



Pain and the Patient Experience

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Abstract

With the continuing opioid epidemic, there is an urgent call for alternatives to narcotics and other addictive medications. Historically, pain theories have moved through the many stages of medicine, predating the scientific method and following through past Descartes declaration that the mind and the body do not influence each other. This article reviews pain theories and practices moving into the era of the Patient Experience, multi-modal strategies for mitigating suffering, and the impact of the patient's environment and social/cultural milieu informing and supporting the patient's own capacity to cope and manage pain. Methods: A broad review was done of studies and critiques that bring together the historic and current attitudes and beliefs about pain, social-ethnic-racial assumptions, to evaluate the state of pain management as medication-driven solutions begin to fail as first options. In addition, the dominant role of mean-making and caregiver beliefs is discussed as they become more relevant in seeking alternatives to opioids. Conclusion: I). The debate regarding what exactly pain is continues to be between the physical or biochemical domain and the mental-emotional-cognitive domain that brings meaning to the experience. II) The Patient Experience of pain is lived rather than theorized, and is known fully only by the patient and is a private experience informed by the unique circumstances and history of each patient. III) The merging of neurological and psychological factors in pain management is well documented but not optimized in strategizing effective pain control methods. IV) Additional studies are needed to better understand the balance between psychological-social-and-clinical factors to arrive at more effective strategic processes in pain reduction.

Keywords: patient experience, pain management, placebo and nocebo response, the meaning response, biopsychosocial factors in pain management, distraction therapy

Introduction

Today, in the 21st Century, pain remains as much a human mystery as it did when the ancient Greek philosopher Aristotle proclaimed that pain was not physical, but emotional. It is such a deeply private experience, that language is often inadequate in being able to accurately describe pain. Even physiologist Max von Frey's detailed Specificity Theory, which hypothesized in 1895 that every organ has its own pain cue and every pain can be assigned to a place on the human body, made it no easier for caregivers to figure out how to relieve suffering (Moayedhi & Davis, 2012).

Since the advancement of pharmacological pain relief, the use of drugs has become the overwhelming preference for pain management. However, the challenge of understanding and prescribing alternative to opioids, including complimentary therapies, has yet to be fully integrated into practice in the U.S. and many parts of the world. Right now, "alternative" tends to translate into lower or controlled dosage, which is not always effective for what patients need. In their effort to understand pain mechanisms, psychologist Ronald Melzack and neuroscientist Patrick Wall (1965) observed that some patients with little injury suffered from extraordinary pain and others with extensive damage suffered little. This led to the Gate Control Theory, where patients' capacities to modulate their pain were based on their experience as well as genetic makeup. Shortly thereafter, Melzack with Kenneth Casey (1969) expanded Gate Control Theory to identify three distinct factors in the experience of pain. These include the somatic, or sensation of pain, the perception of pleasantness or unpleasantness (which can lead to the fight or flight response), followed by "appraisal, cultural values, context, and cognitive state." These steps influence each other and, together, motivate

patients' coping skills. More than medication, the emotional and cognitive power of perception and meaning making together with directed attention, becomes the mechanism for patients to actively participate in their own pain management.

The Meaning Response

Melzack and Wall (1965) first identified the role of meaning in the experience of pain. However, in recent years, the issue of patient perception has taken a prominent place in the literature. Traced to neurological activity, this has put the focus on the whole patient in terms of physical, emotional, mental, and cognitive capacity. The meaning response, often referred to as the placebo effect, provides a real-time example of the role of belief and meaning. Medical anthropologist Daniel Moerman (2002) points to the meaning response as physiologic or psychological effects of meaning in the origins, treatment, and recovery of illness (2002). He also calls the meaning response an autonomous response, one generated within and by the patient's own powers to heal. The role of placebo, which is traditionally used as a sham inert medical substance presented to a patient as an actual medication to cure or treat some condition. Randomized control trials have been the primary users of placebos. However, the question was limited to whether the testing medication would prove more effective than subjective expectations of the patient (Johnson, 2005). According to Colloca and Grillon (2014) Placebo analgesia relieves pain "simply by virtue of the anticipation of a benefit." A review of clinical trials using a placebo (Meissner et al., 2007) suggest that placebos mimic the action of active treatments and effect measurable change in health status, not merely symptoms. Social support and observational learning also lead to analgesic effects. This is not to imply that acute or severe pain does not require medication for relief. Rather, it suggests that the patient's mind can

