Racial and ethnic disparities in cancer pain management sorely test the ethical principle of "justice"—the fair distribution and access to healthcare for all patients. Carmen R. Green, M.D., has been at the forefront of research in disparities in healthcare, particularly pain management. In this unique and provocative article, Dr. Green reviews the plethora of evidence showing that such inequities also exist in cancer pain management. Inequities in health care are an important bioethics concern. Greater awareness by the medical and ethical communities of racial disparities in the treatment of cancer pain may help eliminate these disparities, and thus improve the quality of cancer pain management for racial and ethnic minorities.

The Quality of Cancer Pain Management for Racial and Ethnic Minority Americans: Unequal Burdens and Unheard Voices

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INTRODUCTION

Disparities in health based upon race, ethnicity, and social stratification are well established.1-5 The technological advances that have allowed increased longevity for Americans have not been uniform across racial and ethnic lines nor have they been translated into improvements in the health-related quality of life (HRQL; physical, social, and emotional health) for racial and ethnic minority Americans.6,7 Racial and ethnic minorities have higher morbidity rates for essentially every major disease (e.g., hypertension, diabetes) and especially cancer, as well as increased overall mortality and decreased life expectancy.8 There is growing evidence to support the existence of additional barriers to the optimal health of racial and ethnic minorities.9-10 For example, African Americans are more likely than Caucasian
Americans of similar socioeconomic status to rate their health as fair or poor.11 African Americans are also less likely to have a regular primary care physician and have less access to specialty care including pain management specialists.12

Although inequities in health based upon race date back many generations, it was in the mid 1980s (during the Reagan administration) that the thoughtful discussions regarding health care disparities and how to eliminate them began. The U.S. Department of Health and Human Services, and the U.S. Surgeon General present goals for the nation’s colloquial health in their “Healthy People” documents.13,14 Overall, they present a framework and strategic vision for health promotion every ten years.

Among the many overarching goals stated in Healthy People 2000 were the improvement of HRQL and the elimination of racial and ethnic disparities in health care. Yet, today (2006) cancer remains the second leading cause of death among all Americans, and significant disparities exist for racial and ethnic minorities.3,15 In the face of continuing health care disparities, the United States Congress charged the Institute of Medicine (IOM) of the National Academies of Sciences to assess health care inequities and disparities in health care delivery services in the mid 1990s. The IOM specifically addressed these topics in a scholarly fashion in “Unequal treatment: Confronting racial and ethnic disparities in health care”16 where two sources of disparities were delineated: (1) discrimination (e.g., biases, stereotypes, decision-making) and (2) health care system factors (e.g., legal and regulatory scrutiny). The IOM identified stark differences in the incidence, morbidity, and mortality associated with most solid tumors (e.g., breast, prostate, colorectal, and lung cancer) when minority Americans were compared to Caucasian Americans.17-26 For instance, African American women have a lower incidence of breast cancer, but are more likely to die from breast cancer than Caucasian American women diagnosed at the same stage.23,24,27 In addition, African American men are diagnosed with and die of prostate cancer at a higher rate than Caucasian American men.3,18,20,22 Thus, a significant health status lag persists for racial and ethnic minority Americans with cancer. Reducing and eliminating disparities in health based upon race and other factors remains a goal in Healthy People 2010.13,14 Unfortunately, they will probably remain a goal when Healthy People 2020 is written, since the literature suggests that there are persistent health care disparities today.

In general, the impact of pain upon Americans (especially racial and ethnic minorities) has been largely overlooked. Even the IOM report devoted only a few pages to the topic of acute and cancer pain.16 In fact, no real mention was made to chronic non-malignant pain or chronic pain following cancer treatment, although there is increased awareness about the survivorship. Critical to the alleviation of the burden of cancer in racial and ethnic minorities is the achievement of the goals stated in Healthy People 2010 and the recommendations stated in the IOM report. Of particular interest is the knowledge gap that exists regarding the impact of cancer pain in potentially vulnerable and underserved populations.

