

The Meanings of and Attitudes About Cancer Pain Among African Americans

Salimah H. Meghani, PhD, MBE, CRNP, and Arlene D. Houldin, PhD, APRN, BC

Purpose/Objectives: To describe the meaning of cancer pain and attitudes in dealing with cancer pain among a group of African Americans with cancer.

Research Approach: Qualitative descriptive design.

Setting: Three outpatient medical oncology clinics in the mid-Atlantic region.

Participants: Purposive sample of 35 self-identified African Americans older than age 18 and diagnosed with solid tumors, with self-reported cancer-related pain lasting at least one month in duration and no major surgery in the previous three months.

Methodologic Approach: In-depth, semistructured, taped-recorded interviews were transcribed verbatim and analyzed. Initial codes were categorized into meaningful themes, and the data were analyzed until no new themes emerged.

Findings: Cancer pain was articulated by participants in terms of its physical, emotional, and existential dimensions. Themes related to cancer and pain remained intertwined. Some participants viewed pain as a signal of underlying disease progression and described it as a monitoring strategy for staying ahead of their cancer. Stoicism, faith, and finding meaning in the cancer pain experience emerged as main themes in participants dealing with cancer pain.

Conclusions: The findings suggest that perceived meanings and interpretations of the nature of cancer pain, its causes, and consequences may be important in shaping participants' pain treatment negotiations with providers. Understanding patient-level factors is crucial to fully comprehend pain treatment disparities.

Interpretation: Providers must assume a more proactive role in assessing physical, emotional, and existential dimensions of cancer pain, improving trust and communication, and identifying educational and behavioral interventions for African American patients and families to optimize pain treatment outcomes.

Pain is one of the most elusive symptoms encountered by patients with cancer. In the United States, pain is widely recognized to be undertreated even though the capacity to manage pain has never been better (Bonham, 2001). A growing body of literature suggests that African Americans are less likely to receive guideline-recommended analgesia for cancer pain relief than nonminorities (Anderson et al., 2000, 2002; Bernabei et al., 1998; Cleeland et al., 1994; Cleeland, Gonin, Baez, Loehrer, & Pandya, 1997). Factors leading to undertreatment of pain can be divided arbitrarily according to patient-, provider-, and system-level factors. The bulk of existing research on racial and ethnic disparities in pain treatment has attempted to understand how provider (Anderson et al., 2000; Bernabei et al.; Cleeland et al., 1994, 1997; Tamayo-Sarver et al., 2003) and system factors (Green, Ndao-Brumblay, West, & Washington, 2005; Morrison, Wal-

Key Points . . .

- ▶ Cancer pain remains widely undertreated among minority populations.
- ▶ Disparities in the treatment of cancer pain may arise from patient-, provider-, and system-level factors.
- ▶ An individual's perceived meaning of an illness may be the most important influence on the course of the illness and, by extension, its treatment.
- ▶ Understanding patient-level factors, such as the meaning of and attitudes about cancer pain, is imperative to fully comprehend pain treatment disparities.

lenstein, Natale, Senzel, & Huang, 2000) may affect cancer pain treatment outcomes among minorities. Conspicuously lacking from the growing body of literature are efforts to understand how patient-level factors, such as the meanings of and attitudes toward cancer pain, may shape analgesic-seeking behavior and pain treatment negotiation between patients and providers. The purpose of the current study was to describe the meaning of cancer pain and attitudes dealing with cancer pain among a group of African Americans with cancer.

Meanings play an important role in the formation of human behavior. The widely used theory of human social interaction, symbolic interactionism (Blumer, 1969), suggests that acts are vehicles that symbolize the meanings people have for certain objects or situations. Meaning-making is an ongoing interpretive process that occurs through social interaction and internalization of historic and social processes (Blumer). Treatment of pain, by its very nature, is an interactive social

Salimah H. Meghani, PhD, MBE, CRNP, is an assistant professor of nursing and Arlene D. Houldin, PhD, APRN, BC, is an associate professor of psychosocial oncology nursing, both in the School of Nursing at the University of Pennsylvania in Philadelphia. Funding was provided by an ONS Foundation Trish Greene Research Grant supported by Purdue Pharma L.P., a Center for Health Equity Research and Promotion Competitive Pilot Grant, a Sigma Theta Tau Xi Chapter Research Award, and a National Institute of Nursing Research grant (5 T32 NR 07100) on vulnerable women, children, and families. (Submitted October 2006. Accepted for publication April 3, 2007.)

Digital Object Identifier: 10.1188/07.ONF.1179-1186

process occurring between patients and providers. Despite significant advancements in the understanding of the complex cellular mechanisms responsible for the genesis of pain, no clinical assay or objective test to date accurately measures the experience of pain. The clinical gold standard of pain assessment continues to be that described by McCaffrey (1989): Pain is “whatever the experiencing person says it is and exists whenever he says it does” (p. 7). Thus, pain treatment outcomes are inherently the products of a covert interpretation of the meaning of pain and an overt negotiation between patients and providers.

Previous research has identified the powerful influence of the meaning of an illness experience on its treatment outcomes. The classic work of Kleinman (1988) underscores that, in the setting of serious chronic illness, an individual’s meaning of an illness may be the most important influence on the course of that illness and, by extension, its treatment. Kleinman distinguished disease from an illness experience. Unlike disease, which implies structural or functional alteration, an illness experience is socially constructed and represents the complex interface among individual, cultural, and social realms.

