

# Understanding of the Concept of “Total Pain”

## *A Prerequisite for Pain Control*

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❖ Pain is one of the most common and distressing symptoms described by palliative cancer patients. Despite the fact that pain can be controlled, poor pain relief continues to be a challenge in palliative care. The lack of clarity in how to understand pain for this population contributes to the persistence of poor pain management. Dame Cicely Saunders coined the term “total pain” to characterize the multidimensional nature of the palliative patient’s pain experience to include the physical, psychological, social, and spiritual domains. This article highlights the use of the concept of “total pain” in the assessment and management of pain for cancer patients who are dying and presents a case study to illustrate that optimal pain relief is not possible if all dimensions of “total pain” are not addressed. Nursing implications for clinical practice are discussed. The concept of “total pain” should be the driving force leading to the standardization of pain definition, intervention, and evaluation for palliative cancer patients.

### K E Y W O R D S

cancer  
pain  
palliative care  
total pain

**P**ain is almost an inevitable reality for people dying of cancer. Cancer pain at the end of life (EOL) has evolved from being one of the most neglected public health problems to being recognized as a worldwide health priority. The World Health Organization (WHO) has developed policies and treatment strategies to benefit palliative cancer patients who experience pain.<sup>1</sup> Although pain can be controlled in 85% to 95% of patients through either pharmacological or non-pharmacological methods, poor pain relief continues to be a well-documented reality for many patients.<sup>2,3</sup> It has previously been estimated that up to 25 million people throughout the world die in pain each year.<sup>4</sup> The lack of consensus in understanding the critical aspects

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that comprise the pain experience in the dying or in patients with advanced cancer pain contributes significantly to the persistence of poor pain management. The tendency to focus on the physical component of pain to the exclusion of other contributing aspects is also a major hindrance to proper pain management. The perception of pain in the palliative patient can be influenced by various factors and needs to be understood with a multidimensional approach. The purpose of this article is to present the concept of “total pain,” provide a background on pain theory, and highlight the unique aspects of advanced cancer pain within the context of palliative care. A case study illustrates that “total pain” is the most appropriate approach to address this type of pain.

## ❖ BACKGROUND

### “Total Pain” and Palliative Care

Palliative care is defined by the WHO as the active total care of patients whose disease does not respond to curative treatment.<sup>5</sup> Today, comprehensive definitions of palliative care address the multidimensional aspects of patients and their families, including the physical, psychological, social, and spiritual.<sup>6,7</sup> Although these aspects are central to the philosophy of palliative care, how they are operationalized in the practice of pain control in the palliative care setting remains a challenge. This is problematic because pain demands the same analysis and consideration as an illness itself.<sup>8</sup> Dame Cicely Saunders, key contributor to the modern hospice movement, coined the term “total pain” and suggested that pain be understood as having physical, psychological, social, emotional, and spiritual components.<sup>9</sup> The combination of these elements is believed to result in a “total pain” experience that is individualized and specific to each patient’s particular situation.

The lack of a comprehensive and accepted definition of pain that can serve as a guideline in the management of the palliative patient’s pain presents a challenge to nurses and physicians in their efforts to provide optimal pain management. Breitbart<sup>10</sup> noted that for the clinician, pain represents one of the most difficult diagnostic and therapeutic problems in oncology. It remains a pressing issue because it has been shown that nurses and physicians still lack basic knowledge about pain and its management.<sup>2,11-15</sup> Nurses are responsible for assessing pain and intervening to keep the patient as

comfortable as possible. However, research has shown that one of the main barriers to optimal pain management is inadequate assessment.<sup>11,16</sup> For example, some nurses rely on their own observations rather than directly ask patients to describe their pain.<sup>11</sup> This approach does not allow nurses to adequately assess a patient’s “total pain” because there is no consideration of the patient’s perspective or spiritual, psychological, and social aspects.

