CASE AND COMMENTARY: PEER-REVIEWED ARTICLE
A Womanist Approach to Caring for Patients With Empirically Unverifiable Symptoms
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Abstract
Some illnesses and diseases are not apparent to onlookers. Conditions like chronic fatigue syndrome, fibromyalgia, multiple sclerosis, postconcussive syndrome, endometriosis, and many psychiatric illnesses, for example, have symptoms that are not easily or at all measurable. Both clinicians and health care systems, however, tend to focus exclusively on measurability, which can result in evidentiary overreliance and undervaluation of experience narratives and can have clinically, ethically, and socially important consequences for patients with these conditions.

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Case
LL is 27 years old and has been experiencing fatigue, joint paint, insomnia, and muscle soreness since she was 19. She has visited many physicians during those 8 years but has not found symptom relief. Despite a family history of autoimmune disease, LL's autoimmune serological panels have always been negative. She reports that, since onset of her symptoms as a teenager, different physicians have suggested she is "malingering" and has "conversion disorder,"[1] diagnoses that have followed her for years in her health record. LL's last physician added fibromyalgia[2] to her list of diagnoses and prescribed amitriptyline, duloxetine, and psychological therapy for 8 weeks. Despite LL's having diligently executed interventions as directed, her symptoms persist. LL decided not to return to her last physician, who accused LL of not taking her medications.[3] Most recently, severe exhaustion, muscle tenderness, and spasms have kept LL home for 5 consecutive days, so LL now visits Dr E, a rheumatologist, for the first time in hopes that Dr E will see LL as a credible patient and help her find symptom relief.

Commentary
Black women confront issues of invisibility on many sociocultural levels. Racial bias is a real barrier for Black women and women of color who seek medical care or services

from health care professionals. Social and cultural norms influence how Black women and women of color are perceived and, in turn, how they make health decisions.[4] Katie Love[5] and Harriet Washington[6] write about the painful history of discrimination and wrongful treatment of Black people in the name of science. This history of discrimination persists into the 21st century. Added to this historical trauma is the cultural expectation that Black women will manage disease and cope with suffering by wearing a mantel of Black womanhood, appropriating warrior-themed tropes, and relying on religious or spiritual faith. This expectation of a trifecta of strength is grounded in Black women's survival of oppression, but it can also be considered a detriment to Black women's health.[7] It compounds invisibility by creating a mechanism whereby Black women continue to be silenced on the state of their health.[7] This cultural silencing is a process that is complicated by symptoms that are neither visible to nor easily diagnosed by health care professionals.

This essay focuses on the experiences of Black women and will explore how implicit bias and racism in connection with invisible illness can be ameliorated in the context of evidence-based and patient-centered health care at the individual and organizational level using *womanism* as a rhetorical framework. Such a framework creates what I call, drawing upon the work of Alice Walker, a *womanist ethic of care*.

Evidence as a Source of Bias
The Agency for Healthcare Research and Quality provides the following definition for evidence-based practice in health care: "Evidence-based practice is the use of the best available evidence together with a clinician's expertise and a patient's values and preferences in making health care decisions."[8] However, as Kamlesh Bhargava and Deepa Bhargava[9] and others have pointed out, evidence alone is insufficient for delivery of patient-centered care. Clinicians must overcome implicit or unconscious racial bias and affinity bias (the unconscious preference for those who are more like you) to deliver patient-centered care that applies evidence equally to all. Studies indicate that medical professionals' ability to behave or act without bias is difficult, as burnout and stress, for example, increase the likelihood of racial, gender, and socioeconomic bias that influence treatment and bedside manner.[10,11,12]

A significant challenge to evidence-based care is the assumption that racial and ethnic minorities (ie, Black people and many people of color) are less likely to participate in clinical research. However, Jill Fisher and Corey Kalbaugh[13] dispute this assumption, arguing that when "the entire spectrum of clinical research" is examined, evidence suggests that African Americans are overrepresented in higher-risk, lower-benefit phase I safety studies but underrepresented in phase III therapeutic trials that inform evidenced-based care. The point is that empirical findings cannot be applied to patient care when that information is not there for a particular group of patients. It is time to consider this fact and use patient experience to help fill in the blanks. This reevaluation of the evidence might provide new insights that would bring about positive change in clinicians' perceptions of Black women patients and many patients of color, regardless of gender.

Women as Knowers
Borrowed from Alice Walker, a *womanist ethic of care* refers to narrative construction of Black women's health. This perspective employs an ethos of care and concern for Black women as credible knowers of their lived experiences and of their physical, mental, and spiritual well-being. As Walker notes in the following:

A [womanist is a] woman who loves other women, sexually and/or non-sexually. Appreciates and prefers women's culture, women's emotional flexibility (values tears as natural counterbalance of laughter), and women's strength. Sometimes loves individual men, sexually and/or non-sexually. Committed to survival and wholeness of entire people, male and female. Not a separatist, except periodically, for health. Traditionally universalist...[14]

Layli Phillips describes womanism this way:

Womanism is a social change perspective rooted in Black women's and other women of color's everyday experiences and everyday methods of problem solving in everyday spaces, extended to the problem of ending all forms of oppression for all people, restoring the balance between people and the environment/nature, and reconciling human life with the spiritual dimension.[15]

Womanism is a tool for overcoming the affinity bias and implicit bias found in health care practices that too heavily rely upon measurable evidence, as it centers on methods of problem solving used by Black women and women of color. There is a systemic sociocultural and epistemic hierarchy in the United States, with Black women historically at the bottom. Health care is not immune to differential treatment of people of color, especially Black people and, specifically, Black women. Black women's ability to provide information as they see it and experience it is relevant to responding with care to Black patients' clinical need. Adding their narrative perspectives and insights to considerations of evidence or its absence would likely contribute to healthier outcomes and mitigate health inequity.