Unfortunately, little is known about the meaning of cancer pain among African Americans. In April 2006, a MEDLINE® search using the terms “African Americans” or “blacks” yielded 32,872 entries. However, only nine articles surfaced when the search was combined with “cancer pain.” Of those, only one study (Anderson et al., 2002) explored the meaning of cancer pain and barriers to analgesic use among African Americans (N = 14) and Hispanics (N = 17). Most African American participants (73%) described their pain as “hurt,” and 27% described it as impairment of function and limitation of activity. Only one patient described pain as suffering. Eighteen percent of African Americans pondered the question, “Why me?” Interestingly, despite having an analgesic prescription, 25% of African Americans reported never filling pain medications. Moreover, 42% of African American patients admitted that although they filled a prescription for analgesics, they had not taken the prescribed medication. Reasons for not taking pain medication included unacceptable side effects, no improvement in pain with analgesics, spontaneous improvement in their pain, and fears of opioids.

Previous research suggests that the manner in which different individuals or ethnic groups deal with chronic pain may influence their pain treatment outcomes (Edwards, Fillingim, & Keefe, 2001). Studies indicate that African Americans with chronic pain report lower perceived control over pain, believe that others should be more solicitous when they are in pain (Tan, Jensen, Thornby, & Anderson, 2005), and report greater use of external pain-coping strategies such as praying and hoping (Ang, Ibrahim, Burant, Siminoff, & Kwok, 2002; Edwards, Moric, Husfeldt, Buvanendran, & Ivankovich, 2005; Griswold, Evans, Spielman, & Fishman, 2005; Jordan, Lumley, & Leisen, 1998; Tan et al.). Those perceptions and attitudes also have been found to mediate their use or preference for conventional treatment modalities for chronic pain conditions (Ang et al.).

The findings point to non-access-related factors in treatment outcomes for chronic pain. Insights into meanings African Americans ascribe to cancer pain could address critical gaps in the existing pain disparity literature. To that end, the current qualitative, descriptive study described the mean-

ing of cancer pain and attitudes toward dealing with cancer pain among a group of African Americans with cancer. The inquiry was part of a larger study examining factors affecting the negotiation of treatment for cancer pain among African Americans (Meghani, 2005; Meghani & Keane, 2007).

Methods

Sample and Setting

A purposive sample of 35 participants was recruited from three outpatient medical oncology clinics in the mid-Atlantic region of the United States. Two sites were part of a large, private, not-for-profit healthcare system, whereas the third was part of a government-based healthcare system. The study protocol was approved by the institutional review boards at each of the respective sites. Patients who met the following criteria were invited to participate in the study: (a) self-identified English-speaking African Americans, (b) older than 18 years of age, (c) diagnosed with solid tumors, (d) self-reported cancer-related pain for at least a one-month duration in the previous six months, and (e) no history of major surgery in the previous three months (minor procedures such as port implantation, peripherally inserted central lines, and Hickman catheters were not excluded). Potential participants were excluded if they were too ill to complete the interviews. A deliberate attempt was made to recruit an equal numbers of male and female participants.

Procedures

Participants were recruited over a nine-month period from August 2004–May 2005. Patients were approached by a trained research assistant in the waiting area of an outpatient oncology clinic on the day of their scheduled visit. Depending on the patients’ preference, the research assistant conducted the interview on the same day or made an appointment for a face-to-face interview at the next follow-up visit. If a patient was interested and available for the interview, the consent form was reviewed and signed. Consenting participants completed the investigator-designed demographic questionnaire and in-depth, semistructured, taped-recorded interview lasting 50–70 minutes. The qualitative interviews were designed to elicit in-depth responses about the patients’ meaning of and attitudes toward cancer pain (see Table 1). Participants were compensated \$20 for their time. Permission was sought for a follow-up telephone interview if the research assistant needed clarification regarding the information shared during the initial interview.

Data Analysis

A qualitative content analysis of the interview data using Atlas.ti 5.0 (ATLAS.ti Scientific Software Development) was employed. The audiotapes were anonymized and assigned a unique identifier. The de-identified tapes were transcribed verbatim by a professional transcriptionist into a word-processing document and reviewed by the researchers for accuracy. The data then were imported into Atlas.ti 5.0 and analyzed by a team consisting of the researchers and an expert qualitative data analysis consultant. An a priori coding scheme was developed based on the interview guide. The initial coding structure was refined in an iterative fashion based on an increasing understanding of the data. Initial codes were categorized into meaningful themes, and the data were revisited until no new themes emerged (Hewitt-

Table 1. Exemplar Questions From the Semistructured Interview Guide

| Construct | Exemplar Questions |
|--------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Meaning of cancer pain | Individuals relate to the pain they are experiencing in different ways. What does pain mean to you? What are some of the things that come to your mind when you hear the words “cancer pain”? If you had to describe cancer pain to a friend, what words would you use to make your friend understand how you are feeling? Do you think there is a difference between cancer pain and other kinds of pain you may have experienced? What do you think is causing your pain? |
| Dealing with cancer pain | How do you deal with cancer pain? What helps when you are in cancer pain? |

Taylor, 2001). The intercoder reliability was established by having the qualitative data analysis consultant independently code and categorize about 15% of the interview transcripts. Codes were included if they were identified consistently and reflected a high level of agreement among the coders. An audit trail was maintained on the raw data, field notes and memos related to investigators’ dispositions or observations, and any amendments to the interview guide.

