

Special Edition
**"Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"**

Mini Review

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Holistic Total Pain Management in Palliative Care: Cultural and Global Considerations

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ABSTRACT

Pain is a significant symptom in patients with chronic and life-threatening illness. While pain is traditionally thought of as a physiological experience, total pain recognizes the interplay of psychological, cognitive, social, spiritual, and cultural factors that influence the pain perception and total experience. Comprehensive pain assessment and management are foundational goals within the scope of palliative care, and optimal management depends on addressing each domain of the total pain experience. An overview of the total pain experience is provided, and clinicians should consider psychological, cognitive, social, spiritual, and cultural aspects in assessing pain. Pain management also addresses all domains, and suggestions are provided which address pain management barriers and challenges. First, patients should be educated about the benefits of pain management and importance to adhere to the plan of care. Second, healthcare professionals need education in order to manage pain properly and should adhere to internationally recognized evidence-based guidelines to provide care. Third, barriers to overcome system issues need to be addressed, such as working with governments and Ministries of Health to increase opioid availability for those in need and to ensure that patients can have access to opioids whether in the hospital, home, city, or rural area. While pain is a complex phenomenon, a comprehensive management plan can alleviate suffering for patients and their families.

KEY WORDS: Total pain; Holistic; Palliative care; Culture; Opioid availability.

INTRODUCTION

Palliative care encompasses the physical, psychological, social, spiritual, and cultural domains of patients and their caregivers.¹ Physical symptoms can be problematic when they occur as patients have difficulty focusing on other quality of life (QoL) issues. Pain is one of the most common and problematic symptoms that occurs in conjunction with chronic and advanced illness and requires specific attention. Incorporating comprehensive pain services into any palliative program is paramount.² This review will address the multitude of culturally relevant challenges in implementing pain management services into a palliative care program. The holistic components of pain and their influences on the pain assessment and management plan, and pain assessment and management barriers will be discussed.

TOTAL PAIN

Total pain is a holistic experience that extends beyond the physiological domain and was first introduced by Dame Cicely Saunders in the 1960's. Total pain recognizes the holistic nature of pain and the interplay of psychological and social well-being, spirituality, and culture. Symptoms rarely occur in isolation; rather, they cluster with other symptoms and are influenced by the psychological, social, and cultural characteristics of the individual. These holistic aspects of pain are discussed in the following section.

PHYSICAL PAIN

According to the International Association for the Study of Pain, pain is "an unpleasant sen-

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sory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.” While physical pain is the physiological component, this definition emphasizes the importance of the physical impact on the entire person.³ Other deleterious physical symptoms can occur in conjunction with pain. The most common of these is fatigue.⁴ Dyspnea, drowsiness, sleep disturbance, nausea, and loss of appetite are other physical symptoms that need to be assessed when an individual is experiencing pain.⁵⁻⁷ Depression is a common problem that also co-occurs with pain. Current research is focusing on underlying mechanisms that may be responsible for co-occurring symptoms, also known as symptom clusters. Most importantly, clinicians should recognize that pain may contribute to other symptoms; thereby, managing pain may eliminate other symptoms as well.

PSYCHOLOGICAL PAIN

Emotional distress, depression, anxiety, uncertainty, and hopelessness are all forms of psychological pain that can co-occur with physical pain with depression being one of the most common psychological symptoms.⁸ One systematic review indicated that the co-occurrence of pain and depression is approximately 36.5%. The more intense the pain was, the more likely the individual was to be depressed ($p < 0.05$). Patients with depression may use more affective words to describe pain such as *fearful*. QoL has also been shown to be worse in those with both pain and depression.⁹ Depression is also found to be a significant barrier to manage pain, underscoring the importance of managing depression in order to improve pain.¹⁰

According to the National Comprehensive Cancer Network, distress is an “unpleasant experience of a mental, physical, social, or spiritual nature.” It can affect the way an individual thinks, feels, or acts and can make coping more difficult.¹¹ Distress should be screened for each patient visit. While pain can be a reason for the distress, other reasons should also be noted as all factors can increase the occurrence and severity of the pain experience.^{12,13} In one study, concurrent physical symptoms and psychosocial distress occurred in patients attending a cancer pain clinic compared to those who did not attend the pain clinic.¹⁴ Clinicians should recognize that pain and distress commonly co-occur.

