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Health Disparity and the Nurse Advocate

Reaching Out to Alleviate Suffering

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This article reviews current research in health disparity in the delivery of care to African Americans. These studies provide powerful evidence that, even when controlling for differences related to access, insurance, and socioeconomic status, our healthcare system is deeply racist. While it is difficult to estimate the cost of racial bias in healthcare delivery, this article advances the notion that human suffering is the most significant consequence of racial disparity. Solutions include a renewed commitment to increasing cultural knowledge, a concerted effort to recognizing and studying racism, and creating a role for the community nurse advocate in correcting disparity. **Key words:** *African American*, *human suffering*, *nurse advocate*, *racial disparity*, *racism*

HEALTH disparity is a serious concern for nurses and other healthcare professionals. It takes many forms, occurs at all levels of care, and in all practice environments. It should not be surprising that health disparity has many different meanings. For example, *health disparity* may be defined as the disproportionate burden of disease, disability, or death among a particular group, or it may refer to differences in health status among diverse groups of people. Health disparity may also be defined as the discrepancy between the deaths observed in minority populations and the number of deaths that would be expected if the minority population had the same death rate as did the nonminority population. Finally, health disparities may be described as differences in the quality of healthcare related to racial or ethnic differences as well as age, gender, sexual orientation, or socioeconomic status.[1]

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For the purposes of this article, health disparity is defined as differences in the quality of healthcare on the basis of the client's racial or ethnic group. More specifically, this article will review evidence of racial disparity in the delivery of healthcare to African Americans. Next, the suffering that racial disparity in healthcare engenders will be explored and presented as among its more significant consequences. While increasing cultural knowledge should remain an important part of our efforts to correct racial disparity, recognizing and studying racism must also factor into our solutions. Finally, the role of the nurse advocate in alleviating this suffering will be advanced.

Before citing evidence of racial disparity, it is important to acknowledge that the term conjures up harsh and abrasive words like discrimination, prejudice, bias, racism, and bigotry. These words are often used interchangeably and are usually hard to swallow when directed at us individually or as members of a group. We tend to deny such allegations and to distance ourselves from bigotry and hatred. Overt racism usually draws condemnation and disgust and, depending on the circumstances, it may be considered a criminal act.

Racism is not always as apparent as the behavior of the contemptible fictional villain

who twirls his mustache and delights in the suffering of others, however. It is often more difficult to detect and may be unintentional, resulting from unexamined beliefs or insufficient or inaccurate information. Whether it is intended or not, racial disparity in the delivery of healthcare to African Americans is an example of discrimination. Sadly, evidence of racial disparity in healthcare is abundant.

EVIDENCE OF RACIAL DISPARITY

The Institute of Medicine's (IOM's) groundbreaking work *Unequal Treatment* reviews more than 100 published research studies that reveal disparities in the type and quality of healthcare received by racial and ethnic minorities in the United States. In most of these studies, disparities remained after controlling for a variety of factors, including differences in access to healthcare, insurance, socioeconomic status, and patient preference. The evidence is impressive but pales in comparison to the IOM's acknowledgment that their review "... represents only a fraction of the published studies that investigate racial and ethnic differences in access to and use of healthcare services."[2(p39)]

The research presented in the IOM study cites racial disparity in healthcare delivery that occurs at levels of care and in practice settings that fall outside of nurses' purview. For example, the preponderance of evidence documents institutionalized racism, which is the collective failure of an organization to provide appropriate care on the basis of race or ethnic origin.[3] A study by Krishman et al[4] is a case in point. The researchers assessed adults with asthma enrolled in 16 managed care organizations for care consistent with the National Asthma Education and Prevention Program (NAEPP) recommendations. The findings indicate that in all 5 domains of care developed by the NAEPP, significantly fewer African Americans than whites reported care that was consistent with national guidelines. Differences in care by race were independent of age, education, employment, and frequency of symptoms. While it is possible for at least 2 of the NAEPP guidelines to be carried out by nurses, the study reported patient perceptions of interactions between physicians and clients.

Although studies from the IOM report are consistently client-physician focused, it is important for nurses to understand the scope of racial disparity in the delivery of healthcare. Developing a familiarity with the research in this area will help nurses identify clients at risk, recognize the consequences of racial disparities in the delivery of healthcare, and develop interventions aimed at reducing disparity in care delivery.

