The Meaning of Cancer Pain

Betty R. Ferrell and Grace Dean

PAIN IS the most common symptom of cancer and often the most distressing one. Pain is experienced by cancer patients as well as their family caregivers. Often family caregivers experience pain and suffering through witnessing the patient’s uncontrolled pain. A neglected aspect of managing pain is the individual’s ability to develop positive meaning for their life despite the stress and pain associated with the illness. This article provides a review of the literature related to meaning and pain, an application of the work by Lipowski in the area of meaning in illness, and case examples of patients and family caregivers in their search for meaning in cancer pain.

Nursing intervention in the meaning of cancer pain can make a valuable contribution to an experience often described by patients as “unendurable,” “excruciating,” and “horrendous.” Because pain is often a metaphor for impending death, the meaning derived from this experience may also contribute to and influence the ultimate meaning of death for the individual.

LITERATURE REVIEW

The meaning of pain is influenced by the individual’s personal, social, and cultural experiences. Much of the literature concerning the meaning of pain is discussed exclusively from the perspective of the patient. Ferrell et al’s research in pain, quality of life, and ethical issues over the past 10 years has led to the development of a model describing the search for meaning of pain from the perspective of the patient, family caregiver, and nurse. This descriptive research explored the meaning of pain among patients with terminal cancer and involved semistructured interviews of 10 patient-caregiver-nurse triads. Data analysis showed three major categories of meaning: (1) immediate causes, (2) social and personal effects of the immediate causes, and (3) ultimate causes.

The immediate causes were indicative of a direct causal relationship between pain and cancer. Pain meant the patient had cancer and if the pain increased, the derived meaning was that the cancer had recurred or was progressing. The immediate effects were a direct result of the causes: physical and psychosocial responses to the experiences of pain for each member of the triad. Examples of immediate effects of cancer pain included the loss of control, autonomy, usefulness, and/or the ability to work. The ultimate causes centered around answers to questions such as “Why me?” or “Why him/her?” Nearly every participant stated, “there must be a reason.” The investigators suggested that patient variables such as the patient’s previous and socially influenced experience and cultural diversity may strongly influence the meaning of pain and should be explored in future research.

Research on the relationship between cancer pain and culture is limited; however, knowledge of the variables that influence the experience of pain, such as culture, are essential to understanding the meanings patients develop toward cancer pain. Garro defines culture as the information required

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to behave in a socially acceptable manner in society. Culture influences the meaning of symptoms and the ways in which health problems are treated. Medical anthropology recognizes that symptoms are often seen as representing the meaning of an illness rather than simply as a representation of the disease process. Symptoms may be viewed as an expression of the patient’s world, linked to both the stresses and experiences of that person, and as being composed of cultural and personal meanings. Social aspects involve how families influence patient behavior, how they relate to health and illness, and how ethnic expectations influence the health practitioner/patient relationship.

Sargent’s ethnomethodological study found that the Bariba of Benin, people from northern Dahomey of West Africa, idealized stoic reactions to pain. This nonexpressive response to pain was observed in a number of life events: childbirth, illness, injury, and initiation rituals. In the early 1950s, Zborowski examined how pain was expressed by Jewish, Italian, and “Old American” (defined as white, usually Protestant, and third-generation American) patients in a large urban hospital. Zborowski found differences among all of these groups. The Italians were concerned with alleviating the pain and focused on the immediacy of the pain sensation. The Jewish attitude was future-oriented and focused on the meaning and source of the pain. This was in direct contrast to the “Old American” patients who were optimistic and assumed a mechanistic view of the body as something that breaks down and can be fixed.

Zola’s findings were similar to Zborowski’s. Irish and Italian matched pairs were interviewed on their first clinic visit. Irish patients tended to deny the presence of pain, reported fewer symptoms, and generally viewed pain in a physical sense. Conversely, the Italians reported more pain, more symptoms, and symptoms that were more diffuse. They also felt that their emotions were affected by their symptoms.

Lipton and Marbach studied the interethnic differences in 250 patients seen in a facial pain clinic. The patients were categorized into specific ethnic groups: black, Irish, Italian, Jewish, and Puerto Rican. Reported responses to pain were similar among the five ethnic groups, with differences found in emotional response to pain and in the degree to which pain interfered with daily activities. The investigators concluded that the relationship between the pain experience and ethnicity may be more subtle than previously thought.

It is evident from previous literature that the meaning associated with pain is grounded in the patients’ personal, social, and cultural experiences. In an effort to broaden the view of previous work on the meaning of cancer pain, Lipowski’s model of the meaning of illness is described and applied to the meaning of pain.

