Editors' Note

The symposium in this issue is titled "Experiencing Racism in Health Care: Stories from Health Care Professionals." The editors thank the Centene Charitable Foundation for a gift that supported the publication of this issue and an accompanying open-access VOICES edition of the symposium.

The problem of racism toward healthcare professionals has far-reaching implications for health care professionals themselves, their patients, and society. Minority health care professionals face discrimination in their clinical roles by patients, colleagues, supervisors and instructors. Some of this behavior is overt and reveals conscious racial discrimination. Other times, it is supported by the unconscious bias of individuals or institutional policies. The problem of racism in health care has far-reaching implications for health care professionals, their patients, and society. The symposium presents a collection of stories by physicians, trainees, nurses, chaplains, social workers, and other health care workers from underrepresented racial groups. These stories detail the authors' first-hand experience with racism in the workplace or during training.

When author Dr. Zaiba Jetpuri was just 18 and dreaming of being a physician, she went to interview for her first job as a scribe. "When I arrived at the office to meet [the hiring physician] I could sense something was 'off.' . . . [S]he said I couldn't wear my headscarf (hijab) to work. 'Wearing your headscarf here would make my patients scared.'" Jetpuri was told to "think about it." She sent several follow up emails and even asked her Imam to write an email explaining the tradition of wearing a hijab, but the hiring physician would not change her policy. Jetpuri goes on to say, "I told myself I didn't want this job bad enough to compromise my own integrity, and if this is what doctors' offices are like, then it is not for me; and I let the dream go for a while. Medicine always kept calling to me, and I eventually found other experiences to help my resume when I applied to med school."

In his story, "Chronicles of a Culturally Grounded Chaplain," Mr. Calvin Bradley Jr. recounts, "When I began my career in healthcare chaplaincy, I was invited to have a seat at several "tables." From leadership councils to special committees, I was constantly being invited to serve. [. . .] I began using my voice and pastoral authority to advocate more for my patients, bring awareness to inequities within the systems I served, and challenge the status quo. [. . .] As my passion and influence grew, I was quietly and conveniently uninvited to the next meeting. In some cases, whole projects and committees were completely dismantled, some reestablished under new facades. Ideas I had previously shared that were once downplayed as unreasonable or impossible suddenly became action items and were attributed to being the brilliant ideas of others."

The symposium editor, Gloria A. Wilder, is a pediatrician, public speaker, expert on poverty and social justice, and the Vice President of Innovation and Preventive Health at the Centene Corporation. Three commentary articles, written by Aletha Maybank & Fernando De Maio, Elena Rios, and Nathalie Égalité offer important insights into the authors' stories. Égalité observes, "These narratives likewise include thoughtful considerations on the difficult balance between the pursuit of individual virtues and the creation of systemic conditions necessary to eliminate racial injustice. The recommendations they provide on ameliorating knowledge of racism inspire readers to go beyond the ethical act of testimonial exchange toward the creation of transformative social change."

The research article in this issue, "We're Not Moving Forward": Carers' Demand for Novel Research and Effective interventions for Psychotic Disorders," was written by Paolo Corsico.[1] The article presents findings from focus groups with caregivers of individuals who have experienced psychosis. The author conducted three focus groups with caregivers. The focus group discussions centered around a case study vignette about neurobiological research, with time allotted to discuss the ethical issues of translating research to clinical care. Each caregiver was a close family member of the person with a psychotic disorder or mental health diagnosis. Notably, many of the most debated themes in ethics literature on psychosis and neurobiological research—such as mental capacity to make decisions, returning results, managing unsolicited neuroimaging findings, and data sharing—were absent from the discussion. While this could be because of the way the conversation was moderated, the author also suggests that cargivers' "narratives may reveal a *different outlook* on the moral challenges of technological innovation in psychiatry." This outlook can be understood using an "ethics of care" framework.

The first case study in this issue, written by Saljooq M. Asif, is titled "Phantom Physicians and Medical Catfishing: A Narrative Ethics Approach to Ghost Surgery." Ghost surgery occurs when the surgeon who obtained informed consent does not perform the operation or invasive procedure. Instead, another individual does the surgery. Catfishing refers to the deceptive practice of luring an unsuspecting individual into a relationship (usually over the internet) with a person whose identity is entirely different from the one they portrayed. Asif explains, "Contrary to what might be expected, these bait-and-switch practices occur in institutions other than teaching hospitals and involve healthcare professionals other than residents."

In this case, Asif describes a personal experience whereby his grandfather undergoes a transcatheter aortic valve replacement (TAVR). The patient and his family assume that Dr. B., an experienced cardiothoracic surgeon with whom the grandfather had built a trusting relationship, will perform the TAVR.

On the day of the procedure, Dr. B., dressed in scrubs, wheels the grandfather to the operating room and is optimistic about the grandfather's prognosis. Soon, however, the family is notified that a severe complication has occurred—during the surgery, their grandfather's left ventricle was perforated. Shocked by this news and seeking to understand what happened, the family is informed that Dr. B did not perform the procedure. After delivering their grandfather to the OR, Dr. B. left, and another individual, unknown to the family and to the patient, performed the TAVR. The author explains that the medical catfishing described in this case ". . . distorts the truth via omission and obfuscation," an example of what bioethicist Hilde Lindemann calls immoral work.

This issue of NIB includes a second case study that addresses the important topic of incorporating a team psychosocial approach to understand patient, family, and surrogate decision makers' values and goals. In "It Takes Time to Let Go," authors Tiffany Meyer, Laura Walther-Broussard, and Nico Nortjé describe the case of Mike and his wife, Jo-Anne.