The literature continues to document disparities in cancer and cancer pain care for racial and ethnic minorities in all treatment settings. African American and Hispanic patients are more likely to be under-treated for cancer pain (i.e., pain associated with the disease or due to the treatment of cancer) than Caucasians. This article will provide an overview of the impact of cancer pain on racial and ethnic minorities while providing insight into how well cancer pain is managed in these populations. Lastly, critical unanswered questions are presented as a platform for discussion among interested parties (e.g., health care policy makers, governmental officials, patient, the general public, and those who fund research, and researchers).

**IMPACT OF CANCER PAIN**

Two individuals with the same disease activity can differ greatly in the level of pain they report and its impact on their lives.28,29 Nonetheless, pain is the most common symptom associated with cancer.21,30,31 It is estimated that 60-85% of persons with advanced cancer report severe and persistent pain that undermines HRQL.30 Despite the availability of appropriate pain management modalities, cancer pain is often inadequately treated. Beyond the cost of analgesic medications, uncontrolled
cancer pain can also increase healthcare costs. Retrospective one-year reviews of admissions at two cancer hospitals revealed that 14-26% of unscheduled admissions were due to uncontrolled pain, accounting for nearly $10 million in expenditures. The average length of stay for a patient admitted for uncontrolled pain was 10 to 12 days, nearly three days longer than the length of stay for a diagnosis of pneumonia. These findings are particularly important since minority patients are more likely to receive lesser quality pain care putting them at risk for admission and significant morbidity when they also have a diagnosis of cancer. Given the predicted shifts in the US population (by 2040 racial and ethnic minorities will be in the majority), understanding the impact of cancer pain in racial and ethnic minorities is critically important.

Breakthrough pain (i.e., a transitory increase in pain intensity despite a fixed analgesic regimen) is estimated to occur in 19-95% of cancer patients and is associated with poorer outcomes (e.g., hospitalizations, emergency department visits, and physician visits). Yet, factors that influence breakthrough pain have not been well investigated. Besides causing discomfort for the patient, cancer pain is associated with decreased patient satisfaction, diminished quality of life, and psychological symptoms (i.e., anxiety and depression). Breakthrough pain is associated with increased healthcare utilization and medical expenditures. However, the impact of race and ethnicity was not evaluated leaving us with little literature to guide us regarding the impact of breakthrough pain on racial and ethnic minorities with cancer pain. It is unclear whether breakthrough pain is more frequent or associated with further diminutions in HRQL for minority patients. This is particularly important since the literature suggests that racial and ethnic minorities may be at increased risk for the under-treatment of pain as well as diminished access to pain medications. Nonetheless, minimal information is available on the management of cancer pain in racial and ethnic minorities or the implications of breakthrough pain in this population.

Differences in coping styles (i.e., cognitive and behavioral resources to manage the internal and external demands of the person-environment transaction) and attitudes may influence an individual’s pain experience. Maladaptive coping (e.g., catastrophizing, repression, denial) and poor adjustment (e.g., poor information seeking, passivity) appears to be an important contributor to diminished health and HRQL when an individual has cancer. Depression is a common disorder that affects the health of 5-10% of adults in the United States and is known to affect pain symptoms and coping particularly in individuals with cancer. Green et al. found an increased prevalence of post-traumatic stress disorder (PTSD) and depression as well as increased pain symptoms and decreased ability to cope with pain in African Americans with chronic non-cancer pain.

Since the majority of individuals with depression go without treatment and racial and ethnic minority persons are often reluctant to seek mental health care, minority patients with cancer may suffer substantially more impairment in HRQL due to cancer pain than Caucasian Americans. These findings are particularly important given that more Americans are surviving their cancer and are now living with chronic pain due to their cancer treatment. However, there are no clear estimates of the prevalence of chronic pain following cancer for any population or for minorities in particular, leaving a significant gap in the literature.