Pain is one of the most common and distressing symptoms for palliative patients and their families.<sup>1,10,17,18</sup> The complexity of treating patients with “total pain” is often compounded by the patients’ inability to distinguish exactly which component is causing pain, because all they can express is that “they just hurt.”<sup>19</sup> Patients may not be capable of expressing or even demonstrating an awareness of the fact that the pain they are experiencing is a result of a combination of factors. For example, pain manifested physically can be caused by the combination of a child not visiting, a despondent feeling that “God has left me,” and a bed sore developed during hospitalization. Storey<sup>19</sup> demonstrated in one example how pain in one man could not be controlled until he was reassured that his son would be taken care of after his death. He further highlighted that spiritual concerns also can result in nonresponsiveness to pain medication because it is a “very real component of their pain.”<sup>19(p46)</sup> These examples demonstrate the “total pain” experience, in which effective pain relief follows the acknowledgment and management of the physical, psychological, social, and spiritual dimensions.

### Current Pain Theory

The International Association for the Study of Pain (IASP) defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage.<sup>20</sup> Pain is a subjective perception. Pain is what the patient says it is.<sup>9,20,21</sup> The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment. The central idea of “total pain” being defined by physical, psychological, social, and spiritual aspects is consistent with other current theories of pain. Melzack and Wall’s gate-control theory emphasizes that gating or input modulation by emotions and cognitions determines the pain experience of the individual.<sup>22</sup> Pain is considered a complex perceptual and affective experience determined by attention, anxiety, suggestion, other psychological



variables, past experiences of pain, the meaning of each stimulus, the state of mind of the person at the moment of pain, and the sensory nerve patterns evoked by the physical stimulation.<sup>23</sup> Cohen and Boisvert<sup>24</sup> and Cohen and Mount<sup>25</sup> have described numerous factors, including those related to psychological, social, spiritual, and financial aspects, that contribute to the pain experience for palliative cancer patients. They further state that the interaction of these important variables leads to a more complete understanding of the pain experience. The understanding of pain necessarily includes an assessment of all the factors that contribute to the patient's pain experience and not solely the underlying physical trigger.

The theoretical concept of "total pain" is well accepted in the palliative care literature. For example, Montes-Sandoval<sup>26</sup> and Al-Shahri et al<sup>27</sup> recognized pain from a holistic perspective. Breitbart<sup>9</sup> and Strang<sup>28</sup> described pain in cancer patients as multidimensional by nature. Allard and colleagues<sup>29</sup> mentioned the consequences of pain on physical, social, and spiritual functioning of patients, suggesting there may also be a bidirectional influence between these dimensions. Foley<sup>30</sup> discussed cancer as a chronic disease that requires social, psychological, and spiritual support. Easley and Elliot<sup>31</sup> described unrelenting pain at the EOL that extends beyond the physical realm into the psychological, social, and spiritual ones. The idea that pain at the EOL involves a consideration of the physical, psychological, social, and spiritual aspects is acknowledged, yet the physical determinants of pain often remain a predominant focus in clinical practice.

### The Nature of "Total Pain" in Advanced Cancer

One of the reasons that the conceptualization of pain as "total pain" may not be common in clinical practice is the confusion between the terms "total pain" and "total suffering."<sup>32(p242)</sup> The concept of "total pain" may not completely reconcile with the IASP definition of pain, mainly because it is unclear whether "total pain" "refers to pain or to other forms of suffering." As Harlos and MacDonald pointed out, however, "some patients may be more comfortable using physical pain terminology to describe their suffering."<sup>33(p20)</sup> It is important to respect the language or terminology that patients choose to use when describing their experience.

Clinical assessments that are confined to definitions of pain resulting from real or potential tissue damage

emphasize an acute physical focus of pain. This vision of pain does not adequately capture the chronic nature of palliative pain,<sup>20,26</sup> nor does it recognize the full spectrum of factors that can influence the severity, intensity, or duration of the pain experience. Cancer pain is distinguished from other types of pain that result from other illnesses because of its unpredictable course, which can vary dramatically in severity and duration, depending on the type of treatment and disease progression. Most patients with advanced cancer also report more than one type of pain,<sup>38</sup> which means that although patients may present initially with an acute episode of pain, it can progress to be acute and chronic in an unpredictable way.<sup>28,34</sup> As the cancer trajectory leads toward death, the pain may become an omnipresent phenomenon. Saunders<sup>35</sup> highlighted the chronicity of cancer pain by referring to terminal pain not just as a series of events but rather a situation in which the patient is held captive.