LIPOWSKI’S FRAMEWORK

Lipowski’s research focuses on the way people cope with the stresses and challenges of disease. He believes the way in which people cope is directly related to the personal meaning they assign to the illness and the attitude they hold toward it. Lipowski defines meaning as the subjective significance of all disease-related information that impinges on the patient. Patients evaluate the facts about the illness according to their personal experiences, knowledge, values, beliefs, and needs.

At any given point, one meaning is likely to predominate and affect the patient’s overall emotional state and coping strategy. To determine what the illness means to the patient and better understand the patient’s feelings and behaviors, it is important for health care providers to determine which meaning of illness predominates. Lipowski categorized eight meanings of illness that seemed most prevalent in our culture: (1) challenge, (2) enemy, (3) punishment, (4) weakness, (5) relief, (6) strategy, (7) loss, and (8) value.

Challenge is described by Lipowski as a test for the patient to overcome the obstacles imposed by illness. Illness as enemy is viewed as an invasion. The patient has the opportunity to resist or surrender. Illness as punishment may be perceived as fitting or unwarranted and allows for atonement. When the patient views illness as weakness, it may be perceived as a sign of failure or loss of control. Illness as relief may be a welcome respite from the everyday demands and obligations in health, or it may be comfort from some recent crisis. The meaning of illness as strategy is related to relief and is described as a method to secure attention, support, or compliance from others. Illness as irreplaceable loss is identified as injury or as loss of function that cannot be repaired or replaced. This can lead to major depression and/or resistance to health care provider assistance. And finally, value
is described as all that the patient has been through, the suffering and the uncertainty that has some intrinsic worth. The patient somehow grows from the experience.

Two nurse researchers have applied Lipowski's meanings of illness to their studies of patients' perceptions of pain. Copp interviewed 148 hospitalized patients in pain and found most of Lipowski's categories were represented in the coping styles of the patients. Similar results were observed by Barkwell in her study of 100 patients suffering from cancer-related pain. All eight categories were illustrated in the meaning patients attributed to their pain. However, for the majority of patients in Barkwell's study pain meant challenge (n = 36), punishment (n = 23), or enemy (n = 20).

Table 1 presents Lipowski's eight categories of meaning with illustrative quotations from Ferrell et al.'s descriptive study that involved terminal cancer patient/caregiver/nurse triads. Note that no examples could be found in these data to represent Lipowski's category of relief. The remaining seven categories of meaning were consistent with Lipowski's framework. Of interest was the category of irreparable loss, most subjects mentioned their impending death as the ultimate loss.

CASE EXAMPLES

Three case examples derived from the authors' previous research are presented to illustrate the various meanings ascribed to pain and the role of nurses in facilitating meaning. These cases illustrate how patients can derive positive meaning from pain, ascribe meaning that may be construed as negative, and also struggle in their search for meaning.

Case 1

Mrs A was a 35-year-old mother who cared for her 2-year-old daughter in whom a brain tumor had been diagnosed. The daughter experienced severe head and neck pain and had recently developed an increase in her pain from the tumor growth. Despite the severe pain and poor prognosis, Mrs A spoke of the positive effects of this experience and how she had derived a positive meaning from what most would consider a horrendous experience. Mrs A shared her previous life history, which included having been a member of a gang and heavily involved in drug and alcohol use. At a low point in her life, when she in fact believed that she would likely die from her drug-oriented lifestyle, Mrs A became unexpectedly pregnant. Although her husband chose to leave her because he did not want a child, Mrs A used this opportunity to reform her life and give up drugs to have a "healthy" child. Mrs A described her child as a gift from God who was sent as a "sacrifice" to save her own life.

She described her initial struggles in conversations with God in which she felt the child had been given to her to save her life and was now only to be taken away. However, she had been