COGNITIVE-BEHAVIORAL INFLUENCES

Cognitive-behavioral responses to pain are additional components of holistic total pain. One cognitive response could be the patient’s failure to acknowledge the pain for fear that this represents progressive disease. Other patients may feel the need to *tough* and endure the pain. This cognitive denial of pain, which could be stemmed from cultural or spiritual beliefs, can interfere with optimal management. The cognitive-behavioral domain can also be positively used to address overall pain. Cognitive behavioral therapy that can be used to ameliorate pain in some patients includes building self-esteem, optimism, and mastery of pain control.¹⁵

Catastrophizing is another recognized cognitive trait associated with pain. Patients who exhibit this behavior ruminate or exaggerate their pain, and catastrophizing is commonly linked to depression.¹⁶ Cognitive-behavioral approaches should be considered in the overall pain management plan.

SOCIAL INFLUENCES

The social context of cancer pain is well-recognized. Pain can lead to social isolation, disengagement from meals and other activities, caregiver burden, and inability to afford analgesics to control the pain. Adequate social support is predictive of less distress, depression, and anxiety.¹⁷ The National Comprehensive Cancer Network (NCCN) Distress thermometer includes measurement related to social distress. Again, distress assessment should be incorporated into daily practice. When social distress is detected, psychosocial interventions, including education and coping-skills training may be useful adjuncts to medical management of pain.

SPIRITUAL AND RELIGIOUS INFLUENCES

Spirituality, defined as the need to be connected to a higher power, has a significant association with pain. Religion, on the other hand, includes the practices associated with an organized system. Spiritual and religious influences of pain may vary by religion and even by individual belief within a religion. For example, some patients may feel that God is punishing them, and that their reward in heaven will be greater if they endure pain. In the Muslim faith, some patients feel that pain is considered a punishment from God; however, Islamic teachings report differently.¹⁸ Spiritual and religious beliefs can therefore, be misperceived and influence how an individual perceives the pain and manages the pain. Often a religious leader or chaplain can explore spiritual and religious questions with patients individually, which can add to the overall pain management plan.

Hope is a concept commonly associated with spirituality and is an important component of most religious faiths. Studies reveal hope to be positively correlated with spiritual well-being ($p < 0.01$) and negatively correlated with average pain intensity ($p = 0.02$), worst pain intensity ($p < 0.01$), pain interference with function ($p < 0.05$), anxiety ($p < 0.01$), and depression ($p < 0.01$). Depression especially influenced this relationship, which reinforces the need to manage pain in a holistic manner.¹⁹

CULTURAL INFLUENCES

Pain expression is an individualized experience, which is influenced by culture or ethnicity. It can represent the individual’s conceptual meaning of pain, pain perception, and coping abilities. One systematic review found that some ethnic groups expressed more severe pain. Asians tended to normalize pain whereas westerners were more likely to seek help for their pain.²⁰ A second recent systematic review of 26 studies compared pain responses of African Americans (AA) to non-Hispanic Whites (NHW) and found AAs demonstrated lower pain tolerance.²¹

Another large meta-analysis of 22 studies found Asian patients to have more pain barriers compared to Western patients such as concerns about cancer progression, drug tolerance, fatalism, and pain management barriers.²² This could provide rationale for why Asians may try to normalize pain.

Overall, patients from some ethnic or cultural groups may have difficulty in communicating with their care-providers about pain.²³ Providers as well may have barriers toward patients who are ethnically or racially different than themselves. For example, in one study, Western Caucasian physicians were noted to underestimate pain in 75% of AAs and 64% of Hispanics.²⁴ These patients also reported suboptimal pain management. These overall differences underscore the need for a patient-centered approach for the management of pain.

