Unequal Quality of Cancer Pain Management: Disparity in Perceived Control and Proposed Solutions

Jeanette A. McNeill, DrPH, RN, AOCNS®, Janice Reynolds, RN, BSN, BC, OCN®, CHPN, and Margaret L. Ney, MSN, APRN-BC

Purpose/Objectives: To examine poverty-related and racial and ethnic disparity in cancer pain management.

Data Sources: Published articles, conference proceedings, testimony, and clinical case studies.

Data Synthesis: Disparity in the quality of cancer pain management exists resulting from interactions among patient, provider, and environmental factors. Irrespective of etiology, disparity results in inadequate management of cancer pain for vulnerable populations (poor patients, ethnic and racial group members, older adults) and is unacceptable in cancer care. Inadequate symptom management affects cancer treatment tolerance, exacerbating disparity in treatment outcomes and affecting end-of-life care.

Conclusions: Evidence-based solutions include a systems approach, quality-improvement and quality-assurance processes that expose disparities and enforce evidence-based treatment per national guidelines, and statewide comprehensive cancer planning to target pain management outcomes.

Implications for Nursing: Oncology nurses and interdisciplinary teams must be aware of disparities in cancer pain management for vulnerable groups, intervene to empower patients through customized educational approaches, and simultaneously implement systemwide strategies to ensure effective pain management and targeted monitoring for high-risk patients.

Key Points...

➤ Socioeconomic status, race, ethnic identity, education, insurance status, and geographic location are interlinked in defining disparities in pain management.

➤ Perceived control may mediate outcomes for cancer pain and may influence disparity in quality of cancer care for pain.

➤ All components of cancer pain management have the potential for disparities, including assessment, reassessment, treatment, and end-of-life care.

➤ Evidence-based solutions include appropriate patient education and systems-level revisions to improve timely and appropriate access and to enforce nationally established guidelines.

Case Study

Mr. S.C. is a 53-year-old African American man with a medical history of hypertension, diabetes, and hyperlipidemia. He reported being screened frequently at checkups and wellness examinations at an urban, university-based, county primary-care clinic because he is poor and does not have insurance through his employer. During a routine screening, he was diagnosed with prostate cancer. He was treated in the county system with surgical and radiation oncology with prostatectomy, radiation therapy, and bicalutamide; within two months, his disease progressed with metastasis to bone; antiandrogen therapy was discontinued. He was prescribed morphine for pain and referred back to primary care while he waited a few months for an appointment with medical oncology. Mr. S.C. had stopped taking his morphine because of his fear of narcotic addiction and poor control of his pain, nausea, and constipation. Consequently,

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he experienced opioid withdrawal. During an urgent visit to the primary-care clinic, he reported a pain score of 10 on a 1–10 scale and was prescribed hydrocodone 5 mg with acetaminophen 500 mg every six hours and propoxyphene-N 100 mg with acetaminophen 650 mg as needed for breakthrough cancer pain. Morphine was not prescribed.

**Literature Review**

Pain is a common symptom associated with cancer; a third of patients with cancer present with pain at diagnosis, and approximately two-thirds experience pain with advanced cancer (Dahl, 2004). Pain may be the result of cancer itself, treatment (surgery, chemotherapy, and radiation), tests and procedures, or comorbid conditions. Undertreated pain leads to adverse clinical outcomes, unnecessary suffering, and decreased quality of life (Strassels, Blough, Hazlet, Veenstra, & Sullivan, 2006). Minorities, especially African Americans, are more likely to develop cancer and have it diagnosed at later stages, which predisposes them to cancer-related pain (Dahl; Ward et al., 2004). Other comorbidities, such as heart disease and diabetes, may be sources of pain and can complicate matters for minority patients with cancer, such as Hispanics, African Americans, and Native Americans.

