MBE, NP, Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, 641 Lexington Ave, 7th Floor, New York, NY; Twitter: @BRosa\_PhD; e-mail: rosaw@mskcc.org.

### SUPPORT

W.E.R. is supported by NCI/NIH Award Number T32CA009461.

### AUTHOR CONTRIBUTIONS

**Conception and Design:** All authors

**Manuscript writing:** All authors

**Final approval of manuscript:** All authors

**Accountable for all aspects of the work:** All authors

**Other:** All authors [Manuscript editing]

### REFERENCES

1. Tarbi EC, Meghani SH: A concept analysis of the existential experience of adults with advanced cancer. *Nurs Outlook* 67:540-557, 2019
2. Coyle N: The existential slap—A crisis of disclosure. *Int J Palliat Nurs* 10:520, 2004

### AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated unless otherwise noted. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to [www.asco.org/rwc](http://www.asco.org/rwc) or [ascopubs.org/go/authors/author-center](http://ascopubs.org/go/authors/author-center).

Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians ([Open Payments](http://OpenPayments)).

**Harvey M. Chochinov**

**Consulting or Advisory Role:** Reser Pharma

**William S. Breitbart**

**Honoraria:** Novartis

**Consulting or Advisory Role:** Novartis

No other potential conflicts of interest were reported.

### ACKNOWLEDGMENT

W.E.R., N.C., and W.S.B. acknowledge NCI/NIH Award Number P30CA008748.

**JCO Global Oncol 8:e2200038. © 2022 by American Society of Clinical Oncology**

3. Larsen BH, Lundeby T, Gerwing J, et al: "Eh—What type of cells are these—flourishing in the liver?" Cancer patients' disclosure of existential concerns in routine hospital consultations. *Patient Educ Couns*, 2021. [10.1016/j.pec.2021.11.010](https://doi.org/10.1016/j.pec.2021.11.010) [epub ahead of print on November 23, 2021]
  4. Breitbart W, Poppito S, Rosenfeld B, et al: Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *J Clin Oncol* 30:1304-1309, 2012
  5. Buonaccorso L, Tanzi S, De Panfilis L, et al: Meanings emerging from dignity therapy among cancer patients. *J Pain Symptom Manage* 62:730-737, 2021
  6. Tarbi EC, Gramling R, Bradway C, et al: "I had a lot more planned": The existential dimensions of prognosis communication with adults with advanced cancer. *J Palliat Med* 24:1443-1454, 2021
  7. Knaul FM, Farmer PE, Krakauer EL, et al.: Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: The Lancet Commission report. *Lancet* 391:1391-1454, 2018 [Erratum: *Lancet* 391:2212, 2018]
  8. Sinclair S, Kondejewski J, Jaggi P, et al: What is the state of compassion education? A systematic review of compassion training in health care. *Acad Med* 96:1057-1070, 2021
  9. Emanuel L, Solomon S, Fitchett G, et al: Fostering existential maturity to manage terror in a pandemic. *J Palliat Med* 24:211-217, 2021
  10. Solomon S, Greenberg J, Pyszczynski T: *The Worm at the Core: On the Role of Death in Life*. New York, NY, Random House, 2015
- 

