Abstract

Medically indigent patients, patients of color, those with insufficient health insurance, or patients with severe diseases have a high rate of poor health care quality caused by unconscious implicit and explicit biases. Awareness of the relationship between unconscious implicit bias and negative health care outcomes is increasing in the health care community. The objective of this case study was to examine implicit biases that negatively affected the patient care of a young Micronesian woman with a severe cutaneous disease in Hawai‘i. Her medical care and death may have been affected by a combination of implicit biases, including bias based on her race, type of health insurance, and underlying disease. Implicit biases and their role in health care disparities are often unintentional and not obvious. Increased awareness by health care providers may help to avoid inequities in clinical decision-making and improve outcomes.

Keywords

implicit bias, explicit bias, indigent, psoriasis, lymphoma, health care

Abbreviations

FNA = fine-needle aspiration

Introduction

Unconscious bias exists in health care and has recently been acknowledged in the literature. Health care outcomes of implicit bias include poor patient compliance and a reduction in health care efforts by providers and staff. The death of a young Micronesian woman in Hawai‘i led to the examination of implicit biases that negatively affect patient care. This case report and brief literature review describes the negative effects that implicit biases from health care professionals can have on patient health outcomes. Health care providers are frequently unaware of their unconscious implicit biases toward sex, ethnicity, race, gender identity, insurance status, and disease severity. The authors discuss the factors that contributed to the death of a woman who did not receive appropriate treatment for her lymphoma. Her resulting medical care and death may be the result of implicit bias based on her race, type of insurance, and disease (severe psoriasis) diagnosis.

Case Report

A 46-year-old Pacific Islander woman from Micronesia with Medicaid insurance and a history of severe disabling psoriasis and psoriatic arthritis presented to a Hawai‘i dermatology clinic in March 2011 (Figures 1 and 2). Her psoriasis started during her adolescent years and was treated with numerous therapies including topical corticosteroids, phototherapy (sunlight exposure in Micronesia), methotrexate, cyclosporine, acitretin, apremilast, etanercept, infliximab, ustekinumab, secukinumab, ixekizumab, IL-23 blocker, adalimumab, and guselkumab. The various therapies did not adequately control her psoriasis, but the patient felt that adalimumab helped the most with her psoriatic arthritis. The patient developed multiple squamous cell carcinomas (lymphoma) that complicated psoriasis treatment. She was on adalimumab for approximately 10 years; however, the therapy only controlled her psoriatic arthritis and not her psoriasis. Prior to her development of lymphoma, she switched from adalimumab to the recently approved guselkumab to address the lack of response of previous therapies to her cutaneous psoriasis.

In January 2018, the patient visited a Hawai‘i dermatology clinic for a psoriasis follow-up and an IL-23 blocker injection. The patient reported her psoriasis did not improve and complained of groin pain and fever for 3 days. New-onset erythema, tenderness, and induration of the right proximal thigh were noted. Preliminary diagnosis was abscess with an incision and drainage attempt in the clinic but was unsuccessful. Systemic psoriasis treatment was withheld, and she was sent to the emergency department where a repeat attempt was made to incise and drain the right groin mass; but, again, was unsuccessful. She was admitted for intravenous antibiotics and obtained a CT scan that showed a 5.5 cm right thigh mass concerning for necrotic lymph node versus abscess, as well as widespread lymphadenopathy. A left groin lymph node fine-needle aspiration (FNA) performed 3 days after admission showed peripheral T-cell lymphoma. She was seen once by oncology as an inpatient, discharged, and referred for outpatient lymphoma treatment.

Eight months later she returned to the dermatology clinic having stopped her psoriasis treatments. When asked about treatment for her lymphoma, she described negative interactions on her first and only visit with the outpatient oncology staff and oncologist, stating that “those people weren’t nice to me” and that she didn’t want to go back to see them. The authors believe she was referring to the oncologist’s office staff. She stated that she planned to take “medications from home” and use alternative herbal therapies; however, it was never confirmed that she initiated treatment for her lymphoma. An attempt was made to refer her to other oncologists in the community, but they were not accepting patients with an established relationship with another oncologist and suggested that she go back and see her first oncologist.

Kory M. Johnson MPH; Emma Fixsen MD; David J. Elpern MD; Douglas W. Johnson MD
Thirteen months from her lymphoma diagnosis, she again presented to the dermatology clinic with severe psoriasis, extensive lymphadenopathy, weight loss, bilateral severe leg edema, difficulty walking, and increasing shortness of breath (Figures 3 and 4). The dermatology staff took the patient by wheelchair to the emergency department where she received an inadequate and unfriendly evaluation as observed by the dermatology staff. The patient was quickly sent home because her oxygen saturation was satisfactory, still never having received treatment for her lymphoma. Six days later, she re-presented to the emergency department with severe abdominal pain in septic shock with hydronephrosis from ureteral obstruction by the tumor. She died 17 days later from multi-organ failure secondary to proteus mirabilis urosepsis.

Discussion

Several factors contributed to this patient not receiving appropriate treatment for her lymphoma. Her medical care and death may have been affected by a combination of implicit biases, including bias based on her race, health insurance for low-income individuals, and underlying disease. Implicit bias may have also played a role in her inability to obtain a timely diagnosis and oncologic treatment during both hospital admissions: in the 3-day delay before performing a FNA during her first hospitalization, and not being admitted during her second visit to the emergency department. The patient was sent home from her first hospitalization without receiving any treatment for her lymphoma and had an unsatisfactory follow-up visit at the oncology office. She was later sent home from the emergency department in a debilitated state, only to be readmitted 6 days later with septic shock and dying without treatment for her lymphoma.