modulate the pain and increase (or decrease) the effectiveness and needed dosage using methods that are not pharmaceutical. Patients' pain is their reality, defined not by their diagnosis or prognosis, but rather their experience. Furthermore, the visceral nature of pain takes on the meaning the patient imparts to it in the moment. A positive response to a placebo is not caused by the substance, but rather is generated by the patient's own belief, experience, and expectations. In addition, it is the support and encouragement of the caregivers, including physicians and others, that enhance the effectiveness of all treatments, including those related to patients' powers to heal. A 2015 study published in the journal *Pain* indicated that between 1990 and 2013, the placebo effect was shown to increase while the effectiveness of drugs had diminished, putting into question whether pharmaceutical solutions are the best solution for pain (Tuttle et al., 2015).

Hidden Factors of Culture and Gender

The inequality that exists in pain treatment between white, middle-income patients and those belonging to ethnic minorities, such as Hispanics and Asians, has been well acknowledged (Mossey, 2011). The reasons behind this discrepancy are complex. However, social and ethnic influences may inform patients' willingness to report pain, request help or medication, and ultimately, make public any level of discomfort.

Gender differences also play a significant role in determining the perception and expectations around pain, as well as the effectiveness of pain management. Greenspan et al. (2007) concluded that, "psychological and social variables powerfully influence pain and can often explain more the variance associated with pain than do biological variables." The same is true of gender roles in respective expectations and obligations of men and women. This impacts self-report of pain,

medication use, and prognosis in dealing with chronic pain. There is not enough evidence to determine sex-specific pain protocols, but considerations for gender along with other cultural issues will improve outcomes (Cepeda et al., 2003). The existing conflict between women (especially ethnic minorities and the elderly) who report pain, and male physicians who do not take them seriously, has yet to be openly acknowledged or resolved. The American Society of Anesthesiologists reported (2015) that women are more likely to experience more pain than men. However, they are reluctant to report it and they are often ignored or dismissed. Lovering (2006), in a collaborative study on cultural beliefs and practices that involved woman from different cultures of birth and heritage, found that the gap between how patients respond to pain, the willingness to report their pain, and the beliefs of the nurse/physician had profound influence on whether pain was actually relieved.

Anthropologist Mark Zborowski (1952) posited that social and cultural influences determine what he called "pain expectancy" and "pain acceptance." Pain expectancy sets up a patient to perceive both avoidable and unavoidable pain. Pain acceptance is about the inevitable, something that people must deal with as a result of their own behaviors or cultural mandates. For example, some women opt for natural childbirth as a social or religious rite of passage, while others choose medication. Aside from expectations and acceptance, however, there is pain apprehension and pain anxiety, both of which impact the character of the pain, such as its intensity, duration, quality of sensation, and the emotional response of the patient (Zborowski, 1952).

The Patient Environment is the Patient Experience

Similar to pain, the patient experience lives within the expectations,

perceptions, and meaning derived by the patient in real time. By the time patients report about their experiences, they are in the recent historic past, recalled in ways that may leave out the small details, but also may exaggerate the most negative events. Nothing influences the patient experience more than the environment in which they find themselves. The physical environment surrounds patients 24-hours a day. It is what they hear, see, and smell. It is what touches them and what is beyond them. And, the patient environment is a totality, it is a "...whole (person-in-environment system) [which can be described as] people embedded in their physical, interpersonal, and sociocultural environments. One must treat the totality rather than deal with one aspect of the whole (person or environment) without treating the other." (Craik, Price, & Walsh, 2000).

Malenbaum et al. (2008) found that the patient environment could either increase or lessen pain. They concluded that, "The visual and sensory settings in which we usually treat pain patients probably do little to relieve pain and may exacerbate pain." Mitigating some of the most invasive stressors by masking noise and providing access to natural landscapes, can contribute to a positive space that may lessen the perception of pain. The purposeful design of the patient environment has been the basis of nursing practice starting with Florence Nightingale in the 1800s. Removing or minimizing environmental stressors and providing and optimizing positive distractions, such as nature and music, is the key to optimal pain management. That means if an environmental stressor like noise is removed, something positive, such as music, must be added. External positive distractions mitigate patients' internal self-generated fear and confusion. Finlay and Anil (2016) found that music enhanced pain management capacities and, by creating a positive valance, helped patients manage the experience of time, which can be oppressive. Happy relaxing music

functioned as an anxiolytic and reduced pain. Their findings can be added to the large body of studies that show music to be not only a positive distraction, but also a companion beyond the hospital to manage chronic pain at home.