Selected studies from the IOM report were located for this article. These are reviewed together with several additional studies that add information more closely related to the care given by nurses. Unlike the IOM study that focused on care received by *all* minorities, the articles cited here are limited to the documentation of disparities in healthcare received by African Americans. The findings are consistent and disturbing. Many researchers suggest that disparities in the delivery of healthcare to African Americans may contribute to racial disparities in outcomes such as increased morbidity and mortality in cases of disease or illness, prolonged separation from family members in cases of government interventions when child maltreatment is suspected, and others.

For example, Morton[5] studied the overrepresentation of African American children in the welfare system on the basis of founded allegations of abuse or neglect. This study is another example of institutionalized racism. Disputing conventional wisdom that has historically pointed to the relationship between lower income (poverty) and child maltreatment, Morton found that poverty, used to explain the higher incidence of abuse and neglect in African American children, appears to have no relationship to the incidence of abuse and neglect in Hispanic families. In other words, poor African American families are no more likely to abuse their children than are poor Hispanics, yet African American children are more likely to be removed from their home and placed in the welfare system when

abuse or neglect are suspected. Morton concludes that if poverty were an accurate predictor of child abuse and neglect, it would be consistent for all race groups, and it is not.

The role that nurses play in the overrepresentation of African American children in the welfare system cannot be determined with accuracy. Approximately 8% of reports alleging child abuse or neglect come from "medical personnel," a broad category that is not clearly defined in the Health and Human Services Report on child maltreatment.[6] The manner in which disparity is occurring, however, may be more important to consider than the relative contribution that the nurse's bias makes to the whole.

Morton and others[7,8] suggest that the potential for healthcare providers to associate social or cultural characteristics of African Americans (ie, lower incomes and a higher percentage of households headed by women) with an increased potential for the occurrence of child maltreatment may help to explain this overrepresentation and account for a source of disparity. Buying into these misconceptions is stereotyping. It may cause healthcare professionals to confuse or substitute mistaken beliefs with other more valid indicators of abuse or neglect, resulting in flawed assessments and biased care. The relationship between individual bias or misconceptions and institutionalized racism has not been determined, although repeated stereotyping at the provider level may ultimately be reflected at the organizational level. The consistency of the findings documenting disparity at the institutional or organizational level is difficult to dispute. It is evident in the allocation of healthcare services and resources, as well as in the diagnostic and therapeutic arenas.

Disparity in the allocation of services and healthcare resources is less well documented than is health disparity at the diagnostic and therapeutic level, although the findings are noteworthy. They contribute information that raises concerns and invites further study. For example, Tai-Seale et al[9] found that African Americans are significantly more likely than whites to experience a decline in the rate of service use following mandatory Medicaid (health maintenance organization [HMO]) enrollment. Service use includes physician care and inpatient admissions. Both are disproportionately reduced for blacks following their enrollment in a mandatory Medicaid HMO. The reasons for the decline are not identified, although the study offers several possible explanations that warrant further investigation. Potential explanations include the possibility that not only does mandatory enrollment restrict the pool of providers available to enrollees but also that these providers are less likely to be located near African American beneficiaries. In addition, Medicaid beneficiaries must compete with privately insured clients for physician services, and physicians may be less inclined to see African American HMO clients because they associate race with inadequate prior treatment or increased probability of missing appointments.[9]

Disparity in the disclosure of financial costs and options to patients is a further example of a race-based difference in care delivery. It may potentially affect individuals' willingness to seek healthcare. To illustrate, African Americans are significantly more likely than whites to report being asked about their ability to pay for medical care.[10] At the same time, whites are more likely to be offered payment allowances than blacks. The difference between being asked about the ability to pay and being offered payment options is subtle, although substantial, and imparts a different set of expectations about the medical visit. It is important to ask if disparities in the allocation of services and healthcare resources provide yet another obstacle to receiving care that eventually will lead some African American clients to avoid seeking care altogether.

Health disparity in the diagnostic and therapeutic arenas compounds our concern. The IOM report[2] documents racial and ethnic differences in a wide range of diagnostic and therapeutic procedures in more than a dozen categories, ranging from human immunodeficiency virus/acquired immunodeficiency

syndrome to mental health services. Many studies use large databases and provide evidence of institutionalized racism.

The study by Groeneveld et al[11] of institutionalized racism in the use of potentially life-saving procedures following cardiac arrest is a case in point. It is the first national study of cardiac arrest survivors and sampled all Medicare beneficiaries from 1990 to 1999 who were hospitalized with a diagnosis of ventricular fibrillation or cardiac arrest. The data indicate that blacks have a significantly lower probability of receiving an implantable cardiodefibrillator than do whites. The researchers suggest that at least some of the survival disparity between blacks and whites following cardiac arrest may be explained by the differential rates of cardiac procedures like implantable cardiodefibrillator implantation. The study did not account for patient preference or health-related behaviors, factors that may diminish the strength of the relationship between differential treatment and survival. It did, however, control for comorbidities and multiple demographic, socioeconomic, and clinical factors.