Implicit biases are unconscious associations between a group attribute such as race, and a negative evaluation or stereotype. These involuntary biases can affect the judgment of the physician and staff, as well as interpersonal interactions with patients, despite a conscious desire to treat everyone equally. Compare this to explicit biases, which are held consciously, believed to be correct in some way, and are acted upon by the biased person. Implicit biases against certain patient populations can negatively affect communication and care between patient and provider. This has been shown to impact patient confidence in oncologic therapies. In a study looking at interactions between non-Black oncologists and Black patients, oncologists with

Figure 1. Patient’s Baseline Cutaneous Disease and Deforming Psoriatic Arthritis Located on Hands

Figure 2. Patient’s Severe Psoriasis Affecting Both Legs
higher pro-White/anti-Black racial implicit bias scores (as measured by the implicit association test) had shorter patient interactions, and their communication was rated by patients and observers as less patient-centered and non-supportive. An increase in oncologist implicit bias was also associated with increased patient-difficulty remembering contents of the patient-provider interaction, and indirectly with lower patient confidence in recommended treatments and more perceived difficulty in completing them. Some providers exhibit explicit bias by not participating with Medicaid. Others participate with Medicaid but provide substandard care, which is another form of implicit bias.

In the case presented here, the authors believe implicit bias against the patient’s race may have played a significant role in her medical care and the lack of treatment for her lymphoma. Unfortunately, significant implicit and explicit biases against the Micronesian community exist in Hawai‘i. A recent study from the University of Hawai‘i found that 1 in 4 Micronesians reported experiencing bias against them at work because of their race and 1 in 10 reported discrimination from medical and social services. Another study in Hawai‘i found that Micronesians had higher severity of illness at the time of hospitalization across a variety of categories (cardiac illness, infectious disease, cancer, and endocrine disease) and tended to be hospitalized at a younger age compared to White or Japanese patients. Micronesians were also significantly more likely than the other race/ethnic groups (White, Japanese, and Native Hawaiian) to have Medicaid insurance or be self-pay.

Like many Micronesian patients in these studies, the patient had Medicaid insurance. Both implicit and explicit bias as well as discrimination against patients based on insurance status can affect patient access to care. For example, many physicians may not accept patients with Medicaid insurance because of low reimbursement rates, increased paperwork requirements (prior authorizations, limitations on prescriptions, etc.), high illness burden, and psychosocial demands within this patient population. A 2013 Minnesota Health Access Survey found that reports of insurance discrimination were higher among uninsured and publicly insured adults compared to privately insured individuals. Adults reporting insurance-based discrimination were also more likely to face barriers to accessing care including lack of a usual source of care, lack of confidence in getting needed care, foregoing needed care due to cost, and provider-level barriers (ie, refusal of insurance or to accept new patients). A 2007 study of Florida Medicaid Enrollees found that 14% of respondents reported discrimination based on Medicaid insurance, while
9% reported discrimination based on race/ethnicity, and 6% reported both types of discrimination. Patients who reported discrimination based on either race/ethnicity or insurance status also had worse patient experiences (ie, receiving needed care, timeliness of care, and provider communication) than those who did not perceive discrimination.

Explicit and implicit bias against individuals with severe cutaneous disease may have also played a role in this case. This includes historic discrimination against people with leprosy in the 19th and 20th centuries in Hawai‘i when people diagnosed with or suspected of having leprosy were exiled to Moloka‘i. Patients with skin disorders like psoriasis may face discrimination. A study from 2018 found that laypersons reported social avoidance of people with visible psoriasis, because of misinformation that the disease is contagious. Medical students were also surveyed and reported significantly fewer stigmatizing attitudes than laypersons; however, some of them still had stigmatizing views. Knowing someone with psoriasis or having heard of the disease previously predicted fewer stigmatizing attitudes. Discrimination may also contribute to the psychiatric co-morbidities known to be associated with severe psoriasis. For example, a 2017 review and meta-analysis found that patients with psoriasis, especially among the younger age group, had a significantly higher likelihood of suicidal ideation, suicide attempts, and completed suicides than those without psoriasis.

Barriers to improving health care for people from Micronesia living in Hawai‘i have recently been explored. People from Chuuk, a Pacific Island country in Micronesia, who live in Hawai‘i reported that they do not speak negatively or confront providers about racial discrimination; in fact, they often respond to providers with what they think the provider wants to hear. These barriers bring attention to the biases that negatively impact care for this community and an additional intervention may be needed to help identify and eliminate bias in health care.

The patient’s clinical course and death presented in this case report highlight the importance of recognizing implicit bias among medical professionals. Raising awareness of these biases is the first step to addressing them. Discrimination against individuals with severe cutaneous disease, both implicit and explicit, can have significant negative effects on patients’ well-being and health. Race, ethnicity, or insurance status biases can negatively affect access to care as well as the quality of care received. Health care professionals need to be aware of situations like this to improve the quality of care for all patients by addressing and preventing bias.

Authors’ Affiliations:
- Mount Sinai Health System, New York, NY (KMJ)
- John A. Burns School of Medicine, University of Hawai‘i, Honolulu, HI (EF, DWJ)
- David Elpem MD: The Skin Clinic, Williamstown, MA (DJJE)

Corresponding Author:
Kory M. Johnson MPH; kory.johnson180@gmail.com

References