Results

Tables 2 and 3 summarize the demographic, disease, and pain-related characteristics of the participants who completed the qualitative section of the study. The median age of the participants was 55 years, with a balanced representation of male and female participants. The overall sample was mainly a group of single, educated, middle-class, and insured African Americans. The most frequent primary disease site was the gastrointestinal tract, followed by breast, lung, and reproductive malignancies. Most participants said that they experienced moderate to severe cancer pain in the week prior to the interview.

The interpretation of interview data suggests that cancer pain does not exist for the patients as an isolated reality; rather, it is covered in meaning and interpretation. Furthermore, the meanings are shaped in the process of trying to make sense of the cancer pain experience. The coded interview data revealed three major themes relating to the nature (ontology) of cancer pain, the cause (etiology) of cancer pain, and attitudes dealing with cancer pain (see Table 4).

Ontology of Cancer Pain

In the present study, African Americans described cancer pain in terms of its physical, emotional, and existential dimensions. Overwhelmingly, participants described cancer pain as a feeling of “hurt.” During the 35 interviews, the term “hurt” or “hurting” appeared 190 times. Only two participants described cancer pain as “suffering.” Participants reported their difficulty in describing the nature of cancer pain, and many attempted to describe it in terms of what it was *not*, using phrases such as “not the regular kind of pain” and “something you never want to experience or wish on someone else.” One

63-year-old woman with colon cancer and cancer pain duration of 26 months said, “It’s a pain that I wish on nobody. It can be very devastating at times. It gets me upset. I’m almost afraid. I just don’t like it.”

Some participants provided analogies such as “worse than child birth and labor pains” to describe their experience of cancer pain. Implicitly, those accounts pointed to the enormous and vicious nature of cancer pain that exceeded many participants’ sense of control.

Cancer pain was pain that I could not stand. It had you in tears. It hurt so bad. When I found out, before I found out just what it was, I was home in pain for a whole week. You know, it was, it’s unbearable.

For a number of participants, cancer pain meant limitations. Those patients described their pain in terms of its consequences. A 40-year-old woman with carcinoma of unknown origin and cancer pain duration of 10 months stated, “Pain means limitations in what I do, what I can do, and how much I can move.” Another patient, a 60-year-old man with lung cancer and pain duration of two months, said, “I used to be able to do things I was comfortable doing, things that are being interfered with now. One of my biggest worries was [that] I relied on my strength, and my energy just burned.”

For a subset of participants, the main difference between the experience of cancer pain and other types of pain was the expectation of relief. In the following quote, that expectation was tied not only to the physical aspects of pain but also to the emotional experience of knowing that one is living with cancer.

Table 2. Demographic Characteristics

| Characteristic | Median | Range |
|----------------------------------|---------------|----------------------|
| Age (years) | 55.0 | 33.0–75.0 |
| Income (\$) | 20,000–30,000 | < 10,000 to > 90,000 |
| Characteristic | n | % |
| Gender | | |
| Male | 19 | 54 |
| Female | 16 | 46 |
| Marital status | | |
| Married | 11 | 31 |
| Separated | 2 | 6 |
| Divorced | 7 | 20 |
| Widowed | 1 | 3 |
| Never married | 14 | 40 |
| Education (years) | | |
| Elementary (0–8) | 1 | 3 |
| High school (9–12) | 18 | 51 |
| College (13–16) | 13 | 37 |
| More than college (> 17) | 3 | 9 |
| Current employment status | | |
| Employed full-time | 5 | 14 |
| Retired | 6 | 17 |
| Unemployed | 21 | 60 |
| Other | 3 | 9 |
| Health insurance | | |
| Yes | 32 | 91 |
| No | 3 | 9 |

N = 35

Table 3. Disease and Pain-Related Characteristics

| Characteristic | Median | Range |
|-------------------------------------|--------|-----------|
| Length of cancer diagnosis (months) | 17.0 | 0.3–143.0 |
| Duration of cancer pain (months) | 10.0 | 1.0–143.0 |

| Characteristic | n | % |
|--------------------------------------------------------------------|----|----|
| Cancer diagnosis | | |
| Gastrointestinal | 10 | 29 |
| Breast | 9 | 26 |
| Lung or respiratory | 6 | 17 |
| Prostrate or reproductive | 3 | 9 |
| Other | 7 | 20 |
| Moderate to severe pain (worst pain \geq 4–10) | 32 | 91 |

N = 35

Note. Because of rounding, not all percentages total 100.

With other types of pain, you can take something for it, whether it is prescribed or not, and you'll feel better eventually. With cancer pain, it is more, it is not really physical, but it is mental, emotional. Mentally and emotionally draining because you're treating the cancer, and just the overall idea of having cancer is emotional, so it is different. It is different than a headache. It is different than the pain from a broken arm that you have to take medicine for to feel better.