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<th>Categories of Meaning</th>
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<tr>
<td>Challenge</td>
<td>&quot;It's interfering with your schedule, it's interfering with your plans, it's interfering with your life unless you can stop that pain...&quot; (C)</td>
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<td>Enemy</td>
<td>&quot;... it's bad enough when you're sick, let alone having to fight the pain to boot, and they keep telling me I can't fight the cancer I'm fighting pain.&quot; (P)</td>
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<td>Punishment</td>
<td>&quot;... I don't think it's a bit fair, but I'm like this—it's God's choice... He's (the patient) been a good provider, and I just, I feel like there's other ones out there, those people that live in the street and stuff. Why can't something like that happen to them?&quot; (C)</td>
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<td>Weakness</td>
<td>&quot;We just found out that on her father's side there's lots of cancer which I didn't know until just recently. So I think the weakness is there... I don't say that it's contagious or inherited, but there's a certain weakness that comes about.&quot; (C)</td>
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<td>Relief</td>
<td>* ... I think that the reason that maybe this happened was for the family to get together, because they had, we had Thanksgiving and the family was... There was a unity there, united.&quot; (C)</td>
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<td>Strategy</td>
<td>&quot;This is different. It's not going to go away. It's not going to get any better. The arthritis, at least I had some hope of, you know, easing up sooner or later.&quot; (P)</td>
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<td>Irreparable loss</td>
<td>&quot;It means I got cancer, and it's going to kill me...&quot; (P)</td>
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<td>Value</td>
<td>&quot;... we go through the fiery test and remain true... I will have a seat at the marriage feast, and I can expect another jewel in my crown... I'm going through the very pits of hell, and sometimes I think that this, this is an example of hell and I'm going through it here and I'm not going to have to go through it later on...&quot; (P)</td>
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Abbreviations: P, patient; C, caregiver.

* There were no examples of Lipowski's fifth meaning of illness, relief, found in this data.
able to find great meaning in this experience. She described her child as being “special!” and that God had selected a child who could endure the pain and suffering of cancer. She described her child’s pain as being related primarily to the chemotherapy and radiation, but felt that this pain had served a purpose in that “although her own child would die” this had “paved the way” for other children who would likely be cured from such treatments. She also described herself as being “special!” and that God had recognized her as being a good mother. She stated that “the Lord lets things happen to children whose family will be there for them.”

Whereas some might interpret Mrs A’s beliefs about her child being “a sacrifice” to save her own life as a negative meaning, this interpretation obviously provided great support and meaning for an otherwise unendurable experience. This case illustrates positive meaning derived from an experience of pain by a family caregiver.

Case 2

Beth was a 50-year-old woman with terminal lung cancer who serves as an example of patients who construe negative meaning from the experience of pain. For Beth, pain symbolized death; she matter-of-factly stated, “it means the cancer is gonna kill me,” and she described her pain as being synonymous with cancer. She described herself as “a prisoner” and the pain as “a death sentence.” She accepted pain as normal and as a consequence of cancer and dying, but she spoke of the unfairness of allowing persons to live in pain when “we kill animals who are in pain.”

Beth described her pain as being a means to a quicker death, and stated the pain might enable her to “die before it is too late.” She had resolved the issue that, for her, pain and death were a natural part of life and that pain simply meant that it was “time to die.”

Although this meaning of pain was negative for Beth in that it offered her little consolation and it was the result of a negative perspective of her illness, this meaning seemed to provide her with a means of coping and accepting all that was occurring as inevitable and unavoidable.

Case 3

Mrs B was the mother of a 50-year-old woman, Susan, who had advanced breast cancer. Their story is an example of a patient and family struggling with great distress to cope with the negative meaning of illness and pain. Mrs B described the anguish of bringing a child into the world and feeling responsible for the pain and her commitment to easing the pain. Mrs B constantly described her daughter’s pain as being “unfair.” Mrs B’s greatest struggle seemed to be her inability to continue trusting the God that she had relied on all of her life. She questioned how God could allow her daughter to be in pain, and she referred to her daughter as “a victim.”

Mrs B’s daughter, Susan, had similar descriptions of the meaning of her pain. Pain to her meant that “God had failed me.” She still held to her belief that God was beneficent but that “He was helping other people” rather than herself. She felt she had been “picked out” and the pain was punishment for sins that she believed she had never committed. The degree of shared anguish was enormous between mother and daughter. For example, the mother struggled with the awareness that many of the treatments she performed on her daughter, such as dressing changes, resulted in pain. This case illustrates the shared meanings of patient and family. It also implicitly suggests the importance of spiritual and emotional support for those persons who derive negative meaning from an experience of cancer and pain.

IMPLICATIONS FOR PATIENT CARE

One strategy to alleviate suffering attributed to the negative meaning of pain and illness involves helping individuals to negotiate new meanings. Cassel12 suggested that the suffering of individuals who do not believe that pain can be controlled may often benefit from being shown that the pain actually can be relieved. Informing patients about the source of pain, especially when it is caused by treatment or diagnostic testing rather than a worsening of the illness may also assist patients in finding adaptive meanings for their cancer pain.