Cancer pain is unique because it can arise from various causes. Aside from the physical causes of pain resulting from (1) the tumor pressing on organs, nerves, or bones, (2) anticancer treatments, such as surgery, chemotherapy, or radiation therapy, (3) debility, and (4) benign causes,<sup>36</sup> cancer pain also can be triggered by experiences that are not physical in nature, as evidenced by the model case presented later. For example, the importance of the spiritual aspect of pain is often overlooked in clinical assessments. Spiritual distress is recognized in physical and psychological symptoms, disorders of relationships, and specifically spiritual symptoms.<sup>37</sup> The sociocultural aspect, as evidenced in the model case of Mr. Y presented later, refers to the influence of culture and society to which the patient belongs that color his "expression" of injury. Pain also should be addressed in terms of the impact it has on the family and carers of the patient, making it an important part of any pain definition. In fact, social problems such as their concerns relating to their loved ones often can actually intensify a patient's experience of pain.<sup>36,37</sup> These points are crucial to any assessment of pain with a palliative patient, because concerns of leaving a loved one behind are prevalent among their thoughts of impending death. Similarly, the search for meaning, the search for purpose, or anger at God also may influence their pain.

It is evident that palliative patients with cancer undergo a different pain experience altogether. It is for this reason that the concept of "total pain" is suggested as the most relevant to the palliative population. The



following case study illustrates a patient's experience of "total pain" and demonstrates the usefulness of this concept in treating advanced cancer pain.

### ❖ MODEL CASE

Mr. Y (whose name and other possible personal identifying characteristics have been altered slightly to ensure confidentiality) was a 68-year-old accountant of Arabic descent. He was diagnosed with lung cancer that had metastasized to his liver and his bones. The pain in his bones was even greater during mobilization, with his legs and back being the primary area of discomfort. He needed oxygen to breathe, and with each day his breathing became more of a struggle. He was receiving slow-releasing oral morphine with additional morphine injected via a subcutaneous butterfly for breakthrough relief. He had two daughters aged 12 and 16. His wife had been killed in a car accident 5 years ago, and he had—with the help of his younger sister—dedicated himself to his daughters. All three were a constant presence, spending the night in the family room on the medical unit. He had been flown to New York twice to try an experimental treatment, which had proved unsuccessful. At first, he would state he was in constant discomfort, describing "stabbing, deep pain" somewhere in his chest. He rated it 5 on a scale of 0 to 5. He would moan softly while awake or asleep. His face was constantly contorted in a grimace. After being placed on a morphine drip, the nonverbal cues diminished. However, when asked about his pain, he asked, "Why does it hurt so much?" Interestingly enough, he also stated that "the pain in [his] chest was gone." Yet his pain rating was still a 5. When the nurse probed further, he stated that "it hurt to have to leave [his] girls." Although his sister had helped raise them, he felt a terrible guilt leaving her the responsibility of raising, schooling, and eventually marrying off the two girls. He expressed feelings of despair regarding his helplessness, saying, "I am a useless old man now."

The nurses gently suggested a family meeting to Mr. Y. It was presented as a forum for him to express his feelings to his family and an opportunity for them to share their thoughts and fears with him. A meeting held with staff from social work, medicine, psychology, and nursing enabled the family to voice what they had thought they would not be able to. Mr. Y said he was sorry he was deserting them and was pleasantly shocked to realize it was they who felt guilt at not

being able to help enough. The sister also stated it was not just her duty but also a pleasure to care for her nieces. Furthermore, the two daughters told him he would never be forgotten. Finally, he was angry. He realized his prognosis was poor, yet he was willing to do anything and pay anything to find a way to save himself and prevent his family from losing him. Nothing was successful, and he became increasingly afraid of death. The more pain he was in, the closer to death he believed he was. He would often mumble in Arabic, telling the nurses he was cursing Allah, saying, "He promises heaven after my death, but my heaven is here."

### ❖ DISCUSSION OF THE MODEL CASE

Mr. Y's story demonstrates the need for healthcare professionals to assess and address a person's "total pain" to appropriately care for them. Along with the obvious physical dimension of pain, this patient was suffering socially, psychologically, and spiritually. His physical pain was treated pharmacologically. Once it had been assessed that the slow-release oral morphine and breakthrough injections were not adequate, a subcutaneous continuous infusion of morphine was started. This worked well for the physical aspect for a short period of time.