For many participants in the study, the emotional and existential aspects were primarily different about cancer pain. They commented that cancer pain was different for them because of the emotional burden and uncertainties in terms of knowing what the pain meant. For most participants, pain was a referent for cancer; thus, it did not have an existence of its own but only in regard to the disease. Consequently, cancer pain was embodied in the myriad emotions, fears, and uncertainties associated with the cancer diagnosis, as illustrated in the following account.

When you're saying "cancer," you have to bring a lot of things in there, your emotions and the fearfulness of what's going on with you. You're not sure which way the cancer is going to go, if it's going to arrest itself, and you don't know, so that brings on more pain, more aggravating to the pain. 'Cause the pain, I guess it really is in your mind. So, therefore, when you have all these emotions going on with you, it just makes your pain greater.

Etiology of Cancer Pain

Throughout the interviews, the themes related to cancer and pain were intertwined. When participants were asked what they believed caused their pain, they largely attributed it to cancer, a change in cancer status, or cancer treatment. The participants described living in an uncertain inner world filled with fears, qualms, and doubts about the behavior of their disease—their accounts were replete with questions about what pain meant in relation to disease progression. Different types of pain were suggested to have different cancer-related etiologies. A new onset of pain at a different site was believed

to be caused by the spread of cancer. Similarly, a change in the severity of cancer pain was viewed as a sign of disease progression by most participants.

Pain as a signal: One of the most interesting themes that emerged was the description of pain as a signal—a window into the behavior of cancer and a means of keeping on top of it. One 58-year-old participant with breast cancer and a history of cancer-related pain for 132 months said,

Pain is a distraction. Pain is to let me know that I have something serious going wrong with me. Otherwise, I wouldn't have the pain, and [I'm] a little fearful of what's happening. Why [do] I have this pain? 'Cause it's questionable where it's coming from.

Another participant with liver cancer used the analogy of a heart attack to signify pain as a warning of something serious and underscored the value of listening to one's body, which he believed has its own system of communication.

Before you have that massive heart attack, you had some signs. I don't want to hear, "I had no signs; I felt good." He didn't. He couldn't have 'cause you'll get a sharp pain. That's your body letting you know something is wrong, but we ignore it. We take a pill and keep going. You get signs. You may get a back pain, something shooting up your back; they let you know. Your body [is] not stupid. Your body lets you know when something's wrong.

For a subset of participants, understanding the nature of their pain was "being in tune with your body," which, in effect, gave them a greater sense of control over their situation and disease process. They viewed pain as a tool at their disposal to gauge nuances and advancement of cancer and as a means of effectively communicating it with their providers. For instance, one participant who described her cancer pain as severe dismissed the use of analgesics altogether to better "hear" her pain and stay ahead of cancer.

You need to know where your pain is coming from, if it's the same pain, if it's something different and what

Table 4. Major Themes Identified in Participant Interviews

| Theme | Subthemes |
|--------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Ontology of cancer pain | Physical (hurt, limitation, expectation of relief) Emotional (fears, uncertainties, suffering) |
| Etiology of cancer pain | Pain as a signal of underlying disease and cancer progression A tool for staying ahead of cancer A tool of communication with providers Existential view of causation (Why me? Why not me?) |
| Dealing with cancer pain | Stoicism Consequences of dwelling on cancer pain (If you talk about it, it gets worse.) Concern for self and others Moving on to the next thing in life Medical mistrust and not being believed Survivorship and finding meaning in cancer pain experience Faith and belief in God |

happens when you hide the pain, then, the doctors really can't help you 'cause they don't really know if this is something new that has been laying, I would say, dormant because you have been hiding it with the pain medication. So my thing is, know your pain, get used to that particular pain in that area . . . if it's a strong, stabbing pain, a dull pain, if it's a cutting pain. Get to know your pain so you can describe it, and then they can better help you in that area. So, I don't like to hide pain. I like to know what kind of pain I'm dealing with.

With regard to dealing with pain, the same participant explained,

I just try to do other things to distract myself from thinking of the pain. So if something new unveils, then I can tell [doctors], this pain's a little different than it was last week. But, if you're constantly taking pain medication, three or four times a day . . . how can I identify it if I'm just taking pain medication all the time?

From those accounts, some participants clearly saw their pain as a tool of communication with providers to help them with early and accurate diagnosis. The beliefs about helping the provider appear to have developed as a result of participants' interaction with their environment, rather than in isolation. They acknowledged or implied that they live in a system in which providers treat symptoms. For instance, a 74-year-old participant with breast cancer said, "I started [talking about pain] one time on account of the burning sensation. I started talkin' to him. After he took the biopsies, he told me it was cancer." Thus, some participants believed that they shared the charge of disease identification with their providers.

Moreover, for some participants, attitudes toward taking charge of disease identification may stem from their lack of trust in providers and healthcare system. Some participants discussed perceived racism regarding treatment of cancer pain. A 42-year-old woman with breast cancer stated,

I'm aggressive about my treatment. I want to get well, so I had to tell one of the doctors, if I was your daughter or your wife, and I had to say this, if my skin color was different, then you would do everything that you possibly can to make sure that I was well. I say, treat me the same way.