PAIN MANAGEMENT BARRIERS

The holistic components of pain can strongly influence the individual pain experience. These influences can contribute to some of the major barriers that interfere with optimal pain management in many regions around the world. Pain assessment and management barriers commonly occur in most cultures and involve three levels: 1) patient and caregiver, 2) healthcare professional, and 3) systems. Sadly, these barriers have existed for

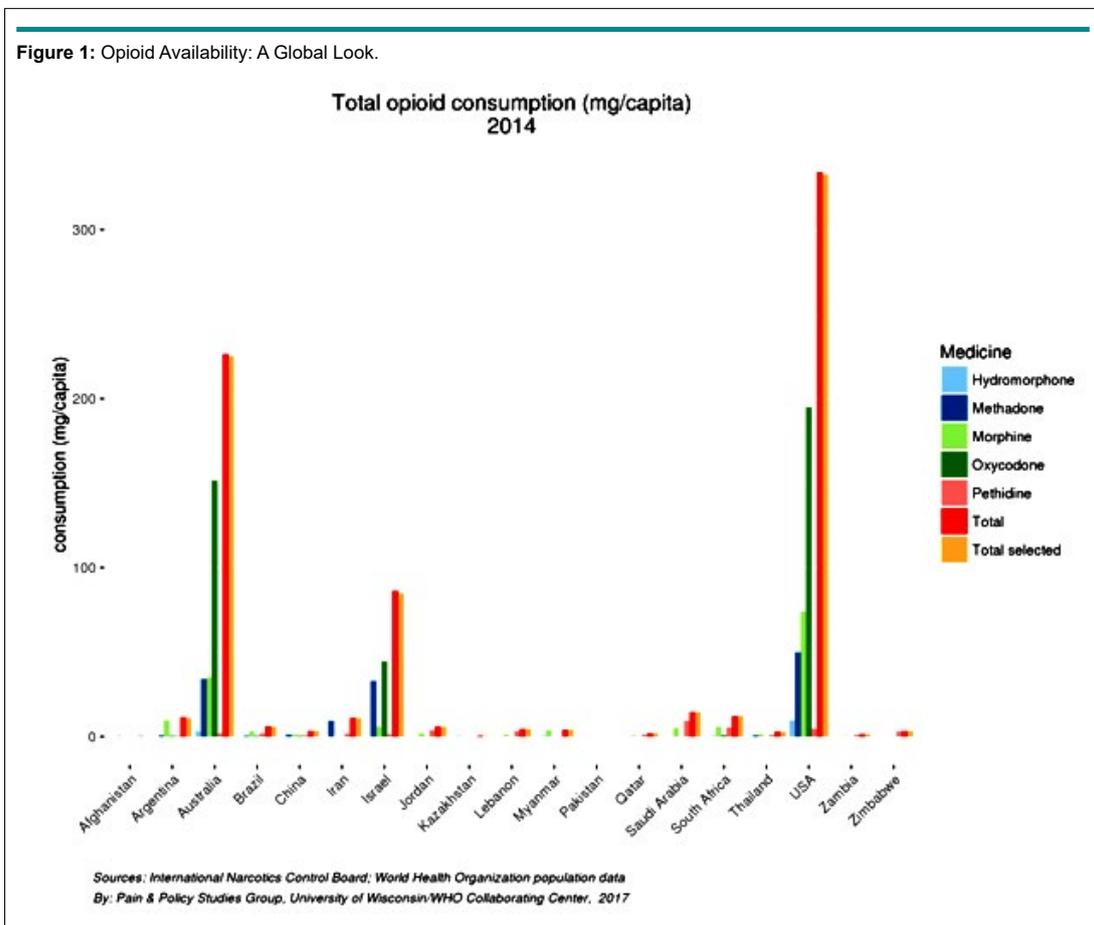
more than 20 years and have not been adequately addressed.