Psychological stressors also contributed to the patient's "total pain." In this case, psychological pain was defined by Mr. Y's feelings of anxiety, fear, guilt, and anger. Further evidence of psychological pain can sometimes be expressed as reactions that may include numbness, disbelief, and anger.<sup>39</sup> For example, Mr. Y's anger was a source of psychological pain and contributed to his overall anguish about his situation. The psychological component of "total pain" also has been referred to as the emotional component.<sup>9</sup> Research has found that such emotions, particularly fear, can actually lower the pain threshold.<sup>40</sup> His constant preoccupation with what would become of his family, his fear of dying, and the guilt he felt in abandoning his daughters the way "their mother had" preyed on his peace of mind. In response to this, the nurse always set aside time to sit at his bedside and listen attentively to his concerns. Despite the family wanting to always be there, they welcomed the chance to leave for a short time while Mr. Y and his nurse talked. A psychologist was also consulted and worked with Mr. Y to help him deal with his anger and guilt.

Although his pain did initially seem to subside (3 on the pain scale of 0-5) with the change in his medication regimen, it continued to fluctuate. He was still unable to sleep at night and was unsure if he would wake up. He always said: “[he] had too much on his mind.” Although he did not display any outward signs of discomfort and pain, he continued to say he still hurt. Through further exploration, the other reasons for his pain were revealed. This shows the importance of the role healthcare providers have in the acceptance of the emotional component of pain.<sup>39</sup>

The social aspect of pain is also much present here. In this case, Mr. Y and his family were extremely close. His social pain is defined by the discomfort or unease caused by the thoughts of harm, pain, or distress to his family. It is for this reason that family and carers need to be included in the social perspective of assessing total pain.<sup>41</sup> Twycross<sup>42</sup> asserted that worries about the family can adversely affect a patient’s perception of “total pain.” As the family’s breadwinner and head of the household, the change in role from provider to patient was particularly distressing for him given the social expectations from his cultural background. Howard<sup>39</sup> noted that this was not uncommon. Many patients find it difficult to cope with a change or loss of a role. In this case, the meeting among Mr. Y, his family, and the interdisciplinary team lifted an incredible burden from the patient and his family. By opening the lines of communication, the healthcare team helped to bring together the patient and the family so that they could face his death together as a family. This case illustrates the idea or shows that it is impossible to “treat physical pain without considering the emotional and social impact of the illness on the patient and the family.”<sup>39(p35)</sup> Similarly, Hanson and Cullihall<sup>13</sup> feel that the concept of “total pain” must be adopted by the nurse and that “open communication with the patient, family and other members of the palliative team” is crucial.

Finally, Mr. Y had begun to question his faith. This was evidence of his spiritual distress, which may have contributed to his pain. Greenstreet<sup>40</sup> stated that one must take care not to equate spiritual suffering with religion. She noted that it is much broader in that it examines the needs of the human spirit. It is not uncommon for “the psycho-spiritual suffering of patients with advanced cancer to heighten the distress associated with physical symptoms.”<sup>27(p307)</sup> Spiritual pain is difficult to capture in words.<sup>37</sup> Spirit “is beyond definition” but can be recognized in any physical or

psychological symptoms, disorders of relationships, and specifically spiritual symptoms (meaningless, anguish, duality, and darkness). In the case of Mr. Y, we can define it as any discomfort or unease resulting from the questioning of his existence, the search for a deeper understanding of the situation, or the threat of his existing belief or value system.

This patient had lost hope in a cure yet had not accepted his death fully. He was unclear of his purpose in life now that he felt he had lost his role of head of the family. Saunders<sup>43</sup> stated that the essence of spiritual pain involves a feeling of meaninglessness and a bitter anger at the unfairness at what is happening at the end of life. The healthcare providers were able to successfully influence this spiritual aspect as well. Hope was reframed from being the hope of a cure to the hope for a peaceful, painless death with his family present. In fact, the mere presence of a nurse or simply “being there” can have a great impact on this type of pain.<sup>40</sup>

The interaction among the psychological, social, physical, and spiritual pain dimensions was evident in Mr. Y’s descriptions of his pain. This complex interplay is illustrated in Figure 1. For example, his loss of hope had both a spiritual and psychological dimension to it. Similarly, when he was in physical pain, one meaning he attributed to it was that of his own impending death. It was a verification of his mortality, a manifestation of spiritual pain. The social pain he felt as a result of the fact he would be “abandoning” his family upset him terribly. This feeling interacted with his psychological pain and resulted in anxiety that kept him up at night

