PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #319
EXISTENTIAL SUFFERING PART 1: DEFINITION AND DIAGNOSIS

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Background Patients with serious illnesses often wrestle with existential questions such as: *Why is this happening to me? What is the meaning of my suffering? Where is God*? Typically, these questions do not indicate psychological pathology. However, for some patients (likely 13-18% with progressive illness), these questions can evolve into clinically significant existential suffering that can erode self-worth, correlate with suicidal ideation, and exacerbate physical symptoms such as pain or nausea (1-3). Palliative care clinicians are often faced with the challenging task of identifying when existential concerns are contributing to suffering in a way that a health care team should intervene. This *Fast Fact* will review the definition of existential suffering and common identification tools. *Fast Fact* # 320 will review suggested care approaches for a patient with existential distress.

Definition There is no widely agreed upon definition of existential suffering, nor an agreed upon term to describe it. Other terms seen in the published medical literature include "existential distress", "demoralization syndrome", and "total pain" (4). One commonly referred to definition is an incapacitating state of despair resulting from an inner realization that life is futile and without meaning (1). Four existential domains have been recognized through which existential suffering can manifest (3,5):

Existential Domain	Description	Clinical Manifestation
Mortality	Awareness of the inevitability of death and a wish for life to continue	Anxiety about dying or the afterlife; concern about separating from loved ones
Freedom	Reality that humans must always choose and all choices have consequences.	Regret about past choices; unresolved conflict with one's self or others
Meaningless	Struggle to find meaning in life despite the universal reality of death.	Loss of purpose; questioning the meaning of their illness, suffering, or faith
Isolation	Sense of isolation from part of a larger community (church, family, etc)	Feelings of abandonment by community or God; a sense of disconnectedness.

Existential and Spiritual Suffering Existential suffering and spiritual suffering are not synonymous although these phenomena often overlap. Spiritual suffering, defined simply as distress due to spiritual or religious concerns, can be conceptualized as a sub-type of existential suffering. When considering the differences between existential and spiritual suffering, several key points warrant emphasis:

- Some patients with existential suffering may not consider themselves to be spiritual and may become upset if a clinician reflexively consults a chaplain.
- Spirituality has vastly different meanings for different individuals. See *Fast Facts* #19 and 274. In its broadest definition, spirituality can include involvement in a secular club or organization (6).
- Spirituality is part of each existential domain; however, it does not encompass all facets of each existential domain. Therefore, all spiritual suffering is existential suffering, but not all existential suffering is spiritual suffering.
- "Spiritual" and "existential suffering" are not terms patients/families are typically familiar or comfortable with. At the bedside it is best to name the distress explicitly or reflect the patient's language characterizing the suffering. For example: "*It sounds like you are trying to make sense of how this could happen."* Or *"you said you've felt very apart from your family and faith community since this began. Can you tell me more about that*?"

Clinical Assessment Tools Clinicians should listen for existential 'cues' in all patients with serious illness, especially when symptoms seem out of proportion to their disease. Such cues can be

expressions of doubt about life's meaning or one's faith or expressed feelings of isolation – e.g. "*no one understands what I'm going through*." Although there are multiple validated assessment tools available to aid healthcare providers in the diagnosis of existential suffering, many of these tools focus on one specific existential domain and others may be too cumbersome to implement into clinical practice. Instead one particularly useful tool involves simply asking the patient: "*Are you at peace?"* (8). A no answer should prompt further exploration of signs of distress, physical or otherwise, with follow-up questions such as *"What's keeping you from being at peace?"* or "*What worries you the most about your illness*?".

Risk Factors No associations were found with existential suffering and time since diagnosis, stage of disease, or type of treatment (1). One systematic review identified the following risk factors (7):

- Poor social support: single patients (including divorced, separated, and widowed) or unemployed.
- Poorly controlled physical or psychological symptoms.
- Self-blame coping factors for illness and low sense of controllability of the illness.
- Low level of physical activity.

Diagnostic Challenges A lack of a universally accepted definition, clinician knowledge deficit, and concomitant psychological, spiritual, or social concerns make existential suffering difficult to diagnose. Furthermore, patients may have difficulty articulating their distress or may not be willing to disclose it if they feel their clinicians are too busy or guarded from discussing existential concerns (4). Not all patients with existential suffering develop clinical anxiety or depression. In general, clinical depression can be defined by a loss of interest or pleasure in the present moment, whereas existential suffering is typically defined by a loss of hope, meaning, and anticipatory pleasure (9,10). Despite these challenges, it is important for clinicians who care for seriously ill patients to elicit existential concerns, as doing so can open opportunities for empathetic connection and clarify treatment options. Collaborating with social workers, chaplains, or psychologists is vital to better understand a patient's suffering.

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