For patients and caregivers, stoicism, failure to report pain, and fear about addiction are common barriers. For health care professionals, failure to consistently assess pain, lack of knowledge about pain management strategies, fears of addiction and beliefs that pain is an inevitable component of cancer are common problems. When supportive care services are available for pain and symptom management, many patients may not even know they exist, because physicians and other professionals may not consistently refer patients to these services.^{25,26} In regards to systems, opioids and other management options may not be fully available in some countries. Opioid use outside of Western societies is minuscule in most of the world (Figure 1). Tight regulations through the governmental agencies such as the Ministry of Health can be a barrier for optimal pain management.²⁷ Additional efforts that address these barriers are imperative to achieve meaningful progress.²⁸

INTERVENTIONS TO ADDRESS BARRIERS

Multiple efforts to address pain management barriers are occurring around the globe. Education for all stakeholders is important to overcome both knowledge and attitude barriers. Education, guideline adherence, medication coaching, and addressing

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fears of addiction and substance use disorders are all potential solutions for improving pain management quality.

PATIENTS AND CAREGIVERS

Educational Approaches

Educational efforts are occurring worldwide. The Middle Eastern Cancer Consortium has played a role to provide pain management education throughout the Middle East for the past two decades.^{27,29} Palliative care education includes the management of pain has also been instrumental in that same region.² Education includes conducting a comprehensive pain assessment and employing optimal management strategies for pain relief. Discussions should also ensue about belief systems regarding pain and fears of addiction which can assist to bridge the gap between suffering and comfort. Two systematic reviews (21 trials) and meta-analyses (15 trials included in one meta-analysis, 26 in another) found that education for patients, caregivers, and healthcare professionals can decrease pain intensity,³⁰⁻³² and the greater the dose of the educational intervention, the better the pain outcomes.³¹ In regards to patient education, repeated face-to-face interactions seem to be the most effective compared to written information.³³ When education is consistently delivered, sustained pain improvements have been demonstrated over time. Healthcare professionals should include pain education in daily care.³²

Education plays an important role in the overall management of pain. More studies and educational models should be proposed to suggest how best to implement educational interventions within the scope of care and to determine the combina-

tion of interventions that is most beneficial and cost-effective for patients and healthcare systems.³⁴

Analgesic Self-Management

One of the biggest patient level barriers is not following the pain management plan of care. Both patients and caregivers can influence the self-management plan. Common reasons for not following the plan are fear of addiction, forgetfulness, and untoward side effects. Studies found that analgesic adherence ranges from 49% to 91% for long acting opioids and as low as 20% for as needed pro re nata (PRN) opioids.³⁵⁻³⁷ Depression and older age were found to be predictors of not following the pain management plan in one study. Additionally, patients were unsure about what their exact medication regimen was comprised of and therefore, it was not followed.³⁶ Reasons for lack of self-management should be carefully assessed with patients and caregivers. Education about addiction, the importance of comfort, and clear instructions about the pain management plan should be provided. The overall message should not be paternalistic but rather coaching and collaborative.³⁸

HEALTH CARE PROFESSIONALS

Education

Not believing the patient’s report of pain is a significant barrier that can significantly impact the quality of pain management.³⁹ Health care professionals should have a therapeutic relationship with the patient, and listen carefully to the patient’s report of pain. While substance use disorders and addiction exist, the undermanagement of pain in palliative care patients is substantial

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Table 1: Pain Terms to Know Data from American Pain Society, 2008; Federation of State Medical Boards of the United States, 2013; International Association of the Study of Pain; 2014.