Research further indicates that African Americans are significantly less likely than whites to receive analgesics following long bone fracture, despite similar reports of pain intensity. Differences in the expression of pain on the basis of ethnicity have not been clearly determined, although selecting patients with similar injury (type and severity of fracture) may increase the probability that they have, at minimum, a comparable physiological basis for their pain. According to a study by Todd et al,[12] emergency department patients with specific well-defined fractures and the absence of confounding medical or surgical problems had nearly identical assessments of pain by physicians and nurses. Despite the physicians' apparent ability to assess pain, however, African American patients in their care had a 66% higher risk of not receiving analgesia than whites. The study controlled for multiple covariates, including payer status, need for fracture reduction, and time since injury. While it is encouraging to note that pain is being assessed, the disparity in the treatment of pain is disquieting.

Because of the comparatively recent use of kidney transplantation in patients with end-stage renal disease, few studies have evaluated racial disparity in the delivery of care to this population. Several issues complicate the findings. To begin with, there are fewer donor matches available to African Americans than to whites, and, in addition, fewer African Americans select renal transplantation as an option than do whites.[2] Despite these concerns, however, research indicates that among patients who select transplant as an option, African Americans are significantly less likely than whites to be referred for, or to receive, a renal transplant. African Americans are also less likely than whites to be placed on a waiting list.[13]

The larger and better-known studies of racial disparities in the delivery of healthcare have been conducted in the area of cardiovascular disease and its treatment. While it is beyond the scope of this article to review this particular body of evidence in its entirety, the IOM report reviewed 26 studies, indicating that they provide "some of the strongest and most consistent evidence for the existence of racial and ethnic disparities in care."[(2p39)] Studies by Schulman et al[14] and Brown[15] were not included in the IOM report, but are relatively typical of those that were. In these studies, African Americans are significantly less likely than whites to be referred for cardiac catheterization[14] or to undergo cardiac catheterization, percutaneous transluminal coronary angioplasty, or coronary artery bypass graft surgery.[15] All data were adjusted for age, insurance status, and secondary diagnoses. Health disparity for African American women in these studies is noteworthy. Both Brown and Schulman et al found that black women were significantly less likely to receive appropriate referral and treatment for cardiovascular disease than all other race and gender groups.

African American women suffer from health disparity in other therapeutic and diagnostic areas as well. For example, Bradley

et al[16] found that African American women are significantly more likely to receive breast-conserving surgery than whites despite the fact that, as a whole, African American women are more likely to present with late-stage breast cancer. African American women are also more likely to have no surgery for breast cancer than white women. The results of this study and others like it are complicated by the fact that low socioeconomic status is associated with unfavorable breast cancer outcomes, regardless of race, and that African American women are more likely to have lower incomes than white women.[16]

An analysis of data from the National Maternal and Infant Health Survey reveals further evidence of racial disparity in healthcare delivery to African American women. As a whole, they are less likely than white women to receive breast-feeding advice from Women, Infants and Children (WIC) counselors, despite the documented benefits of breast-feeding. Researchers note that these findings are particularly troubling in light of the existing disparity in morbidity and mortality between African American and white infants. Interestingly, disparity was not evident in breastfeeding advice from medical providers.[17]

The suggestion that race independently influences the delivery of healthcare from so many different perspectives is alarming and has aroused the passions of many. The consequences of racial disparity in the delivery of care are equally disturbing. These include increased morbidity and mortality, inaccurate care plans and inadequate treatment based on imprecise assessment (including risk assessment), ineffective communication between provider and patient, and inequitable resource allocation. Consequences that are less likely to be identified include mistrust, decrease in the frequency of physician visits, and failure to seek healthcare.

The solutions to race-based differences in healthcare delivery are as complex as the origin of bias, discrimination, and stereotyping. For example, Martin[18] encourages physicians to scientifically evaluate ethnicity and pain management practices rather than to consider emotional or anecdotal experiences. It is precisely these types of anecdotal experiences, however, that broaden our respect for the intricate nature of cultural diversity and the potentially devastating human consequences of racial disparity in the delivery of healthcare. Because institutionalized racism is a collective failure and a systemic problem, it tends to be faceless, distant, and anonymous. In addition, the consequences of racial disparities in the delivery of healthcare are not always as apparent as the empirical evidence, and it is therefore easy to overlook or ignore them. Personal narratives help us to understand the extent to which health disparity renders patients invisible and misunderstood.