Environmental interventions focused on reducing pain and suffering must have cross-generational and cross-cultural appeal. Musical preferences of patients reflect personal history, events, people, and peer identity. They are best when chosen by the patient. However, using music that is unfamiliar, but feels familiar allows patients who are unable to self-select or who are with family and friends will create an inclusive environment. Popular music or someone else's music preferences may inadvertently cause stress, anxiety, or sadness depending on the circumstances. Therefore, music that is comforting without triggering a negative emotional response allows patients respite from ongoing worries and creates an unbiased, positive musical valance.

The effectiveness of multi-modal stimuli increases effectiveness in relieving pain. Kline (2011) found that exposure to nature images together with music was most effective in relieving acute pain than either used alone. The mechanism for this was linked to distraction theory and the intensity of engagement.

Immersive Technologies

Research to date has shown that immersive technologies, such as virtual reality (VR), calm and distract patients, lessening the sensation of pain. VR has been shown to be effective in providing relief from pain regardless of what kind of pain it is. In a pilot study conducted by Cedars-Sinai Medical Center, Los Angeles, Calif., in collaboration with Samsung, adult patients reported a 24 percent drop in pain scores after using VR goggles to watch calming content (Mosadeghi et al., 2016; Tashjian et al., 2017). Other initial studies with pediatric patients found that playing

immersive video games provided such a powerful distraction that their pain also dropped significantly. The research team under the direction of Dr. Walter Meyer at Shriners Hospital for Children in Galveston, Tex., believes that when children's attention is drawn into a virtual and three-dimensional world, less attention is available to process incoming pain signals. As a result, children with severe burn injuries may experience up to 35-40 percent less pain and discomfort during daily baths and wound dressing changes (Hoffman et al, 2011). A further benefit of using virtual reality is reducing anxiety levels that patients feel before and during wound care sessions. Virtual reality may also improve patient cooperation with the wound care nurse during wound debridement.

Power of Imagination

The power of imagination that allows a viewer to be lifted into a different place is what makes a media experience both attractive and effective. However, to do that, the content must provide one or more of the four components put forth by Ulrich (1984) and Kaplan and Kaplan (1989): 1) It must feel like a patient is being taken to another place, sufficiently different from where they normally are; 2) It must be coherent, understandable; 3) It must be complex enough to be engaging, have a quality of "fascination"; and 4) It must be compatible with the patient and serve the expectations or purpose of the environment.

"Fascination is drawn by stimuli that are reasonably complex, coherent, and legible and yet hold some mystery." (de Kort et al., 2006). This definition makes real why overly familiar images may not be engaging. The variety of natural landscapes can offer both complexity and variety to qualify for the fascination as defined. And being able to understand and make meaning of the visual journeys provides the coherence that transforms the physical environment into a healing environment.

Giving Control to Patients

Today's patients want to be self-efficient in managing their own conditions. Calling for a new prescription does not put the control back into the patient's hands or mind or body. The use of complementary therapies are now more prevalent because they are not only effective, but they allow patients to participate in their own recovery, guide their own treatment plan, and become functional according to their own values and preferences (Baker, 2017). Patients' capacity to cope with pain, the level at which they are comfortable, if not pain free, is directly related to their expectation, emotional affect, acceptance and trust in their treatment. Studies that have looked at mood and attitude have repeatedly shown this correlation.

Understanding and designing the context in which patients must manage their pain is a key to optimal levels of medication and function. The less medication and the greater sense of control on the part of the patient, the better the outcomes. More so, providing patients with tools that can help them learn how to manage their own pain will lead to better long-term outcomes.

There is a financial and human price to pay for the use of pharmaceutical solutions, as well as a cost benefit for the use of alternative methods. Side effects from morphine, oxycodone, Percocet, and other opioids and opioid substitutes are numerous and can lead to death. In the elderly, they are particularly dangerous in comparison to non-steroidal anti-inflammatory drugs (NSAIDS) including a greater risk of having a cardiovascular event, GI bleeding, four times as many fractures, increase risk of additional hospitalization for an adverse drug event, and, at the worst, death.