For the study's sample, cancer and pain were so intricately tied that participants used phrases such as "when pain will go in remission" to imply when pain would be controlled.

Dealing With Cancer Pain

An interesting pattern of reasoning was evident as participants tried to come to terms with their cancer pain. Implicit in some accounts was the question, "Why me?" Two different kinds of mental approaches were articulated. One subset of participants seemed to indicate that they led a healthy life, never smoked, ate right, and had no one in the family with cancer. That group attempted to make sense of the "Why me?" question within a biomedical framework, as evidenced in the following account.

I'm not sure. The cancer diagnosis has been a total surprise to me. Basically, I have been healthy. I eat well and if I stop and think about it, I couldn't tell you what

there was about my lifestyle that . . . would bring the cancer on.

The other subset of participants, however, depended on insights from religion and faith to make sense of the "Why me?" question. They attempted to reason the deeper meaning of the question by extending it to "Why not me?"

I'm 30-some years, got a good job, good wife and family. I'm like, Why me? Why me? I don't owe you a million dollars. I don't eat no more than anybody else eats. I eat the same steak you eat. I don't do nothing. I'm in church. I honor God with my life. Somebody want me? Why not me? You chose me to go through this and I could be an inspiration for somebody else.

Those who understood their illness within the "Why not me?" framework believed that their experience with cancer pain had a purpose. Themes such as being chosen by God, being chosen to exemplify human stewardship, being an inspiration to others, and knowing something good would come out of the experience emerged in the accounts. None of the participants in this study directly attributed cancer or pain as a punishment. However, two participants made somewhat paradoxical statements, implying that pain was not a punishment but that it might have come as a result of doing something wrong. A 72-year-old man with breast cancer and cancer pain duration of two months said,

What I see is sometimes the pain might come to me as if I did something wrong. It is not a punishment, it is a, what do you call it? It is something that I should have to repent of right away, you know. It is something like that. I don't feel that it is a punishment.

A 43-year-old participant with sarcoma with a history of cancer-related pain for 143 months believed that enduring pain was a way for him to relieve his moral burdens.

The pain medication helps to keep it at a normal level. There have been times when the pain goes beyond 8, 9, or whatnot, that means I can sit there and look at you and talk as I'm enjoying the pain. Once it gets to a certain point, then, it's like my whole body, my whole character, my voice, everything changes in me, and I just carry it. And for me, it's more of a moral thing. I feel as though that this is something that I have to [do], that my body is paying for because of the life that I've lived for me to have all this.

Endurance and stoicism were the overarching themes that emerged in the accounts of dealing with cancer pain. Subjects described dealing with their pain in terms of suppressing, hiding, ignoring, facing, and accepting it. To them, dealing with cancer pain was a personal and an individual matter. Some of the beliefs that participants articulated in dealing with cancer pain may have important clinical implications.

Stoicism

If you talk about pain, it gets worse: A number of participants believed that "if you talk about pain, it gets worse" or becomes even more real. As evident in the following quote, those beliefs ranged from mere superstition to a logical idea about the psychological amplification of pain.

What comes out your mouth is what it is gonna be. For example, if I say, "Well, I'm old, I'm old." Okay, I know very well . . . I'm young. But you say, "You're old." Yeah, I'm old, you know what I mean? That is an example on that. Even with pain, don't accept it. . . . I go on to the next thing. Because then my thing, if you continue to start talking about your pain, you know, it just gets worse, mentally it gets worse. Psychologically, you just start thinking about, yeah, well the pain is here. Pain. Then you get caught up.

Concern for self and others: Concern for self and others was another reason for being stoic. Participants identified two reasons for hiding pain from their families and friends. First, they were unsure of family members' ability to deal with the situation and did not want to burden or frighten their families or friends. By virtue of living with cancer pain, subjects believed they were a little more adept at dealing with it than people around them: "To me, I think that I'm coping a little better than [family] are and I'm the one with the disease. . . . I'm concerned about that. That's why I hide the pain."

Second, they acknowledged that cancer pain is "nobody else's business but your own"; thus, participants felt that family or friends simply could not understand their experience without having experienced it themselves. Some participants feared rejection as a result of constantly complaining about pain. Therefore, not talking about pain was seen as a way to maintain relationships and retain a sense of self-worth.

You got to be in the situation. They say they understand, but you only understand the whole cancer process. . . . Nobody wants to hear you keep saying you hurt. There's nothing they can do for you. You keep saying, "I hurt, I hurt, I hurt." What can people really do for you? You keep telling other people that you hurt all the time. So, I just think, "I'm fine." I always say, "I'm fine," you know?

Moving on to the next thing in life: Strikingly, many in this study described their cancer pain as an around-the-clock phenomenon that they had come to accept as a part of everyday life. Complaining about or dwelling on pain was viewed as a barrier to moving on to the next thing in life. Many participants said that they refused to succumb to cancer pain or its physical or emotional consequences. Implicit in the accounts was a sense of urgency in terms of time, and cancer pain was seen as a distraction from the real goals of life. Focusing on what they could do despite their cancer and pain gave patients a greater sense of self-worth and control over their situation. One participant said,

I think it becomes a part of everyday life. You come to realize that there are things that you are just not gonna be able to do, so there is no need to dwell on it. Just forget that and think about what it is that you can do for yourself now to make you feel a little bit better. I think you have to do that sometimes and it helps. I think we can compound our problems by thinking about what we haven't accomplished. We have to learn acceptance. I think that probably ought to be able to face reality. This helps a lot. This is part of clearing your mind.