Table 2 describes several nursing interventions that may facilitate the development of positive meaning for persons experiencing cancer pain. First and foremost, clinicians should remember that the priority intervention is to provide the most aggressive pain management available to achieve

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<th>Table 2. Nursing Interventions to Facilitate the Search for Meaning in Cancer Pain</th>
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<td>Provide aggressive pharmacological pain management to achieve optimum pain relief</td>
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<td>Include nonpharmacological interventions that enhance a sense of control</td>
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<td>Assist patients in verbalizing and understanding the cause of their pain. Clarify physiological causes of pain</td>
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<td>Explore with patients and family members their images of pain including metaphors, visions</td>
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<td>Overcome barriers to optimum use of analgesics, such as fear of addiction</td>
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<td>Distinguish the feelings or meaning attributed to pain from those beliefs about death</td>
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<td>Empower patients to assume an active role in pain assessment and management</td>
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<td>Explore the losses associated with the illness and pain</td>
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<td>Facilitate discussion between patients and family caregivers to acquire a shared meaning of pain</td>
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<td>Encourage comparison of the patients pain to pain experienced by others</td>
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<td>Identify limits to pain that patients perceive to be necessary or deserved</td>
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<td>Facilitate spiritual interventions including spiritual counseling, rituals, prayer</td>
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<td>Explore pain as a sign of hopelessness and foster altered hope consistent with advancing disease</td>
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optimum relief. Clinicians should also include nonpharmacological interventions that enhance a sense of control. Relieving physical pain and providing optimum relief will enhance the patient's ability to find positive meaning and to experience a peaceful death.

Patients can also be assisted in verbalizing and understanding the cause of the pain. For example, clarifying the physiological cause of pain will help patients distinguish those pains that have a known physical origin and may help dispel unrealistic attributions of pain as punishment or other causes. Nurses can help patients and family members explore their images of pain to show the metaphors of death or other issues that require attention. Conversations with patients about their beliefs will often reveal fears of addiction or other barriers that can interfere with the optimal use of treatments that relieve pain.

Previous research has shown that beliefs about pain are closely linked to the fear of death. Distinguishing feelings and meanings attributed to pain from those beliefs about death will also assist in deriving positive meaning. Nursing interventions that empower patients to assume an active role in their pain assessment and management, such as the use of pain logs or diaries and active involvement in pain treatment decisions, also create a sense of control and hope. Pain may also be linked to a sense of loss, and nurses can assist patients with exploring those losses that are related to pain. For example, patients have often described living quite independently for years after the diagnosis of cancer and only when the cancer became painful did they begin to lose their ability to work, drive, or care for their family.

The meanings for cancer pain for patients and their family members may be similar or incongruent. Patients often do not discuss their pain with family members to avoid upsetting them; therefore, facilitating communication between patients and family caregivers is an important nursing intervention. Open and honest communication between patients and caregivers ensures improved pain management for patients and knowledge that caregivers are providing appropriate comfort.

Previous research has shown that one of the most effective coping strategies used by patients is defining their own experiences as being less disruptive than those of others in similar circumstances. Patients and families find meaning in the knowledge that they are part of a larger community of suffering. For example, parents of children with cancer pain often benefit by sharing their experiences with other parents, and women with breast cancer frequently develop close bonds and mutually supportive relationships with other women who are living with breast cancer.

Patients often attribute their pain to previous actions. They may believe that pain is necessary or deserved. Exploration of such beliefs and referral to chaplaincy or other spiritual supports may help patients resolve guilt about previous life events. Patients often see pain as a sign of hopelessness, which they equate with advancing disease and ultimate death, and enhancing hopefulness is essential to promoting positive meaning.

CONCLUSION

Nurses are the primary health professionals for patients in pain and their family caregivers. Nursing interventions that assist patients in deriving some kind of positive meaning from pain and suffering are essential to helping these individuals live with advancing disease and experiencing a peaceful death.

Cancer is a devastating disease and the experience of pain makes this disease even more intolerable. Nurses can assist individuals in their search for meaning as they cope with this very stressful circumstance. There is a famous story about a Chinese master painting a landscape. As he is nearly finished with the masterpiece, a drop of ink falls on the white scroll and the disciples standing around him gasp, believing the scroll is ruined by this assault. Without hesitating, the master takes the finest of hair brushes and, using the tiny globe of ink already fallen, paints a fly hovering in the foreground of the landscape.

Expert oncology nurses can assist patients and their families in their search for positive meaning in the face of pain. Pain is more than a symptom, it is an all-consuming experience. In the words of Rene Leriche, "Physical pain is not a simple affair of an impulse travelling at a fixed rate along a nerve. It is the resultant conflict between a stimulus and the whole individual." This search amid suffering gives meaning to the experience of pain and to the experience of life.
REFERENCES