For instance, racial disparity is evident in our understanding of black motherhood, and the impact of negative social scripting on the process of avoiding adolescent pregnancy. Martyn and Hutchinson[19] studied negative social scripting in a small sample of young African American girls who chose to delay pregnancy despite cultural messages (negative social scripting) that encouraged childbearing as a means of achieving adulthood. The participants describe the context of their lives as a continual reinforcement to remain poor, undereducated, single mothers, who often become dependent, abused women. Even though these negative social scripts were attributed to the community, and not specifically to the adolescents' encounters with healthcare professionals, it is not unreasonable to imagine that nurses may interpret early childbearing as a likely consequence of being poor, black, and female.

According to the girls, recognizing positive role models was the most significant factor in avoiding pregnancy. Most participants had more than one positive influence whose role was to support better life choices and protect them from risk. Role models or influences included parents, parent figures, partners, and communities.[19] Understanding negative scripting and the nature of the role model or positive influence appears to be an essential skill for the nurse advocate who

seeks to intervene with clients at risk for early childbearing.

The concept of black motherhood and maternal work is also addressed in research conducted by Banks-Wallace and Parks[20] and Boyle et al.[21] While these studies were conducted utilizing different samples, the "central mothering task" that emerged was protection. Both groups of women wanted to shelter their children from racism, negative stereotyping, and ameliorate oppression in their lives. These studies of black motherhood emphasize the negative impact of stereotypes and labels. In Boyle et al, mothers of adult children with human immunodeficiency virus resisted the label of caregiver, telling researchers, "I wasn't just his caregiver, I was his mother! There's a difference, you know."[21(p123)] Interviewers recognized that the term "caregiver" had emerged from the white middle class ethos of healthcare professionals and replaced the word with "mother" in subsequent interviews. As a result of their experience, Boyle et al caution healthcare professionals to "be cognizant of the labels that we put on others, labels that fit our reality, but not the deeply personal context of 'caring' for family members."[21(p130)] It is important to ask, however, if labeling represents a disparity in the delivery of healthcare.

Labels and stereotyping are the result of prejudging the individual realities of our clients and assuming that they are similar to our own. In a manner of speaking, they help us understand the world and to make sense of confusion. Labeling and stereotyping are far less benign than this. According to Boyle et al,[21] they trivialize and marginalize the individual. Care based on inaccurate perceptions in the form of labels, stereotyping, or prejudice is not just and has the potential for creating disparity in all that nurses do for their clients.

Disparity also exists between White Americans' understanding of concepts like person, health, and family, and how these words are used and understood by African Americans. McCollum[7] notes that blacks are often at a disadvantage in family therapy because therapists may not understand the composition of black families. For example, the traditional father-husband role is often inconsistent with the earning power and the opportunities afforded to black men in America. Family roles and composition are more flexible and considered strengths of the African American family. According to McCollum, developing an understanding and awareness of the historical and current experience of being black in America will help establish trust and facilitate the therapeutic relationship.

In Fongwa's study of quality-of-care issues, notions of health were tied often to negative experiences with healthcare providers and the overriding perception that "proof of insurance is not a guarantee of quality care."[22(p31)] Consequently, many of the themes identified in this study have negative connotations. For example, the term "healthcare militancy" was assigned to strategies for obtaining deserved care. While healthcare militancy may be considered harsh, and bring to mind confrontational or belligerent behavior, for the participants in this study, it included being frank with providers, clearly describing symptoms and feelings, and asking for referrals to specialists.[22] It enabled patients to obtain appropriate care and avoid situations in which their needs and concerns were discounted, misunderstood, or overlooked. On the other hand, to providers who are not African American, healthcare militancy may be perceived as unacceptable or aggressive behavior and contribute to a breakdown in clinical communication.

The use of folk idiom may also contribute to a breakdown in clinical communication and interfere with the provider's ability to elicit, understand, and respond to patient concerns. For example, Snowden[23] revealed that blacks are more likely than whites to describe mental health symptoms using somatic complaints rather than expressions of hopelessness or demoralization. In other words, for African Americans, the symptoms associated with seeking mental health services typically include shortness of breath, dizziness, and trembling. It is important to understand that

failure to recognize the idiom or phrasing of distress in African American clients will affect recognition, diagnosis, and treatment of mental health problems as well as trust in the provider.