Evidence is mounting that patients who are economically disadvantaged (i.e., poor) are more at risk for cancer, late stage at diagnosis, and poorer outcomes (Green et al., 2003; Ward et al., 2004). Ward et al. analyzed data from Surveillance, Epidemiology, and End Results statistics on cancer mortality and U.S. Census Bureau information to present an overall view of variances in cancer mortality and morbidity across economic, ethnic, and racial groups. In every aspect of the trajectory, ethnic and racial subgroups and the poor had disproportionately higher mortality rates and shorter survival. For example, the incidence of cervical cancer was highest in Hispanic women, almost two-fold greater than for white women; the mortality rate for all cancer sites combined was highest in African Americans, with African American men 1.4 times more likely to die from cancer (particularly lung, colon, and prostate) than their white counterparts. In terms of survival rates, members of communities in poorer census tracts were 10% less likely to survive than those in more affluent communities.

The poor are disproportionately more likely to be ethnic or racial minorities (Green et al., 2003). When compared with non-Hispanic whites, members of racial and ethnic minority groups exhibit lower educational status, higher rates of poverty, and, subsequently, reduced access to health care (Ward et al., 2004). Location also may play a part in health care and pain management. Both inner-city and rural areas can influence socioeconomic conditions as well as healthcare affordability and availability (Fiscella, Franks, Gold, & Clancy, 2000). Evidence is accumulating that disparities in pain management exist for the poor, as well as for members of ethnic and racial minorities (Green et al.; Bonham, 2001; Cleeland et al., 1994). The subpopulations may overlap significantly.

Poverty refers primarily to low socioeconomic status but also includes inadequate information and knowledge, substandard living conditions, and limited access to health care (Freeman, 2004; Ward et al., 2004). In the homeless segment of the population, more than half lack health insurance (Kushel & Miaskowski, 2006). Some homeless people are insured by the Veterans Administration and various managed-care services (Hatton, 2001). The United States is home to more than 40 million uninsured people (Dahl, 2004; Garson, 2006). Many of the uninsured and underinsured are the poor, including those who are poor and employed (Garson). Another major segment of the uninsured are minorities. According to Hall (2005), in the first years of the 21st century, most Latinos (60%) and more than 40% of African Americans lacked insurance. Rural residents are less likely to be insured than urban residents (Garson). Having health insurance facilitates access to the healthcare system and thus earlier detection of cancer (less pain than with advanced cancer), treatment (which influences pain and symptom management), and palliative and end-of-life care (Garson; Ward et al.). The uninsured have a higher morbidity rate (Garson). Availability of medication is a particular problem; although insurance can limit what medications are covered, those without insurance must pay for all medications out of pocket. Regarding pain management, some patients may consider not only what medications are best for their situations (pain medicine is not one type fits all) but also what they cost (some pain medications are quite expensive). Patients without adequate means or insurance coverage often must choose which prescriptions to fill because of demands on their resources (Dahl; Garson).

Many layers to the issue complicate the root causes. Disparity may be found in all phases of pain management, from assessment of pain to effective treatment (Cintrón & Morrison, 2006). Another important component of pain management is collaboration between patients and families and interdisciplinary healthcare teams to develop and implement effective pain management regimens. The poor are much more likely to have inadequate, inappropriate, or nonexistent pain management (Freeman, 2004). Patients and families who are of lower socioeconomic status lack resources and familiarity and often are less well-educated regarding what comprises good pain management. This is compounded by limited access to pain medications, including provider resistance to prescribing opioids and pharmacies that limit dose strengths and types of medications as a result of excessive regulation or space limitations (Dahl, 2004; Hall, 2005; Morrison, Wallenstein, Natale, Senzel, & Huang, 2000). Therefore, distinguishing whether disparities arise from minority status, poverty, lack of education, lack of healthcare access, or some combination is difficult, if not impossible (Cintrón & Morrison; Freeman). Mr. S.C.’s case illustrates many of the issues—he is African American, has been diagnosed with late-stage prostate cancer, is poor, is served by county medical clinics because of his lack of private health insurance, and lacks knowledge regarding opioids and effective symptom management. Perhaps this case also involves provider resistance or lack of skill to prescribe opioids or to teach patients effective pain management.