Medical mistrust and not being believed: African Americans have a long history of racial discrimination and medical

abuses. As a result, one question in the current study inquired about participants' perception of or experience with discrimination or bias from their providers. A majority of participants said that their healthcare providers believed them, as evidenced in one patient's comment: "I don't know. I think they see pain as pain. They probably treat everybody the same way." Nevertheless, in elaborating on their experience of pain treatment, a number of participants perceived that their providers did not believe them and that their pain was not taken seriously. Some patients believed that obtaining a prescription for opioids was accompanied by a demeaning litany by providers on the abuse potential and the street value of the drugs. Others implied that they had come to accept that situation as an inevitable part of their medical care. One participant stated,

The only thing I just want to add is that a lot of black people feel, especially when we're in pain, that we aren't believed, and that is the main problem with us. And we accept that, that we're not gonna be believed. So therefore, we don't make that a major issue. And then when anything is offered to us, the first thing that's being thrown up in our face is that, well, it's got a street value. You don't need to hear that.

Actual or internalized racism may result in passivity and lack of negotiation of treatment for cancer pain among African Americans.

Survivorship and Finding Meaning in Pain

One of the subthemes in participants' stories was the concept of survivorship. Participants viewed living with cancer as having a second chance to accomplish their life goals. Participants talked about the worth of things in life, which many may take for granted, such as their ability to talk to others, "smell the roses," or even feel pain. Human stewardship was another subtheme that emerged in patient accounts of dealing with cancer pain. By participating in activities such as self-help groups and talking to others with cancer, patients found meaning in their own experience. Living with cancer and pain was described as a transcendental experience that gave individuals new meaning in life, provided strength, and helped them uncover new potential in themselves. Renewed meaning and the significance of life were described as an impetus for dealing with the everyday experience of cancer and pain.

The bad just gives me so much insight into life, appreciation for life. You know, really the good, I've found a lot of good in cancer. I think that I have been strengthened, and I have become a better person because of cancer. I have a lot of coping skills.

Faith and Belief in God

Faith and belief in God were at the core of the African Americans' experience of dealing with cancer and pain. About 212 references were made by 35 participants on themes relating to Christian faith, God, church, prayers, and the Bible. When asked what helps with pain, most participants described holding on to their faith to get through the cancer and pain experience: "I pray, I read my Bible, and I have a strong faith in God. I'm not done until God says I'm done. I'll hold on to that fact; it keeps me going every day." For those participants, praying, meditating, reading the Bible, and talking to God were buttresses on which they leaned to find strength and meaning.

Discussion

Few studies have investigated the role of meaning and attitudes toward cancer pain in pain treatment outcomes among African Americans. The study's findings suggest that perceived meaning and interpretation of the nature of cancer pain and its causes and consequences play an important role in shaping participants' pain treatment negotiations with providers. The three major themes emerging from analysis of the study data relate to the nature of cancer pain, the causes of cancer pain, and dealing with the cancer pain experience.

The study participants described the nature of cancer pain with regard to its physical, existential, and emotional dimensions. Overwhelmingly, participants described the physical dimension of cancer pain as a feeling of "hurt." That finding is consistent with Anderson et al. (2002), who reported that more than 70% ($n = 31$) of African Americans in their study described cancer pain in the same way. The emotional dimension of cancer pain embodied considerable fear and uncertainty stemming from trying to make sense of what the pain meant. Most African Americans in this study attempted to understand their cancer pain within a biomedical framework and did not see it as a retribution, punishment, or means of salvation, which suggests that patients' willingness to endure cancer pain may be driven by factors other than existential beliefs. Those other factors must be understood and addressed by clinicians.

In the present study, the fears and uncertainties leading to beliefs in endurance stemmed from perceived direct association between pain and cancer. The strong association between pain and cancer among African Americans has been identified previously (Abbott, Taylor, & Barber, 1998). Abbott et al. found that African Americans believed that pain was the first symptom of the presence of cancer. That belief remained strongly grounded even after an educational intervention. Similarly, in the current study, participants did not view cancer and cancer pain as ontologically independent categories. For them, pain was a window to the behavior of their underlying disease. Some participants described pain as an unpleasant but useful tool with multiple important functions (i.e., keeping them on the top of their disease, guiding them through the uncertainties of cancer, and helping them in effective communication with providers about disease-related concerns). The symbolic meaning of pain as a signal had important implications for subsets of African Americans' sense of control over their disease process and, in turn, their negotiation of treatment with their providers.

The attitude toward "knowing one's pain" and "staying ahead of cancer" may be rooted in the issue of trust in providers and healthcare system. Some reports have identified an association between medical mistrust among African Americans and their adherence to preventive cancer care (O'Malley, Sheppard, Schwartz, & Mandelblatt, 2004; Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004). The role of mistrust in adherence to a prescribed medical regimen may be more important in the setting of cancer pain because of the perceived direct association of cancer pain to survivability and a lack of confidence in providers' ability to identify cancer progression in a timely manner. The findings point to the importance of understanding participants' worldviews in any appropriate setting of cancer pain treatment.