Research by Brown et al[24] adds to our understanding of African American perceptions of health. In answer to the question "What does health mean to you?" African Americans are more likely than whites to answer in value-related responses like spending time with their family and maintaining quality of life than in physical-related responses like mobility and being in good shape. Again, understanding the health values of African Americans is essential in establishing trust, as well as planning interventions.

Finally, contemporary media, social, and political images of African Americans may bias our understanding of the notion of person and negatively influence the delivery of healthcare. For example, African American women have been characterized by "colonizing images" like the welfare mother, matriarch, mammy, and other inaccurate and inappropriate descriptors that serve to marginalize and diminish them.[21,25] While colonization is not a new word, colonizing images has become part of contemporary dialogue. Because colonizing images attempt to separate and identify individuals and groups by attaching unfavorable and oversimplified labels, they stand to have a negative impact on care delivery. According to Taylor, "Colonizing images are easily embedded within the labels that we use to determine nursing and medical diagnoses and frequently devalue African American women and their life experiences."[25(p43)]

Colonizing images threaten accurate perceptions of the African American man as well. Aggression and poverty are often erroneously associated with the African American man, primarily because research on the African American middle class has not kept pace with social changes in the African American community.[7] According to the IOM,[2] the attitudes and practices that arise from these often unexamined misconceptions may result in uncertainty in clinical communication and decision making, and will lead to disparity in the delivery of healthcare.

The evidence cited here is impressive and convincing. Racial disparity exists in healthcare access, treatment options, and outcomes. Whether institutional or individual, the allocation and use of services and resources is affected. Compounding factors that include stereotyping and labeling, negative social scripting, and colonizing images serve to perpetuate and, in some ways, intensify the disparity because they provide "acceptable" explanations.

DISPARITY AND HUMAN SUFFERING

Although the evidence is substantial, many do not find it compelling. Perhaps it is because there is no "face" to the issue. Allowing suffering into the conversation shifts its focus and helps to put a human face on health disparity. Nursing and biomedical ethics literature contains scattered definitions of suffering. Signs, symptoms, and synonyms of suffering include, but are not limited to, despair, pain, hopelessness, shame, and voicelessness. Conceptual correlates between the scholarship literature related to suffering and the health disparity research cited here include mistrust, invisibility (patients are overlooked), unknowing (patients are misunderstood), and loss of humanity (patients' needs and concerns are discounted).

Putting a face on suffering is not as simple, however, as listing the behaviors and experiences associated with it. Green's photo essay *The Human Face of Health Disparity* puts "humanity into the numbers."[26(p303)] Pictures of minority patients are featured next to brief summaries of landmark health disparity studies. The photo essay reminds us that the ultimate consequences of health disparities are born by individuals and their social worlds.

Imaginative literature (poems, plays, novels, etc) is written by those who respond to the perceived triumphs and losses of others around them. It provides us with a conduit

through which we may study society, as well as explore the experiences of individuals and their social worlds. As such, then, imaginative literature allows us to examine suffering and helps also to put a face on health disparity. Literary analysis is a relatively new approach to nursing scholarship and while it is considered often the aegis of literary critics and philosophers, literary analysis has many advantages for nurses, particularly in the study of sensitive issues, or disturbing topics that may be considered taboo, or involve other prohibitions like racism. Often these topics cannot be examined fully by conventional means of inquiry alone, making literature a reasonable adjuvant in our search for knowledge and understanding. Excerpts from novels by esteemed African American writers are particularly helpful in this endeavor.

The first excerpt helps us to understand mistrust and loss of humanity as signs of suffering that result from racism. If the reader listens carefully, the messages of the story will most likely be unexpected and unsettling. Reflexively, those who are not African American may find themselves saying, "No, not me. I am not like the people these characters mistrust and despise." The novels speak for themselves, however, and it is up to the individual reader to accept or deny their truths.

Beloved[27] is a powerful example of human suffering and race hatred, as well as Morrison's unique style of writing. In it, she *foregrounds* trivial information and *backgrounds* what she refers to as shocking knowledge. This literary technique protects the reader from confrontation with painful details, at the same time it provokes a desire to know them. The passages excerpted here are long, but they are important to consider in their entirety. To comprehend them fully, however, the reader must be privy to the context in which they occur.

In a lengthy monologue, Stamp Paid, a freed slave, recalls the bloody and lawless aftermath of the Emancipation Proclamation of 1862. During the Reconstruction that followed, and for decades after, free blacks were hunted down, tortured, and often lynched by the infamous nightriders.