Aberrant Behavior	Behaviors indicative of prescription drug abuse, some of which are more indicative of abuse or addiction.
Abuse	Use of a drug for nontherapeutic purposes to obtain psychotropic effects.
Addiction	A primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.
Diversion	Unlawful channeling of pharmaceuticals from legal sources to the illegal marketplace.
Illicit Substance	A substance that is not legally permitted or authorized.
Misuse	Use of a prescription drug without a prescription or in a manner that is not prescribed.
Narcotic	An archaic term for an opioid analgesic; currently the term is used by law enforcement to describe illicit substances with a potential for abuse such as heroin, cocaine, or methamphetamine.
Opioid	A medication that exerts its primary pharmacologic response by its binding to the opioid receptors in the central nervous system (CNS). This term is preferred to the term "narcotic".
Physical Dependence	A state of adaptation manifested by a drug class specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist.
Pseudoaddiction	Pattern of drug-seeking behavior in patients with pain who are receiving inadequate pain management; can be mistaken for addiction.
Tampering	Manipulating a pharmaceutical to change its drug delivery performance.
Tolerance	A state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug’s effects over time.

and professionals should advocate for better pain relief in their regions.⁴⁰ Understanding the differences between addiction, tolerance, and physical dependence, and understanding the differences of addiction and other high risk behaviors is the first step in overcoming this knowledge gap. A list of terms is included in Table 1.^{3,41,42} When clinicians have this knowledge, they can then educate patients and caregivers which will decrease some of the overall fears of addiction, especially in palliative and end-of-life care. Education has been shown to improve attitudes about pain.⁴³ Finally, education is important in improving health care professional knowledge and opioids, which opioids to prescribe, and co-analgesics that can improve overall comfort. Pain management is both an art and a science and requires specific education. Clinical guidelines are one way to educate clinicians and ensure that all patients receive consistent, quality pain management.

Clinical Practice Guideline Adherence. While a plethora of guidelines exist to assist clinicians in managing pain,^{41,44,45} studies reveal that only 22% to 45% of clinicians use a pain guideline.^{26,46} Some efforts are underway to encourage clinicians to use practice guidelines. In one study setting, nurse practitioners received weekly feedback on patient pain scores and how consistent their recommended interventions aligned with clinical guidelines. This audit and feedback intervention resulted in significantly less overall pain interference and interference with general activity and sleep. Satisfaction with pain relief increased significantly from 68.4% to 95.1%.⁴⁷ Environments and staff culture are important considerations prior to implementing evidence-based guidelines.⁴⁸ Electronic reminders and tools to translate guidelines into practice are additional strategies, but further work is needed in this area.⁴⁹

HEALTHCARE SYSTEMS

Healthcare systems around the world can interfere with quality pain management. Laws regarding who can prescribe opioids, which opioids are available, and access issues, especially for rural populations can significantly influence care. One of the most important systems issues is opioid availability, which is further discussed below.

Opioid Availability

Opioids are the mainstay of pain management, and yet opioids are not widely available in many countries. Opioids are usually regulated by each country's government, often the Ministry of Health (MOH). Historical problems with opioid addiction, other fears, and current use influence the amounts of opioids allotted in each country. Economics play an additional role. Some of the poorest countries in the world are often found to have the lowest opioid amounts per capita.⁵⁰ A recent analysis of global morphine consumption found significant disparity between high and low-income countries. Overall, 21% of the world's population (high income) consumed 92% of the total global morphine. And yet the majority of cancer deaths (70%) occur in low to middle

income countries (LMICs),^{51,52} demonstrating a desperate need to increase opioid availability and pain management efforts in these countries. However, richer nations can also have restrictions on opioids, and so each country should be individually assessed. Figure 1 includes opioid availability comparisons for a variety of countries around the world. To note is the high consumption of Western countries versus those in other parts of the world. Turkey has recently opened a morphine production plant, hoping to increase the availability of opioids in Middle East. Nurses and other health care professionals are meeting with their MOH to try and increase opioids in their respective regions in order to improve pain management in palliative care patients.

SUMMARY

A number of challenges interfere with quality pain management for palliative care patients. Understanding the holistic experience of pain is the first step in addressing the physical, emotional, social, spiritual, and cultural components of the pain experience. Once holistic total pain is embraced, addressing barriers is imperative to improve pain management efforts. Patient and caregiver related barriers, clinician barriers, and systems barriers.

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