Faith, stoicism, and finding meaning in the cancer pain experience emerged as main subthemes in African Americans' cancer pain experience. Consistent with previous studies

(Anderson et al., 2002; Ang et al., 2002; Ashing-Giwa et al., 2004; Ibrahim, Zhang, Mercer, Baughman, & Kwoh, 2004), the current study underscores the significance of prayer for African Americans dealing with chronic pain. Furthermore, the present study builds on prior findings that suggest that African Americans are stoic in dealing with cancer pain (Anderson et al., 2002). The qualitative nature of the current study allowed a deeper understanding of the factors related to stoicism among a group of African Americans. Four factors related to stoicism were identified. First, participants believed that dwelling with pain or talking about it can amplify their pain experience and diminish their ability to control their situation. Second, stoicism was grounded in the fear that complaining or talking about pain with friends and family members may turn them away, resulting in social isolation and lack of support at a crucial time in their lives. Concern for the well-being of family and friends was the third reason articulated by African Americans in relation to stoicism. Many participants commented that cancer pain was a personal experience and even close family and friends would not be able to understand that experience or have reserves to cope with it. The theme also was reported in a study of women with breast cancer (Ashing-Giwa et al.). The researchers found that among a subset of African Americans, family members' coping difficulties with participants' cancer hampered mutual dialogue and the provision of emotional support. Medical mistrust and perceptions of not being believed by providers surfaced as another theme related to stoicism. African Americans have long history of institutionalized racism and medical abuses (Benedek, 1978; Brandt, 1978). In the setting of cancer treatment where patients grapple with many emotional and physical transitions and burdensome treatments, the perception of not being believed may be one additional burden faced by African Americans that can discourage a milieu of mutual trust and communication. Perception of racial bias in medical settings may have grave implications for patient-provider relationships and cancer pain treatment outcomes. The current study's findings suggest that participants' reasons for maintaining stoicism may be multifaceted. Unlike prevalent beliefs that stoicism reflects strength and endurance, the findings of the current study suggest that stoicism may embody a sense of strength and helplessness in dealing with cancer pain.

Limitations

This study has several limitations. Although an attempt was made to purposively obtain a diverse group of participants based on their demographic, pain, and disease characteristics, the final sample was comprised of predominantly educated, middle-class, and insured African Americans. Nevertheless, the group was diverse with regard to their cancer pain duration and disease characteristics, allowing for richness of qualitative data. Moreover, given the qualitative nature of the present study, the researchers did not account for type and stage of cancer, comorbidity burden, history of drug dependency, and amounts and strengths of opioids used by the participants in understanding their attitudes toward analgesia for cancer pain. Future studies with larger samples are warranted to account and control for those variables.

Implications for Nursing

Patients' meanings and attitudes about cancer pain may have important implications for pain treatment negotiations

between patients and healthcare providers. Meanings shape individual appraisals of an illness and whether and to what extent treatment may be required. Nurses and other healthcare providers must understand and incorporate patients' worldviews in appropriate treatment of cancer pain. Clinicians should ask patients, "What has it been like living with pain? Why do you think you have this pain? What do you think will help your pain?" Patient responses will help clinicians tailor appropriate interventions based on the meanings held by the patient. Clinicians should use patients' appraisals of their illness to ensure pain management is congruent with their beliefs, values, and cultural orientation (e.g., how much pain control is desirable, tolerance of side effects, willingness to discuss the disease and its impact on quality of life). In addition, African American patients bring unique cultural and historic experiences to a setting of cancer pain treatment. Nurses and other healthcare providers must understand that African American patients' beliefs in stoicism may stem from personal experiences (e.g., "If you talk about pain, it gets worse.") and historic experiences

of medical mistrust. Thus, the findings point to the need for a more active and proactive role on the part of healthcare providers in assessing physical and emotional dimensions of cancer pain, helping patients through illness-related uncertainties, and improving trust and communication. Moreover, many African American patients in this study did not report their pain because they were more concerned about the well-being of their families and friends and believed that their loved ones may not understand their experience of cancer pain. That finding underscores the need to involve patients and their families in educational and behavioral interventions aimed at optimizing cancer pain treatment outcomes among African Americans. Assessing the cancer pain concerns of patients and having a plan of supportive care targeted to patients and families are important steps in ameliorating racial disparities in pain treatment.

Author Contact: Salimah H. Meghani, PhD, MBE, CRNP, can be reached at meghanis@nursing.upenn.edu, with copy to editor at ONFEditor@ons.org.