Beloved is a fictional account of Sethe, an escaped slave who attempts to kill her children and herself when confronted with the possibility of being captured by her former master and returned to his plantation. Sethe is shunned by the community for having murdered her youngest child before being stopped by the slave owner. Her friend Stamp Paid understands her anguish and is trying to explain why Sethe has become a recluse. He knows that "the white folks had tired her out at last."[27(p180)] Stamp Paid's monologue is filled with anger and despair as he explains to the reader that in 1874, 12 years after the emancipation,

> . . . whitefolks were still on the loose. Whole towns wiped clean of Negroes; eightyseven lynchings in one year alone in Kentucky; four colored schools burned to the ground; grown men whipped like children; children whipped like adults; . . . necks broken. He smelled skin, skin, and hot blood. The skin was one thing, but human blood cooked in a lynch fire was a whole other thing.[27(p180)]

He continues by explaining what had finally worn *him* out:

> It was the ribbon. Tying his flatbed up on the bank of the Licking River, securing it the best he could, he caught sight of something red on its bottom. Reaching for it, he thought it was a cardinal feather stuck to the boat. He tugged and what came loose in his hand was a red ribbon knotted around a curl of wet wooly hair, clinging still to its bit of scalp. He untied the ribbon and put it in his pocket, dropped the curl in the weeds. On the way home, he stopped, short of breath and dizzy . . . he turned to look back down the road he was traveling and said, to its frozen mud and the river beyond, "What *are* these people? You tell me, Jesus. What *are* they?"[27(p180)]

Recalling Morrison's writing style, we notice that the latter passage begins at the Licking River with the image of red cardinal feather, a familiar and beautiful object. As the writer continues to foreground relatively trivial information, our attention then moves to a pretty red hair ribbon, another common object, and we realize that our vision is being

corrected and our focus *sharpened*. Probably, without realizing it, we have bent our head closer to the ribbon to examine it more closely, when our senses are assaulted with the painful details and the shocking knowledge. The ribbon is attached to a curl of hair and a bloody chunk of scalp, undeniably belonging to a little black girl whose fate we can only imagine.

It is impossible to make sense of the extreme cruelty, violence, and human degradation that could have ended in this scene and the Licking River. The text tells us that Stamp Paid becomes dizzy and short of breath, and that it was "the ribbon" that "had worn out his marrow."[27(p180)] In this novel, suffering is consistently described in visceral terms involving the heart, lungs, and bone marrow. It is as unbearable as anything the reader can imagine. Reading "that anybody white could take your whole self for anything that came to mind. Not just work, kill, or maim you, but dirty you. Dirty you so bad you couldn't like yourself anymore. Dirty you so bad you forgot who you were and couldn't think it up"[27(p251)] humbles and shames the reader. In addition, the excerpts reveal inhumanity, hopelessness, and exhaustion; indicators of human suffering that resulted from racial violence and bigotry.

Scenes like this are repeated throughout *Beloved* and echoed in the oeuvre of many contemporary African American writers, musicians, artists, and choreographers. It is reasonable to ask if understanding is possible. It is not reasonable to remain indifferent.

Beloved is a complex novel and cannot be analyzed fully here. In it, white folks are the authors of slavery and unfathomable oppression and suffering. *Beloved* articulates clearly the suffering and the legacy of slavery that African Americans struggle to preserve. Contemporary scholars, like McCollum,[7] reinforce its message when they instruct us to be aware of the historical and current experience of being black in America to facilitate the therapeutic relationship.

A final brief excerpt speaks to the invisibility and unknowing that contribute to a loss of the sufferer's humanity. The excerpt is, at the same time, simple and profound and supports evidence that suggests that African Americans are, at least to some extent, *unknown* to us (European Americans), and that racial disparities may be a consequence of inaccurate perceptions and insufficient knowledge. For example, research by Copper-Patrick et al suggests that "physicians may lack understanding of patients' ethnic and cultural disease models or attributions of symptoms."[28(p588)] This "lack of understanding" or unknowing has been documented in many studies.[22,23,29] Imaginative literature not only confirms the empirical evidence but it also adds a human face to the language of science.

Bambara's novel *The Salt Eaters* provides us with an extreme example of "unknowing." A black character, Porter, tells his friend, Fred Holt, that the nature of the black man is unknowable to whites, explaining in this sentence, "course, when we look at us with their eyes, we disappear, ya know?"[30(p159)] The gravity of Porter's comment should not be overlooked, nor should it be given short shrift. Of the many consequences of disparity in the delivery of healthcare, the inability to understand and recognize the unique nature of African American clients is among the most devastating. It contributes to human suffering and has potentially life-threatening implications.