Clinical outcomes of using nature imagery and music reflect a reduction in the need for pharmacological intervention in some patients by as much as 29 percent (Rudin et al, 2007). Studies (Devine, 1996)

also reflect alternatives to pharmaceutical intervention can reduce side effects and hospital length of stay by an average of 1.5 days. Since hospitals are responsible for the cost of additional patient days beyond what Medicare pays, additional savings could be significant. The average daily inpatient cost is \$1,986. (Kaiser State Health Facts, 2015).

The use of non-pharmaceutical pain management protocols carries few risks and is far less expensive. However, more important, it puts patients in control of their own health and provides effective and meaningful tools to be used following hospitalization or any procedure.

Where We Are Now

In January 2017, the Joint Commission called for comments on new standards on acute pain assessment and management standards for its hospital accreditation program in the U.S. and abroad. Noticeable is the second standard listing that requires hospitals to promote “access to non-pharmacologic pain treatment modalities (this may include alternative modalities, such as, chiropractic, relaxation therapy, music therapy),” (Baker, 2017). Acknowledging the ways in which pain is experienced and managed by the patient offers multiple methods for assisting patients. Whether using distraction therapy, relaxation practices, guided imagery, or self-selected therapeutic modalities, patients come with their own arsenal of personal, physical, spiritual, and emotional strength. The inherent bond of mind and body is key to relieving pain and mitigating suffering. Research has found that patients’ capacity to manage their own pain is directly related to how they perceive their own ability to control their pain. Keefe et al. (2008) concluded that self-management of pain succeeds in part because patients believe that they can control their own pain. The National Institute of Medicine stated in

2011 that “Pain beliefs correlate with outcomes.” On the other side, “Pain Catastrophizing,” which occurs when patients exaggerate its threat and believe they cannot control it (Keefe et al., 2000), makes it difficult for patients to manage their pain. Therefore, creating a healing environment, offering methods that empower patients’ own restorative capacities, and engaging with patients in understanding their individual circumstances is the optimal systemic process of addressing acute and chronic pain.

In his book, *The Culture of Pain*, David Morris (1991) points to the long trajectory, from Plato to opioids that moved pain from being an emotion to being a disease deserving of its own specialty and clinic. And yet today, the treatment for pain considers first the physiology, the neurological pathway to and from the brain. Patients in the U.S. have come to expect (and demand) immediate relief without engaging in meaningful dialogue to address the complexities that contribute to pain and suffering. The most powerful pain management tool is the patient him/herself. Rather than conceptualizing the mind-body connection as being forced or theoretical, the unification of physical, emotional, spiritual, and psychosocial factors defines the whole person experience and holds the key to pain management. All evidence and studies around pain suggest that pain is an experience to be managed in its many dynamics by multi-modal methods with patient experience being at the center. At this point, with the newest research in neurology and the use of brain imaging technologies, we have a better understanding of how inherent responses trigger a chain of neurological responses. Self-management of pain is moving from being a hope to a tested. In the future, medications may be provided according to the complexities of coping and pain tolerance. Furthermore, non-pharmaceutical strategies have been shown to be effective and with little risks.

Providing a positive distraction that uses patients' capacity to focus their thinking outside of their condition can help restore patients' sense of beauty and hope in a life worth living. As patients are more engaged and information is shared with them, the threshold of pain will rise and the promise to support patient self-care and help them manage their own pain will become a reality. In the meantime, more research is needed regarding multi-modal strategies to avoid opioid dependency with more short and long term effective self-management.

Conclusion

Pain is experienced as a whole-person event being filtered through the same factors that evaluate the patient experience. While pain and suffering have long been thought to be either physical or psychological, studies have shown that not only is pain both somatic and mental, but it is also informed by prior experience, social and cultural values, and expectancy. The involvement and arousal of neurological systems is without doubt. However, perception and meaning are equal partners. More studies that consider how these pathways meet and how they impact each other, are needed in order to arrive at safe methods of relieving suffering with minimal or no use of opioids.

Conflict of interest

The author declares no Conflict of Interest (COI) related to this paper.

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