**Perceived Control**

Figure 1 depicts the cancer trajectory from prevention through survival. Although dependent on cancer type, survival and quality of life certainly vary, and most patients enjoy some period of survival after treatment. However, for the economically disadvantaged and certain racial and ethnic groups, the period may not occur or may be substantially shortened as a result of disparity in care at every point on the trajectory. As Freeman (2004) noted in his comments on disparities in
In this article, the authors propose that perceived control may be a more pervasive factor in the occurrence of disparity across the cancer trajectory, influencing not only pain-related outcomes but also other aspects of disease and symptom management and even treatment effectiveness. This may be a fruitful avenue for future research. For the purposes of this discussion, confined to the occurrence and treatment of pain, Figure 1 illustrates the proposed influence of perceived control. Mr. S.C.’s case illustrates well the various influences on his pain management plan and his adherence to that plan; his lack of perceived control over management of side effects and fear of addiction resulted in his lack of adherence to the prescribed medication, which led to increased pain and suffering. Furthermore, and also illustrated by the case study, the occurrence, management, and outcomes of pain related to cancer are intertwined with factors related to prevention, early detection, effective treatment, and survival and quality of life. Delay in diagnosis and lack of timely access to care result in poorer treatment outcomes. So the proposed effect of perceived control can be a pivotal potential area for intervention to improve outcomes for those who are experiencing disparity.

Components of Pain Management and Potential for Disparity

Assessment

All areas of pain treatment have the potential for disparities in management. However, assessment is the crucial point in the pain management cycle and influences the remainder of the symptom experience. When reassessment is added to the overall assessment concept, then assessment can be seen as the pivotal component. Abundant evidence exists of disparity in assessment for racial and ethnic groups, the poor, those who are less well-educated, and older adults (Bonham, 2001; Herr et al. 2004). The fact that individuals in any of those groups may have overlapping membership in other vulnerable groups compounds the problem.

Additionally, characteristics of the subgroups—such as a passive attitude toward health care found in some older patients or a distrust of Western medicine by some minority patients—further intensify the potential for deficits in assessment and reassessment. Patients often want to be “good” and therefore do not report pain or are not assertive in requests for pain management or revisions in pain management plans. The attitude was found to be common in older, less educated, and lower-income adults (Dahl, 2004). In a study of 709 older adults with hip fractures, Herr et al. (2004), found that in the first 24 hours following admission, only 5.5% of patients had every-four-hour pain assessment and only 26% of patients were assessed at eight-hour intervals within the 72-hour study period. Reassessment only occurred 22% of the time in the first 24-hour period, and at a rate of 15% for the 72-hour study period. In another study, Anderson et al. (2000) found that of 108 African American and Hispanic patients with pain related to metastatic cancer, 31% of African American and 28% of Hispanics received analgesics of insufficient strength to manage their assessed pain. Furthermore, physicians underestimated pain severity in 74% of African Americans and 64% of Hispanic patients. Inadequate pain assessment remains a major barrier to optimal pain management.

cancer care, “There is a critical disconnect between what we discover and what we deliver, between what we know and what we do for all people” (p. 72).

Vallerand, Hasenau, Templin, and Collins-Bohler (2005), in their discussion of disparities related to cancer pain, proposed that the element of perceived control may be a mediating factor influencing the occurrence of disparities in pain, symptom control, and functional status. They studied 281 patients with cancer, 35% of whom were African American, whose mean age was 55 years and who had a variety of cancer diagnoses, primarily breast, lung, colon, or head and neck. The study variables included pain intensity and distress, functional status, knowledge, perceived barriers, and perception of control over pain. Perceived control over pain was measured with a set of three questions that included belief that pain was controllable, belief that they were in control of their pain, and whether they believed their pain was controlled at that time. African American patients had more pain, higher symptom distress, and lower functional status than whites overall. The investigators controlled for covariates (education, marital status, gender, employment, and metastasis) using analysis of covariance and found that differences in pain intensity were significant. Examining predictors of the disparities, the investigators found that perceived control was the single predictor of disparity; when it was controlled, differences in pain-related distress and functional status were reduced. Vallerand et al. concluded that perceived control may mediate outcomes of cancer pain treatment. They proposed that a feeling of control can empower patients, making them active participants in pain management efforts.