Given that human suffering is among the many consequences of racism and therefore racial disparity, the question becomes, what do we do with the information presented in research, scholarly reports, and these novels of suffering? Can they help us correct racial disparities in the delivery of healthcare?

CORRECTING RACIAL DISPARITY

Correcting racial disparities in the delivery of healthcare may result from asking, what is inequitable and how can we fix it? We are, in fact, morally compelled to respond to these questions. According to the first provision of the American Nurses Association's *Code of Ethics for Nurses,*[31] nurses have a responsibility to provide care with respect for human

dignity and the uniqueness of the individual. In addition, the delivery of healthcare must not be restricted by the client's socioeconomic status, personal attributes, or the nature of the health problem. It is also essential that care is both non-prejudicial and nondiscriminatory. This provision assumes that nurses are at the point of care, however. It is imperative in discussions of health disparity to ask how our responsibility is to be carried out in situations and in settings in which nurses are *not* at the point of care.

Nurses must first understand which clients are at risk and how to recognize the consequences of racial disparities in the delivery of healthcare. In order for this understanding to be achieved, however, nurses need to recognize and study racism and disparity in healthcare delivery. To date, most of these studies have been conducted in disciplines other than nursing, but without nursing research into racism and health disparity, correcting racial disparity will remain an unattainable goal. Nurses must draw on their moral responsibility to respond to human suffering and become acknowledged participants in the nation's efforts to correct health disparity by studying racism in healthcare delivery.

A growing number of nursing studies[32–34] aggressively call for research into the concept of racism. Cortis is a case in point, and warns that "racism will not disappear simply because nursing refuses to recognize it for fear that it will somehow detract from their 'professionalism.'"[32(p62)] Developing models of cultural competence without engaging in research into racial disparity in the delivery of healthcare sanitizes the issues and is a discredit to the nursing profession.

Studying discrimination as clients experience it[35] as well as the extent to which prejudice affects the care given by nurses are logical extensions of the existing research into racial disparity in healthcare delivery. It is naïve to assume that nurses are not participants in the discriminatory practices of the healthcare system. The degree to which our individual culpability is examined is perhaps one of the more valid indicators of the sincerity with which we approach racism and the suffering it engenders.

Imaginative literature can, again, inform our understanding.[36] In many African American novels, blacks are unwilling to forgive whites for having enslaved their ancestors. In fact, white Americans' attitude toward blacks, in and of itself, is as unforgivable as the physical reality of slavery. Even the possibility of real friendship with white folks is out of the question. These are unsettling accusations and they create discomfort. The consistency with which they appear, however, demands our attention and consideration. Coincidentally, evidence of mistrust is not a phenomenon attributed only to black novels. Boyle et al remind us that "staying out of the White man's way is a survival tactic used by generations of African Americans."[21(p124)] While the meaning revealed in the novels should be validated by research with human samples, understanding our role in racial disparity will enable us to respond to the suffering it engenders on a deeper and more personal level.

In the meantime, it is important to act aggressively to challenge racism by developing new frameworks of nursing care and transforming nursing curricula to reflect our responsibility as nurse advocates. To begin, nurses will need to consider the question, how do we cultivate advocacy? The answers range from the philosophical and legal to the merely practical. For example, *advocacy* may be defined as the nurse's fundamental way of being-in-the world,[37] or it may be connected to the nurse's theoretical view of human beings and their health experience.[38] According to Mitchell and Bournes, "Advocacy, like caring, is a concept that requires theoretical ties before its meaning can be understood."[38(p205)] The nursing model, then, determines the advocacy approach. The problem-based model of nursing is a case in point.

Approaches to advocacy based on the traditional problem-based model of nursing are inherently paternalistic and they may ultimately be self-serving, resulting in harm to the patient or community. In this model, patients

may or may not be involved in identifying what will promote their health or well-being.[38]

Nightingale, on the other hand, tells us that "what the nurse has to do . . . is to put the patient in the best condition for nature to act upon him."[39] The "idea" of advocacy is attributed to Florence Nightingale who designed nursing interventions for the weak, dying, and suffering patient. Like Nightingale, who was chiefly concerned for the patient's environment, the contemporary nurse advocate must demonstrate a similar concern for the current state of our healthcare environment and the problem of racial disparity in the delivery of care.