References

- Abbott, R.R., Taylor, D.K., & Barber, K. (1998). A comparison of prostate knowledge of African American and Caucasian men: Changes from pre-screening baseline to postintervention. *Cancer Journal From Scientific American*, 4, 175–177.
- Anderson, K.O., Mendoza, T.R., Valero, V., Richman, S.P., Russell, C., Hurley, J., et al. (2000). Minority cancer patients and their providers: Pain management attitudes and practice. *Cancer*, 88, 1929–1938.
- Anderson, K.O., Richman, S.P., Hurley, J., Palos, G., Valero, V., Mendoza, T.R., et al. (2002). Cancer pain management among underserved minority outpatients: Perceived needs and barriers to optimal control. *Cancer*, 94, 2295–2304.
- Ang, D.C., Ibrahim, S.A., Burant, C.J., Siminoff, L.A., & Kwok, C.K. (2002). Ethnic differences in the perception of prayer and consideration of joint arthroplasty. *Medical Care*, 40, 471–476.
- Ashing-Giwa, K.T., Padilla, G., Tejero, J., Kraemer, J., Wright, K., Coscarelli, A., et al. (2004). Understanding the breast cancer experience of women: A qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncology*, 13, 408–428.
- Benedek, T.G. (1978). The "Tuskegee study" of syphilis: Analysis of moral versus methodologic aspects. *Journal of Chronic Disease*, 31(1), 35–50.
- Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., et al. (1998). Management of pain in elderly patients with cancer. SAGE study group. Systematic assessment of geriatric drug use via epidemiology. *JAMA*, 279, 1877–1882.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.
- Bonham, V.L. (2001). Race, ethnicity, and pain treatment: Striving to understand the causes and solutions to the disparities in pain treatment. *Journal of Law, Medicine and Ethics*, 29, 52–68.
- Brandt, A.M. (1978). Racism and research: The case of the Tuskegee syphilis study. *Hastings Center Report*, 8(6), 21–29.
- Cleeland, C.S., Gonin, R., Baez, L., Loehrer, P., & Pandya, K.J. (1997). Pain and treatment of pain in minority patients with cancer. The Eastern Cooperative Oncology Group minority outpatient pain study. *Annals of Internal Medicine*, 127, 813–816.
- Cleeland, C.S., Gonin, R., Hatfield, A.K., Edmonson, J.H., Blum, R.H., Stewart, J.A., et al. (1994). Pain and its treatment in outpatients with metastatic cancer. *New England Journal of Medicine*, 330, 592–596.
- Edwards, C.L., Fillingim, R.B., & Keefe, F. (2001). Race, ethnicity and pain. *Pain*, 94, 133–137.
- Edwards, R.R., Moric, M., Husfeldt, B., Buvanendran, A., & Ivankovich, O. (2005). Ethnic similarities and differences in the chronic pain experience: A comparison of African American, Hispanic, and white patients. *Pain Medicine*, 6(1), 88–98.
- Green, C.R., Ndao-Brumblay, S.K., West, B., & Washington, T. (2005). Differences in prescription opioid analgesic availability: Comparing minority and white pharmacies across Michigan. *Journal of Pain*, 6, 689–699.
- Griswold, G.A., Evans, S., Spielman, L., & Fishman, B. (2005). Coping strategies of HIV patients with peripheral neuropathy. *AIDS Care*, 17, 711–720.
- Hewitt-Taylor, J. (2001). Use of constant comparative analysis in qualitative research. *Nursing Standard*, 15(42), 39–42.
- Ibrahim, S.A., Zhang, A., Mercer, M.B., Baughman, M., & Kwok, C.K. (2004). Inner city African American elderly patients' perceptions and preferences for the care of chronic knee and hip pain: Findings from focus groups. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 59, 1318–1322.
- Jordan, M.S., Lumley, M.A., & Leisen, J.C. (1998). The relationships of cognitive coping and pain control beliefs to pain and adjustment among African American and Caucasian women with rheumatoid arthritis. *Arthritis Care and Research*, 11(2), 80–88.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.
- McCaffery, M. (1989). *Pain: Clinical manual for nursing practice* (2nd ed.). St. Louis, MO: Mosby.
- Meghani, S.H. (2005). *Factors affecting the negotiation of treatment for cancer pain among African Americans*. Unpublished dissertation, University of Pennsylvania, Philadelphia.
- Meghani, S.H., & Keane, A. (2007). Preference for analgesic treatment for cancer pain among African Americans. *Journal of Pain and Symptom Management*, 34, 136–147.
- Morrison, R.S., Wallenstein, S., Natale, D.K., Senzel, R.S., & Huang, L.L. (2000). "We don't carry that"—Failure of pharmacies in predominantly nonwhite neighborhoods to stock opioid analgesics. *New England Journal of Medicine*, 342, 1023–1026.
- O'Malley, A.S., Sheppard, V.B., Schwartz, M., & Mandelblatt, J. (2004). The role of trust in use of preventive services among low-income African American women. *Preventive Medicine*, 38, 777–785.
- Tamayo-Sarver, J.H., Dawson, N.V., Hinze, S.W., Cydulka, R.K., Wigton, R.S., Albert, J.M., et al. (2003). The effect of race/ethnicity and desirable social characteristics on physicians' decisions to prescribe opioid analgesics. *Academic Emergency Medicine*, 10, 1239–1248.
- Tan, G., Jensen, M.P., Thornby, J., & Anderson, K.O. (2005). Ethnicity, control appraisal, coping, and adjustment to chronic pain among black and white Americans. *Pain Medicine*, 6(1), 18–28.
- Thompson, H.S., Valdimarsdottir, H.B., Winkel, G., Jandorf, L., & Redd, W. (2004). The Group-Based Medical Mistrust Scale: Psychometric properties and association with breast cancer screening. *Preventive Medicine*, 38, 209–218.