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Because pain is a subjective symptom frequently without “evidence” to substantiate it, healthcare professionals tend to discount it or even disbelieve it when they are not well educated in pain management or when a social disconnect exists (Tait & Chibnall, 2005). For example, a social disconnect can occur in encounters involving minority patients, the poor, or substance abusers that involves negative attitudes or responses from uninformed healthcare providers. Lebovits (2005) highlighted the irony that the invisible nature of pain makes it more likely to be discounted or omitted in assessment, whereas racial origin often is easily observable and seems to hinder pain assessment, as documented by numerous authors.

Treatment and Evaluation

Appropriate treatment for pain relies to a great extent on good communication and trust between healthcare providers and patients with cancer. Pain management must be a collaborative process. Characteristics of providers and patients (and families) may contribute to the effectiveness of collaboration, although little research has addressed the topic, except in the area of racial and ethnic differences. In a review of racial and ethnic disparities in pain management, Tait and Chibnall (2005) noted that minority patients reported less inclusion, especially when partnerships were “race discordant” (i.e., the patient and physician were of different races). Minorities also reported less confidence in the medical system than did non-Hispanic whites. Other aspects of discordance, such as gender and socioeconomic status, have not been reported in the literature as influences on pain management, and further research is needed.

Minority patients with cancer treated in centers with primarily minority population bases have been shown to be three times more likely to have inadequately controlled pain than Caucasian, more affluent patients (Anderson et al., 2000; Cleeland et al., 1994; Vallerand et al., 2005). A study of 116 women in two programs with the aim of advocating, assisting, and supporting women with cancer in an urban area of northern California (Eversley et al., 2005) found that being of low socioeconomic status, being Latino, and having a mastectomy followed by chemotherapy were important indicators for increased symptoms and poor pain management.

Patients with substance-abuse problems can encounter great difficulties in gaining appropriate pain management; this is another area in which pain management disparities exist (Passik & Kirsh, 2005). Healthcare professionals sometimes are unwilling to treat pain in such individuals because of fears of regulatory concerns, drug diversion, contributing to patients’ addiction, or moralistic terms (Passik & Kirsh).

Assuming adequate assessment and management, one of the greatest difficulties for urban and rural poor is availability of the pain medication ordered for them even when they are able to pay for it. Pharmacies in rural and inner-city areas may choose not to carry opioids or newer analgesics for a variety of reasons, ranging from fear of robbery (because of illicit use) to low demand (Vallerand et al., 2005). Other reasons cited by urban pharmacies are restricted pharmaceutical formularies because of costs and agreements, limited physical space, and excessive mandatory documentation (Headen & Masia, 2005). Even when medications are available, homeless patients with cancer pain may have difficulty obtaining them and retaining them for use (Kushel & Miaskowski, 2006).

The poor are among those who are uninsured or insured by Medicare or Medicaid. Many times, the costs of drugs are not covered by those plans or formulary restrictions limit the types and amounts of medications approved and available. Analgesics are not “one size fits all,” which influences the effectiveness of pain management. Other important adjuncts to pain management, such as physical therapy, frequently are not covered expenses and therefore are out of the reach of the poor (Eversley et al., 2005).

Although few would dispute that pain management at the end of life is an ethical right, it remains more readily available to the portions of society with money than those without. The University of Michigan News Service (2005) reported that older adults with incomes greater than $70,000 suffered less pain at the end of life than poor older adults. Hospice, an important source of effective pain management at the end of life, is used less by minorities. Because of frequently compromised access to the healthcare system for the poor and minorities, members of the subgroups are not directed into the hospice system. The same difficulty may prevent them from re-enrolling if they leave the system. Kapo, MacMoran, and Casarett (2005) indicated that African Americans who left the hospice system were less likely to be re-enrolled before dying. The authors could not determine with the data available why that was so; however, they suggested that inadequate healthcare access might be a determining factor. Similarly, Struessels et al. (2006) suggested that less use of hospice was a result of inadequate healthcare access. If inadequate healthcare access leads to decreased referral to hospice, then the uninsured, as well as rural and urban patients with lower socioeconomic status irrespective of race or ethnicity, also would have decreased access (Gibson, 2001). Finally, in their analysis of long-term care services in rural areas, Hutchinson, Hawes, and Williams (2005) noted that minorities, rural populations, older adults, and the poor used hospice services the least.