Cultivating advocacy is an important step in correcting the problem of racial disparity. Schools of nursing have a responsibility to develop and teach models of nursing care that are based on respect for the client's life choices and include an understanding of the importance of folk idiom, kinship bonds, ancestry, and cultural wisdom (also known as traditional inherited knowledge), rather than the individualistic, empiricist orientation of frameworks developed for European American clients. New frameworks of care must also consider current research that documents racial disparity in the delivery of healthcare to African Americans and other minority groups.

Several factors complicate the development of these new frameworks. First, information regarding folk idiom, kinship bonds, cultural wisdom, and ethnic and cultural disease models currently occupies little more than a footnote in already bloated nursing curricula and continuing education programs. In addition, faculty are often not qualified or prepared to address issues related to cultural diversity and current research that documents racial disparity in healthcare delivery. Educational frameworks will undoubtedly require serious attention to reprioritizing and rethinking the importance of health disparity.

Next, innovative frameworks of nursing care must be developed with an understanding of current research and the knowledge that the racial disparity documented in these studies is occurring at levels of care and in practice settings that fall outside of nurses' purview. How should racial disparity in healthcare delivery be addressed when nurses do not have direct access to patients in settings where discriminatory care or service is occurring? Possible answers include using novels of suffering[36] and stories of practice written by nurses[35] in classrooms to increase the perspective of nursing students in relation to advocacy. In addition, developing an independent role for the community nurse advocate must become a priority for the profession. This new role will not diminish the advocacy responsibilities of nurse generalists or specialists but will enhance our ability to correct racial disparity in the delivery of healthcare.

The development of the community nurse advocate role is complicated, in part, by a lack of clarity in the nursing literature related to advocacy. While cultural competence has been part of the healthcare landscape for several decades, an improved understanding of advocacy and a role for the community nurse advocate are clearly needed. To begin, we must consider the practice arena of the community nurse advocate and the notion of vulnerability. Most scholars contend that vulnerability is "the core condition that is most frequently cited as demanding advocacy action."[40(p130)] Nursing interventions at the community level, then, may assist in the identification of vulnerable clients and the development of strategies for obtaining appropriate and unbiased healthcare.

A brief return to the language used to describe suffering in studies that document racial disparity in healthcare delivery makes the vulnerability of these individuals, groups, and communities clear. Individuals sought protection from negative stereotyping, oppression, and a variety of risks.[19–21] In addition, patients' needs were often discounted, misunderstood, and overlooked.[7,22] The power of these ideas cannot be diminished simply because they are not measured in quantitative research, or by the IOM study. The vulnerability revealed merely by

the words used to describe patients' experiences with healthcare providers and the healthcare system should serve as a wake-up call for nurses.

Identifying vulnerable patients, however, will present an unprecedented challenge for nurse advocates. It will require a community, rather than individual, orientation. Familiarity with current research will enable the community nurse advocate to identify populations at risk and to develop interventions that increase their ability to identify and to access appropriate care. Nothing short of teaching "care-seeking militancy"[22] will be acceptable as a corrective action. Community nurse advocacy must take advantage of the opportunities and exposure offered by the media, churches, schools, and community groups. Finally, wise elders, formal and informal community leaders, representatives from religious or faith groups, and healthcare professionals from African American or the ethnic community of concern must be tapped as more than token participants. Research has clearly demonstrated that the white middle class ethos colors our perception to the point of cultural blindness. It results in flawed assessments, biased care, and is ultimately reflected in the suffering endured by our clients as well as increased morbidity and mortality in cases of disease or illness.

In conclusion, discrimination, prejudice, bias, racism, and bigotry, like cultural blindness, are more than harsh and abrasive terms, they are wrongs. Acknowledging the existence of racial disparity in the delivery of healthcare is the first step, however, in reversing this wrong. Accepting our individual culpability is difficult, but it is a necessary second step. Attempting to ease suffering and correct racial disparity in the delivery of healthcare is not only consistent with the American Nurses Association's *Code of Ethics* but also with Nightingale's challenge to nurses as well. Nightingale could not account for human suffering and saw it as an unreasonable consequence of sickness. Throughout her career, she challenged nurses to attend to it. The suffering that results from racism, and racial disparities in the delivery of healthcare to African Americans, is as unreasonable as anything Nightingale could have imagined. She wrote that suffering was poorly understood because it is difficult for "any one in good health to fancy him or even *herself* into the life of a sick person."[39(p102)] Interestingly, the ability to imagine the life of the sufferer and to act on another's behalf describes precisely the role of the nurse advocate. Righting the wrongs of racial disparity in care delivery is a moral imperative, it is within nurses' purview, and it cannot wait.

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