PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #417
TOTAL PAIN
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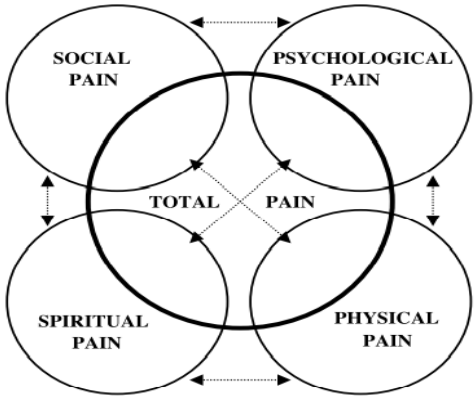
Introduction: Pain is a common, multi-dimensional symptom which compromises quality of life for many patients with serious illness (1,2). Understanding the concept of *total pain* and its dimensions should be a prerequisite for clinicians who care for patients facing a life-limiting illness (2). This *Fast Fact* discusses the concept of *total pain* along with, evaluation and management strategies.

The concept of total pain: Nociception refers to neural encoding of impending or actual tissue damage (3). Pain refers to the subjective experience of actual or impending harm and is influenced by past experiences and expectations (3,4). A serious illness can fundamentally disrupt previously established expectations for the future. Dame Cicely Saunders, the founder of the modern hospice movement, recognized this and applied the term *total pain* as having physical, psychological, social, and spiritual components interacting upon one another (5-7). See the figure below used with the author's permission (2). While clinicians often focus on the physical pain component, the effect of a life-limiting illness on the spiritual, social, and psychological components often gets overlooked. Consequently, treatable suffering may get missed or overmedicated.



The total pain experience - an interactive model: The interaction among *total pain* components is often complex, yet evident in patients with serious illnesses (2,8-15). For example, loss of hope can have a spiritual, existential, and psychological dimension which may compound the intensity of physical pain if the patient attributes pain with impending death. As suffering intensifies, the family's sense of helplessness may compel them to visit the patient less frequently. Thus, physical pain may exacerbate social and psychological pain from a perceived sense of abandonment (8,12). Clinicians cannot fully care for patients with life-limiting illnesses without assessing for all domains of total pain. Since no one person or discipline can manage total pain, interdisciplinary teams (IDTs) are vital to address *total pain*.

Evaluation and management strategies of total pain: Listening to the patient's illness narrative with unhurried presence is key to developing a therapeutic presence that fosters assessment of all four domains (16). Elizabeth Kubler-Ross taught that dying people commonly yearn for love, touch, and communication (16). She stressed the importance of not just pharmacotherapies and interventional-based analgesics, but sitting, listening, and holding hands to enable care for all components of total pain (16). See the table below for an example of each component can be assessed and addressed.

Total Pain Component	Description	Manifestation	Example	Intervention towards resolution
Physical	Nociceptive, visceral, or neuropathic pain from known tissue injury (1)	Pain leads to impaired function and social isolation from fear of exacerbations away from home	Epigastric pain radiating to the back from unresectable pancreatic cancer	Celiac plexus block significantly improves patient's pain and function (17).

Psycho-logical	Anxiety, hopelessness, helplessness from medical uncertainty (15,18).	Adjustment reactions, despair.	Disengaging from clinical care plan, spending excessive time searching the web	Meeting with the IDT for a serious illness discussion addressing what to expect and how the patient defines quality of life.
Social	Fear of dependency on family; loss of role as provider to family (19);	Loss of dignity and sense of worth (13).	Family conflict as the patient declines recommended care and voices an urgency to return home.	Facilitate discussions between patient and caregivers to help find solutions for the patient's changing clinical status and family role (2).
Spiritual	Despair from inner realization that life is finite and without meaning (16)	Feelings of disconnection and abandonment by community/God.	Questioning the meaning of life and the dying process – "*Why me*?" (20)	Involve clinicians (e.g., social worker, psychologist, chaplain) with skill sets to enable exploration of the patient's distress from dying (21).

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