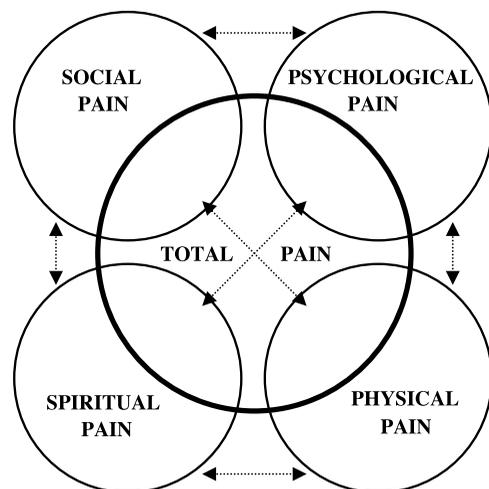


Figure 1. The total pain experience: an interactive model.



with worry. It is important to note that although not all patients experience all the components of the concept of “total pain,” the comprehensive and effective treatment of pain includes the complete assessment of these domains.

As Figure 1 shows, the different aspects of “total pain” may or may not necessarily manifest as physical pain. For example, his psychological pain caused him to state that he “still hurt,” although he was not describing any physical signs of discomfort. At times, Mr. Y continued to describe his pain as a 5 on the pain scale because he was unable to stop the psychological torment he experienced as he thought of his family. In this case, the social and psychological aspects of his pain seemed to be more important contributors to “total pain” than physical aspects.

### ❖ NURSING IMPLICATIONS FOR CLINICAL PRACTICE

This case study highlights the fact that pain assessment must include aspects that go beyond the mere physical triggers and manifestations of pain. A clinician’s understanding of “total pain” is a necessary prerequisite for effective pain management at the EOL. The treatment of only physical symptoms without a proper exploration of the other dimensions of the patient’s experience results in an incomplete and often inappropriate pain regimen. This would have been the case with Mr. Y had the assessment and intervention for his pain prematurely stopped with the outward signs of pain. The interacting issues related to his family, his spiritual angst, and his own fears and anxiety had to be understood and acknowledged, which in turn strongly influenced his physical pain and even at times manifested as physical discomfort. This knowledge allowed for appropriate treatment and the subsequent alleviation of Mr. Y’s pain.

In this case study, one of the main interventions was to hold a family meeting with all of the available family members along with the nursing, medical, social work, and psychology staff. In palliative care, the family meeting can be an effective way to allow for all members of the family to be heard and understood, allow for observations of relationships among family members, and provide a forum to voice and acknowledge feelings.<sup>44,45</sup> In Mr. Y’s case, the family meeting was crucial for validating or dispelling beliefs that contributed to his psychological, spiritual, and social

pain. Members of the family were also able to express their own feelings and worries and support one another. In this way, when one family member was reassured, it influenced the pain of another, which demonstrated the importance of understanding the social aspects of pain.

Communication was an essential intervention. With the assessment of “total pain,” the fact that Mr. Y was in great need of psychological support became evident. As a result, the nurses were able to provide appropriate interventions, such as active listening at his bedside and the family meeting, to address and discuss his fears and concerns. The provision of psychological support for patients and families confronted with a life-threatening illness is one that is often overlooked<sup>46</sup> and can be even more undermined when physical pain becomes the main focus of treatment plan.

### ❖ CONCLUSION

Pain control is a central component of symptom management for many patients at the EOL. Nurses have the unique opportunity to care for these patients at this time. As a result, these nurses have the responsibility of pain management. The assessment of pain is a critical part of this pain management. Without a clear conceptualization of pain for the palliative cancer patient population, it becomes difficult to assess patients’ pain appropriately. Understanding that people experience “total pain” is critical for nurses and other healthcare professionals. The pain caused by physical, psychological, social, and spiritual causes may contribute to the patient’s pain experience. Without a complete and thorough assessment of these dimensions, an accurate picture of the patient’s situation cannot be obtained. The case study highlighted the need for “total pain” to serve as the basis for pain assessment in order to intervene successfully. Ultimately, whether patients report pain, hurting, or suffering, it is important to assess these experiences through a multidimensional lens that allows for the appreciation of all possible causes and influences. In this way, nurses are in a better position to understand the pain experience and provide optimal pain management at the EOL.

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