Differences in the attitudes of racial and ethnic minority persons regarding their healthcare have also been demonstrated. For instance, when considering cancer pain, concerns about addiction and side effects have been noted to affect the way that African Americans cope with their disease. It follows that these factors may lead to increased morbidity and further disparities in the health of racial and ethnic minority Americans with cancer (and pain), which is of significant public health importance. Overall, there are data to suggest that cancer patients (particularly minorities) under-report their pain severity and use less medical services. Of particular significance is how coping differences and maladaptive coping styles impact minority patients when faced with a cancer diagnosis and cancer pain.

MANAGING CANCER PAIN

In addition to differences in coping and HRQL, differences in the physician-patient re-
lationship, treatment strategies, and ability to obtain pain medication are noted for racial and ethnic minorities.\textsuperscript{44} Overall, the medical care received by racial and ethnic minorities has been repeatedly shown to be less than that received by Caucasian Americans.\textsuperscript{16,76} More specifically, the under-treatment of pain has been shown to diminish quality of life, increase morbidity, and contribute to mortality.\textsuperscript{77-79} The inadequate treatment of cancer pain has also been consistently shown to increase physical and emotional symptoms while contributing to greater distress for patients and their families.\textsuperscript{56}

Optimal pain care involves evaluating many complex cultural, social, and spiritual issues. Many different therapeutic modalities are currently available to treat cancer pain: (1) over the counter drugs (e.g., acetaminophen, ibuprofen), (2) non-pharmacologic techniques (e.g., orthoses, prostheses, physical therapy, counseling, cognitive behavioral therapy), (3) complementary techniques (e.g., prayer, massage, acupuncture, music therapy, relaxation techniques), (5) opioid analgesics and (6) spiritual care. The potential for physiologic (e.g., physical dependence) and social (e.g., diversion) side-effects often limit the use of prescription opioid analgesics in patients with cancer pain. Low income and minority patients may be at risk for stereotyping by clinicians that further limits their access to opioid analgesics to legitimately treat their pain, although there is no data to suggest that they abuse prescription opioid analgesics more than Caucasians.\textsuperscript{37,80,81} More specifically, both Morrison and Green showed that racial and ethnic minorities are significantly less able to get their opioid analgesia prescriptions filled in their local pharmacies suggesting significant structural barriers to accessing quality pain care.\textsuperscript{12}

While the literature continues to document the benefits of optimizing pain control, it unfortunately remains under treated. Advanced techniques (e.g., nerve blocks, surgical procedures and devices) also provide benefits for cancer patients but are generally more costly. However, these techniques should be used as part of a multi-model approach that respects the patient’s goals and values in order to improve function and quality of life. Thus, nowhere is multidisciplinary pain care more important than in the cancer patient with pain. Clearly, these modalities and educational efforts should be done in partnership with the patient. Nonetheless, there is very little literature examining the efficacy, effectiveness, or efficiency of these modalities or access to specialty pain care in an ethnically diverse population with cancer. Surprisingly, Anderson showed that brief educational strategies directed at the patient did not reduce disparities in cancer pain care.\textsuperscript{82} The good news is that most physicians report a goal of absolute and complete pain relief or adequate pain relief without distress for patients with cancer pain, although their care may be less than optimal.\textsuperscript{69,83-86} This suggests that strategies designed to improve physician education may improve the quality of pain care.

Schulman et al. and other investigators have identified disturbing differences in the treatment of pain based upon the patient’s age, race, and gender.\textsuperscript{50,87-89} However, little is known about how patient demographic and cultural factors influence pain-seeking behavior and treatment.\textsuperscript{90} Cleeland et al. identified that racial and ethnic minorities with cancer were at increased risk for the under-treatment of cancer pain.\textsuperscript{34} In a study using 31 racial and ethnic minority persons (14 of whom were African Americans), Anderson reported that some patients were concerned about discussing their pain because they thought it was something that they should be able to bear.\textsuperscript{34} In a survey of 13,625 elderly nursing home residents with cancer pain, Bernabei et al. revealed that African Americans were 63\% more likely than Caucasian Americans to receive no pain medications whatsoever.\textsuperscript{91} Up to 40\% of the African American residents reported daily pain and 25\% received no analgesics whatsoever.