Hospice frequently is not an option for those whose home situations (e.g., homeless, housing without indoor plumbing, high-crime areas) are less than ideal for home care. The option of inpatient hospice or hospice in a long-term care facility does not always exist. In addition, if a care facility is of poor quality or unpleasant (which may occur in facilities for those of lower socioeconomic status), family members may perceive that pain relief will be unsuccessful. Miettinen, Tilvis, Karppi, and Arve (1998) studied close relatives (N = 371) of older patients who had died within the previous two-year period in Finland. Finland is very different than the United States in that it is ethnically homogeneous and medical treatment is available, but pain management in dying patients still was handled poorly. The lack of effective care was viewed negatively by family members. Participating family members indicated that 57% of their loved ones suffered from moderate to severe pain and that as many as 22% of them had received ineffective treatment for pain.

Patient, Family, and Provider Education

A lack of formal education affects not only earning potential but also general medical awareness, such as the ability to know what the components of good pain management entail and to advocate for it. Language and communication barriers, influenced by lack of education and reduced ability to talk to healthcare providers, influence the availability and effectiveness.
of pain management (Eversley et al., 2005). Educating patients about their right to pain management and about what constitutes good pain management allows them the autonomy to feel that they have control of their pain (Vallerand et al., 2005). Minority patients may have less partnership with their healthcare providers, which may influence their perception of control. This is especially true when relationships between healthcare providers and patients are racially discordant. Tait and Chibnall (2005) found that patients had greater satisfaction with pain treatment when providers and patients were of the same race.

The family is an essential component of pain management, particularly for some racial and ethnic groups, and should be well educated so that they can help patients adhere to the pain management plan and avoid subversion (caused by family members’ misconceptions and incorrect beliefs). In facilities caring for the dying, families who do not have sufficient information on all aspects of cancer (diagnosis, prognosis, and treatment choices) may assume that pain relief will most likely be ineffective (Miettinen et al., 1998).

Finally, health literacy is a huge barrier to pain management. Minority groups are disproportionately affected by low health literacy as well as lower economic status. More than half of Medicare and Medicaid recipients read at the fifth-grade level or lower (Glassman, 2007). Those with low health literacy spend more time in hospitals and are less able to take their medications appropriately (Glassman).

**Evidence-Based Solutions**

The challenge of ending disparities in cancer pain management can and must be met. A systems approach, advocated by McNeill, Sherwood, and Starck (2004), can bring about the monitoring of and improvement in outcomes that are needed to ensure high-quality cancer pain management for all patients. The components of a systems approach (modeled on programs in the aviation industry) include a commitment to teamwork, resolution of communication gaps and opportunities for miscommunication, and system-level changes in documentation, ordering, and follow-up to prevent mismanagement of pain. The elements and critical indicators in an effective plan have been proposed by the American Pain Society and guide high-quality cancer pain management (Gordon et al., 2005). (The guidelines can be ordered at www.ampainsoc.org/pub/cancer.htm.)

In most institutions and agencies, quality-assurance systems already are in place but have been limited by the way the systems collect data (Fiscella et al., 2000). Beyond the institutional level, community and statewide initiatives can help establish good pain management for all patients with cancer.

Using the components of pain management—asessment, treatment and evaluation, and patient education—as one axis, Table 1 summarizes evidence-based solutions to enhance perceived control on the part of patients and families; improve communication, particularly with high-risk patients; and address the economic and sociocultural environmental factors that influence cancer pain management.

Fiscella et al. (2000) proposed five principles to address socioeconomic, racial, and ethnic disparities in health care in general. The principles can be applied easily to cancer pain management. First, recognize that disparity in pain management is a significant problem. Second, identify the deficits in current approaches to data collection regarding discovery of disparities. For example, some systems do not analyze cancer pain management outcomes data by age, ethnic group, or pay status, which needs to be rectified so that disparities in outcomes can be obvious. In addition to looking at outcomes, the third principle proposes stratifying clinical performance measurement data by population groups (e.g., race and ethnicity, socioeconomic status, insurance status, age).