A necessary step towards healthier outcomes for Black patients is to face racism in health care. For example, Denise Hooks-Anderson and Reynaldo Anderson[16] used autoethnography to identify and locate intersecting oppressions that marginalize Black people along the lines of race, class, and gender within the health care system and determined that the behavior of clinicians who otherized Hooks-Anderson, who was a chronically ill patient with lupus, resulted in improper care and concern for her. Similarly, Elizabeth Desnoyers-Colas[17] shared a personal narrative as a service member returning home with what the media initially dubbed "Gulf War Syndrome," an illness fraught with debilitating health problems that no one could explain and no one would believe. Desnoyers-Colas describes how the stoicism of duty and honor (a cultural norm) was not enough to overcome her symptoms and that speaking up about the disease to health professionals did not prompt their belief in or relief from her symptoms.[17] She began researching, experimenting, and collecting empirical evidence for herself to find relief. Using a womanist ethic of care when approaching women's—especially Black women's—experiences of empirically unverifiable symptoms is one way to center patients' experiences during clinical encounters and mitigate bias in health care.

Responding With Care
A womanist ethic of care would bring an added dimension to patient-centered, evidenced-based care. Womanism draws on inclusion to center lived illness experiences of Black women. Let the words and experience of a patient be the first thing counted in remediating the suffering from invisible illness: when a woman describes her symptoms, believe her. Symptom verification and identification will come. Health care professionals need to stop and consider a patient's experience without dubious condescension and must recognize a patient's narrative's truth, even when one can neither measure nor see symptoms.

When employing a womanist ethic of care, one must do more than express empathy. There are still action steps that require one to question oneself, perhaps by asking, "Is

this the diagnosis or treatment plan I would come to if this were a White middle-class patient, myself, or a family member?" Womanism can be taught as a clinical skill of regard for patient's epistemic authority, perhaps as a part of learning bedside manner or cultural humility.[18] Students and clinicians are obligated to cultivate and practice the self-awareness necessary to overcome biases that increase the likelihood of the continued invisibility of Black women's illness experiences.

References

1. Galli S, Tatu L, Bogousslavsky J, Aybek S. Conversion, factitious disorder and malingering: a distinct pattern or a continuum? *Front Neurol Neurosci*. 2018;42:72-80.
2. Spaeth M, Briley M. Fibromyalgia: a complex syndrome requiring a multidisciplinary approach. *Hum Psychopharmacol*. 2009;24(suppl 1):S3-S10.
3. Hayes SM, Myhal GC, Thornton JF, et al. Fibromyalgia and the therapeutic relationship: where uncertainty meets attitude. *Pain Res Manag*. 2010;15(6):385-391.
4. Madlock Gatison A, ed. *Communicating Women's Health: Social and Cultural Norms That Influence Health Decisions*. Routledge; 2016.
5. Love K. Voices from the past: understanding the impact of historical discrimination on today's healthcare system. In: Madlock Gatison A, ed. *Communicating Women's Health: Social and Cultural Norms That Influence Health Decisions*. Routledge; 2016:7-17.
6. Washington H. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans From Colonial Times to the Present*. Doubleday; 2006.
7. Madlock Gatison AD. *Health Communication and Breast Cancer Among Black Women: Culture, Identity, Spirituality, and Strength*. Lexington Books; 2016.
8. Evidence-based decision making. Agency for Health Care Research and Quality. Reviewed April 2018. Accessed November 30, 2020. https://www.ahrq.gov/prevention/chronic-care/decision/index.html#:~:text=Evidence%2Dbased%20practice%20is%20the,in%20making%20health%20care%20decisions
9. Bhargava K, Bhargava D. Evidence based health care: a scientific approach to health care. *Sultan Qaboos Univ Med J*. 2007;7(2):105-107.
10. Dyrbye L, Herrin J, West CP, et al. Association of racial bias with burnout among resident physicians. *JAMA Netw Open*. 2019;2(7):e197457.
11. Johnson TJ, Winger DG, Hickey RW, et al. Comparison of physician implicit racial bias toward adults versus children. *Acad Pediatr*. 2017;17(2):120-126.
12. Hardeman RR, Burgess D, Phelan S, Yeazel M, Nelson D, van Ryn M. Medical student socio-demographic characteristics and attitudes toward patient centered care: do race, socioeconomic status and gender matter? A report from the Medical Student CHANGES study. *Patient Educ Couns*. 2015;98(3):350-355.
13. Fisher JA, Kalbaugh CA. Challenging assumptions about minority participation in US clinical research. *Am J Public Health*. 2011;101(12):2217-2222.
14. Walker A. *In Search of Our Mothers' Gardens: Womanist Prose*. Harcourt; 1983.
15. Phillips L, ed. *The Womanist Reader*. Routledge; 2006.
16. Hooks-Anderson D, Anderson R. The culture of medicine: a critical autoethnography of my encounter with the healthcare system. In: Madlock

Gatison A, ed. *Communicating Women's Health: Social and Cultural Norms That Influence Health Decisions*. Routledge; 2016:18-27.

17. Desnoyers-Colas E. Duty, honor, country ... sickness: finding strength in my personal battle with Gulf War syndrome. In: Morant Williams K, Morant FS, eds. *Reifying Women's Experiences With Invisible Illness: Illusions, Delusions, Reality*. Lexington Books; 2017:95-108.
18. Aneese AM, Nasr JA, Halalau A. A prospective mixed-methods study evaluating the integration of an evidence based medicine curriculum into an internal medicine residency program. *Adv Med Educ Pract*. 2019;10:533-546.

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