Furthermore, Green and Wheeler demonstrated considerable gender-based variability in physician treatment of cancer pain and the pain of terminal illness.\textsuperscript{69,83} To complicate things further, Morrison et al. revealed that when New York City pharmacies were adjusted for crime rates, those in minority neighborhoods were significantly less likely to stock opioid analgesics than those in non-minority neighborhoods.\textsuperscript{92} In a statewide study, Green et al. showed that minority and low-income neighborhoods were less likely to stock sufficient opioid analgesic supplies than non-minority.\textsuperscript{12} Regardless of income, minorities were
less able to access opioid analgesics suggesting that socio-economic status did not influence access for minorities but had a significant impact for non-minorities.12 Thus, minorities are at risk for poor pain assessment while physician variability, sub-optimal treatment strategies, and decreased ability to obtain pain medications may also adversely affect HRQL for minorities with cancer pain.

Physician responses to a series of clinical vignettes revealed considerable variability in their knowledge, perceptions, and goals regarding pain management.33,85,93 Surprisingly, over 30% of the Michigan physicians reported that they had not received any pain management education during their medical training (i.e., medical school, residency training, or via continuing medical education). Yet, they reported that they frequently treated pain complaints while expressing confidence and satisfaction with their cancer and terminal illness pain care whether they had experience treating it or not. Most physicians (> 80%), reported a goal of either absolute and complete pain relief or adequate pain relief without distress for the management of cancer pain and the pain of terminal illness. Using clinical vignettes, significant gender-based differences in their treatment of advanced cancer pain were noted as well. For example, better treatment (including referral to a pain management specialist) was chosen for men more frequently than for women despite similar cancer pain problems. Thus, physician perceptions may lead to variability and the unintentional under-treatment of pain (especially for minority persons). These studies emphasize the importance of physician variability in pain management, while supporting the need to study the quality of pain care from the patient’s perspective.

**CRITICAL UNANSWERED QUESTIONS**

The World Health Organization views pain relief as a human right. Yet, despite evidence supporting the critical importance of race and ethnicity in the healthcare experience, most studies of the cancer pain experience were done in Caucasians. There is limited awareness of the role of race and ethnicity on pain symptom managements in racial and ethnic minorities with advanced cancer.94,95 Yet, the adequate assessment and treatment of cancer pain is critically important in order to improve the overall health, coping, and HRQL of an increasingly diverse and aging nation. Furthermore, the literature has primarily focused on the experience of African Americans and Hispanics. Clearly, the experience of other racial and ethnic minorities (e.g., Native Americans, Asian Americans) need to be examined such that interventions designed to improve HRQL. Furthermore, future investigations into pain assessment measures must be culturally and linguistically sensitive such that the experiences of other underserved and vulnerable minorities (e.g., low income, elders) are considered. Beyond examining African Americans and Hispanic Americans, a great deal can be learned by understanding pain in other understudied minority groups such as Asian Americans and Native Americans leading to improvements in the health of all Americans. The role of patient level factors such as coping differences, attitudes, access and satisfaction with care, cultural beliefs, decision-making amongst racial and ethnic minority patients, as well as the role of co-morbidities (e.g., HIV/AIDS, deprivations, PTSD, substance abuse history) for all patients are also necessary. Additional research on clinician decision-making as well as variability in decision-making is necessary to understand the role of race and ethnicity in minorities with cancer pain. Long-term outcome data are extremely limited and racial and ethnic identifiers should be incorporated to monitor progress in eliminating disparities. It remains unclear whether breakthrough pain is more pronounced in minorities or whether minorities are at increased risk for chronic pain. It is possible that beyond diminishing HRQL, the mere prevalence of breakthrough pain is a sign of diminished quality of care. By understanding differences in the provision of pain care in an increasingly diverse and aging society, interventions can be developed to facilitate healthier lives for all Americans thereby reducing the unequal burden of pain in racial and ethnic minorities with cancer. Clearly, innovative multi-disciplinary research in combination with advocacy and public policy efforts are necessary to adequately address this potentially devastating public health problem.36,37
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