The fourth principle addresses the need for population-wide monitoring to be adjusted for population group characteristics (race and ethnicity and socioeconomic status). Finally, Fiscella et al. advised implementing economic reimbursement strategies to adjust payment for services to minority and poor populations, giving the example of Great Britain, where more deprived areas receive higher reimbursement because of higher need.

On the statewide level, one avenue for bringing into greater visibility not only the existence of disparities related to socioeconomic status, race and ethnicity, or location (e.g., inner city, rural) but also offering the potential for solutions is the use of a comprehensive cancer-control plan (CCCP). A review of the CCCPs at www.CancerPlan.org shows that although most address the subject of cancer pain, it is mentioned only superficially such as “good pain management should be available” or “healthcare professionals should receive education in pain management.” The Maryland Comprehensive Cancer Control Plan (Nesbit et al., 2004) is an example of an approach that not only identifies disparities but also incorporates solutions. The plan specifically addresses barriers related to pain management, such as preferred drug lists, pharmacy and medication availability, rural patients’ access, minority risk for undertreatment or no treatment, and lower levels of insurance in certain communities. Selected strategies to improve treatment of the disenfranchised include the following.

- Uniform reimbursement for pharmacologic and scientifically based nonpharmacologic pain management therapies regardless of therapeutic medication class, choice of drug or therapy, medication delivery (i.e., route), site of service, or disease phase
- Assistance for pain therapy payments for patients at or below 250% of the federal poverty level
- Requirement that pharmacies have pain management medications, particularly opioids, readily available for older adult and opioid-naïve patients as well as those who need higher doses
- Requirement that all healthcare providers be competent in symptom assessment and management of pain in patients with cancer

Strategies deal with increasing public knowledge and awareness of cancer pain, giving patients the right to appropriate and adequate pain management, dismissing myths regarding pain management, and empowering patients and families to communicate with their healthcare providers (Nesbit et al., 2004).

**Practice, Educational, and Research Implications**

Awareness, empowerment, and accountability are keys to resolving disparities in pain management in everyday practice. An urgent need exists for continuing education and heightened awareness for all members of the interdisciplinary...
team, not only those in the specialty of pain management, regarding the existence of disparities. If care providers are not aware of the difficulties associated with vulnerable groups (the poor, racial and ethnic groups, and older adults) with pain management, they cannot seek to remedy them. Secondly, intervention programs to empower patients and families should be offered that are culturally sensitive and based on appropriate literacy levels. Patients with cancer and their families need to be instructed on their right to pain management as well as the components of effective pain management. Healthcare professionals must understand not only the necessity of educating their patients and patients’ families but also how to provide appropriate instruction related to the cultural and educational characteristics of certain population groups. A critical component of empowerment is assessment of patient and family resources. This must begin at the initial encounter so that the planned regimen will be feasible and attainable and so that resources can be located to assist with provision of the most effective management possible. Finally, healthcare providers and organizations must be accountable to provide high-quality pain management to all patients.

Freeman (2004) recommends that all uninsured patients with cancer and their families need to be instructed on their right to pain management as well as the components of effective pain management. Healthcare professionals must understand not only the...
a cancer diagnosis should receive immediate medical coverage so that full access to treatment and excellent symptom management are available. In addition, research studies of cancer disparities should be supported to diminish bias and to influence public policy makers about the economic cost of treating later-stage cancers.

Further research is needed urgently. The American Pain Society (2004) identified disparities in pain care and has urged professionals to resolve them through clinical care, education, and research. For instance, a preliminary study by Keefe et al. (2005) examined partner-guided cancer pain management at the end of life. Although the study was not stratified according to income or race, the results are applicable to effects related to literacy and culture. The study incorporated education on pain management by a nurse educator as well as training on relaxation and coping skills. Outcomes included partners’ (N = 78) increased confidence in their ability to help their significant others with pain management, helping buffer caregiver stress, and giving useful coping skills to both.

**Conclusion**

Disparity in cancer pain management exists for members of vulnerable population groups. Interventions targeted at the individual level (in the form of customized education, empowerment, and family involvement) and at the system level (increasing healthcare provider competence, improving access to health services, being sensitive to vulnerable populations, and instituting system-level protections) are mandated to rectify the issue.

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