

Low Right Care

Reducing Overuse and Underuse

Avoiding Racist and Judgmental Clinical Documentation: Helping to Achieve Health Equity

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Patient perspective by Helen Haskell and John James

Case Scenario

A patient files a complaint with hospital administration after reviewing his electronic health record through the patient portal. His new primary care physician began his documentation by describing the patient as a “55-year-old African-American male with uncontrolled blood pressure due to noncompliance with medical care.” The patient had recently started a new job and could not pay for his prescriptions because his health insurance coverage had not taken effect yet. The patient did not attend follow-up visits and a recommended cardiology consultation because he could not afford the copayments for the visits. The patient identifies as Dominican Hispanic, not African American, and feels he was being stigmatized for his race and socioeconomic status and was a victim of stereotyping and racial bias.

Clinical Commentary

Medical education teaches that documenting the history of the present illness begins with age, race, and sex.¹ However, this documentation approach has been associated with negative effects on patient care, leading to stereotyping and bias in medical encounters.¹⁻³ Clinicians receive inconsistent education on how documentation of race affects clinical decision-making.^{1,3} Historically, the use of racial categories

was based on the mistaken belief that there are inherent biologic differences among races. It is now understood that these differences are predominantly the result of structural racism instead of biology.⁴⁻⁶

The 21st Century Cures Act, which mandated that patients have unrestricted access to their medical records, has brought increased attention to clinical documentation. Inappropriate documentation can be perceived by patients and families as offensive and judgmental and can have negative effects on future patient participation in shared decision-making.^{6,7} In a 2018 study of nearly 23,000 patients, 1 out of 10 respondents reported feeling judged or offended by something they read in their outpatient notes due to their perception that it contained errors, surprises, labeling, or evidence of disrespect.⁷ Patients who identify as Black are more likely than those who identify as White to have comments using negative words or connotations in their history and physical documentation and may be subject to systemic bias in physicians’ perceptions of their credibility. This “testimonial injustice” is a potential mechanism for racial disparities in the quality of health care.^{8,9}

TAKE-HOME MESSAGES FOR RIGHT CARE

Structural racism and implicit or unconscious bias of clinicians are prevalent in the U.S. health care system.

Documentation of race in the history of present illness should be avoided unless directly relevant to the care of the patient.

Stigmatizing language in the medical record can lead to inferior patient care and treatment bias.

Clinicians should advocate for antiracist care practices that use shared language and create a system that is equitable for people of all races, religions, sexual orientations, genders, and cultural groups.

Low Right Care Alliance is a grassroots coalition of clinicians, patients, and community members organizing to make health care institutions accountable to communities and to put patients, not profits, at the heart of health care.

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CME This clinical content conforms to AAFP criteria for CME. See CME Quiz on page 503.

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The stigmatizing language used to describe patients in medical records can influence other clinicians and physicians-in-training in their attitudes toward the patient and their medication-prescribing behavior.¹⁰ This is an important and potentially damaging pathway by which bias can be propagated from one clinician to another.¹⁰ Stigmatizing language in the electronic health record may alter treatment plans, transmit biases between clinicians, and alienate patients.^{11,12}

Inequitable access to high-quality health care in the United States is the direct result of structural racism in health care policies. The COVID-19 pandemic highlighted and exacerbated the fact that racial and ethnic minority groups are often devalued, disempowered, and denied equal access to essential medical resources.¹³ One of the most visible inequities is in health insurance coverage. The federal government has acknowledged that “inadequate health insurance coverage is one of the largest barriers to health care access, and the unequal distribution of coverage contributes to disparities in health.”¹⁴ Most people in the United States continue to access health care through employer-sponsored insurance; however, many people from racial and ethnic minorities are employed in low-wage jobs that do not provide adequate health insurance.¹⁵

PROMOTING ANTIRACISM

Since the 2002 National Academy of Medicine’s (formerly the Institute of Medicine) report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, racial and ethnic disparities in health care have not only persisted but worsened.¹⁶ Care inequalities result from structural racism in system design and clinicians’ implicit or unconscious bias.¹⁶ A 2017 meta-analysis reviewed 105 studies on the relationships between racial discrimination and health outcomes among U.S. patients who identified as racial or ethnic minorities. Findings indicated a statistically significant effect size associating racial discrimination and poor health, with the most significant adverse effect on mental health.¹⁷

Patient care and documentation should incorporate thoughtful practices that focus on avoiding racism and bias while also promoting antiracism and health equity.⁴ Similar guidelines need to be applied to ethnic identity, shared language, religion, and culture.^{4,18,19} Documenting race in the medical record is rarely indicated and, when relevant, should be based on the self-identification described by the patient.^{5,19} The use of the one-liner documentation of race should be abandoned. When indicated, race can be noted in the relevant areas of the medical or social history and should include health outcomes affected by social determinants of health.^{5,20-22}

Thoughtful strategies should be implemented to avoid stigmatizing language. These strategies include using person-first language, inclusive language, and quotation marks

for the patient’s self-identification, and avoiding labels, language that blames the patient, casting doubt on their subjective experiences, and terms that undermine their experiences.^{5,20-22} Improvements in the documentation of race should standardize language to describe patient-identified race and ethnicity, appropriately contextualize racial or ethnic differences in disease burden, and impart evidence-based medical knowledge.¹⁹ Discussing racism and implicit or unconscious bias during medical training is essential to address health inequities and improve care for all.¹⁹

Patient Perspective

For this patient, struggles with health equity exist at interpersonal and systemic levels. The physician applied an erroneous racial label without consulting the patient. The physician also used disparaging language in the documentation and did not investigate why the patient was not taking his prescribed medication or following up with appointments as recommended.

One concept that is integral to equity is respect, which in a medical context means engaging patients in conversation and tailoring recommendations as much as possible to their preferences, life circumstances, and personal obstacles to treatment. It also means avoiding potentially disrespectful words or actions, including condescending attitudes or using terms such as “noncompliance” and “nonadherence,” implying that the patient does not have legitimate reasons for not following the physician’s recommendations. Labels, particularly if they are incorrect, demonstrate a lack of interest in the patient and raise concerns about suboptimal care. Physical appearance does not necessarily reflect the complexity of an individual’s genetics. It is advisable not to make assumptions about patients’ racial or ethnic heritage, but to ask.

At a systemic level, the inequity in this case involves the failure of the U.S. health care industry to moderate the high cost of health insurance and out-of-pocket payments that disproportionately affect certain patient groups. One of us, who lives in a state where income eligibility for Medicaid has not been expanded as in most other states, was asked to help care for a friend recovering from surgery who received a bill for an amount nearly equal to her husband’s annual income. In addition to her physical pain, she experienced deep emotional distress from this unexpected and unaffordable medical bill. This scenario happens far too often in the United States. News reports suggest that millions have lost Medicaid coverage as the COVID-19 pandemic ended.²³ We ask that the medical community voice the need for everyone in the United States to have safe and affordable health care. The expansion of Medicaid is one important way to do that.

Resolution of Case

The hospital administrator recognized racist stereotyping and bias within the patient’s medical record documentation and physician-patient communications. The administrator

personally apologized on behalf of the institution. The physician was counseled and, after significant self-reflection, called the patient and apologized. The hospital instituted new policies and educational programs to promote appropriate documentation and unbiased patient communication.²⁴ In addition, the hospital initiated an antiracism training program with local community-based organizations and governmental agencies. The patient was satisfied with the response from the hospital and physician and joined the hospital's community board.

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