Mike is dying of cancer and travels eight hours by car with Jo-Anne for a routine appointment. At the appointment, Mike's physician discovers that he is very ill and admits him to the ICU during the height of the COVID-19 pandemic. Jo-Anne is allowed to stay by Mike's side, though she is alone—hours away from home—and isolated due to the hospital's COVID-19 visitation policy. The

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[1] *The term 'carers' is a British synonym for 'caregivers' and was the term used throughout this study, which was conducted in the United Kingdom.*

psychosocial team of social workers, a chaplain, and an ethicist recognize that Jo-Anne's support network is far away. They try to intervene and help her navigate the situation. At first, the team struggles to get close to Jo-Anne. After some time, they gain her trust, and Jo-Anne allows them in to offer support.

The psychosocial team seeks to understand Jo-Anne's motivations and beliefs and shares these with the medical team. After two weeks, the team decides that the care they are providing Mike is futile, though medical futility is based on value judgments. The care team ascertains that Jo-Anne believes Mike will regain full mental capacity—in other words, the treatment is not futile in her view. The medical care team has difficulties understanding Jo-Anne's position and works together with the psychosocial team to help Jo-Anne understand the gravity of Mike's condition. With patience, and after several conversations, Jo-Anne reflects upon Mike's life and finally works through her denial. She instructs the medical team to focus on comfort measures and Mike dies a short time later with Jo-Anne by his side.

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James M. DuBois, Ana S. Iltis & Heidi A. Walsh

Introduction
Experiencing Racism in Health Care: Stories from Health Care Professionals

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Abstract. This symposium includes twelve personal narratives from individuals who have experienced racism in the workplace or during training. Racial minority health care professionals face discrimination in their clinical roles by patients, colleagues, supervisors, and instructors. Some of this behavior is overt and reveals conscious racial discrimination and structural historic racist policies. Other times, it is more subtle, supported by the unconscious bias of individuals, individual or systemic microaggressions or by institutional policies that may have been written to address more egregious acts. The problem of racism in health care has far-reaching implications for health care professionals, their patients, and society. Racism, bias, microaggressions, tokenism, and other forms of oppressive behaviors cut like a razor to the fabric that holds societies together. When unchallenged in healthcare, these acts fuel infant and maternal mortality, decrease life expectancy in communities of color, and result in a myriad of health disparities while limiting the pool of qualified minority (or other) providers allowed to serve.

Funding. Thank you to the Centene Charitable Foundation for funding this narrative symposium.

Key Words. Racism, Workplace Discrimination, Organizational Policy, Health Professionals, Medical Ethics, Narratives, Quality of Care

Introduction

> "Of all the forms of inequality, injustice in health care is the most shocking and inhuman."
> — Dr. Martin Luther King, Jr. in his1966 speech to the Medical Committee for Human Rights

Racism requires complicity. The idea that a single individual can create and maintain systemic abuse is not true. It requires that the collective go along with stereotypes, turn a blind eye to discrimination and disregard the impact of privilege. We see numerous historic and modern-day examples of the acceptance of racism, abuse, and bias being ignored, minimized, or even turned against the victim who reports the act. Often the person who was verbally assaulted has the abuse reinforced by those who respond by telling them to ignore it, move on . . ."no one is racist in our department." We hear the pattern of righteous indignation taken by White colleagues when Black colleagues call out racism or bias. "Not everything is about race," "Don't play the Black Card!" and "I am not racist," are common responses reporters of racist acts hear. The American health care system is in fact dependent upon the products of racism, discrimination, and bias to fuel the necessary supply of disease and disparity that fund poor health outcomes. The American system of health grows not from primary prevention, wellness, or positive health outcomes but from a never-ending stream of disease, chronic care, and disability that arguably reinforce negative outcomes as profit drivers. It is, therefore, not surprising that racism, discrimination, and bias are natural allies in a system that requires disparity to maintain its infrastructure.

In February 2021, a shocking example of the impact of racism in medicine occurred when leaders from the American Medical Association's journal (JAMA) produced a podcast on structural racism between Dr. Ed Livingston and Dr. Mitchell Katz, "Structural Racism for Doctors—What Is It?"(Livingston, 2021, February 23). Livingston was at the time the Deputy Editor of JAMA, and Katz was an editor at JAMA Internal Medicine and CEO of NYC Health + Hospitals in New York City. These highly decorated leaders in healthcare declared that structural racism in medicine did not exist because physicians cannot be racist. The podcast was later pulled from the AMA website.

> From the JAMA Podcast Transcript
>
> Dr. Ed Livingston: [. . .] I think the term racism might be hurting us, because as I articulated, my response to it is just what you and your explanation of my response is: I don't feel I'm a racist. I grew up in a family where racism was reviled and my parents taught me never to hate based on what peoples' colors are or their religion because they had suffered the most extreme violence because they were Jews, and they said 'that's wrong,' 'it's fundamentally wrong, you can't do that,' so I grew up kinda anti-racist. That just never, ever . . . (sic) even think about a person's race or ethnicity when you're . . . when you're evaluating them. Yet I feel like I'm being told I'm a racist in the modern era 'cause of this whole thing about structural racism, but what you're talking about isn't racism as much as that there are populations that . . . it's more of a socio-economic phenomenon . . . that have a hard time getting out of their place because of their environment, and it isn't their race, it isn't their color, it's their socio-economic status, it's where they are. Is that a fair assessment?
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> Dr Katz: Yes, I mean, I think I mean, I . . . the . . . so you are not a racist, and also we are not going to end structural racism by focusing on individual peoples' attitudes. . . .

The striking ignorance displayed in the podcast was an embarrassment to every practicing physician/provider and an assault on minority communities throughout the nation. It exposed a dangerous, resistant, pervasive infection within healthcare—blaming communities, minority groups, and patients for social determinants of health. The myth that leadership, academic, or scholarly appointment endows the leader with a shield of virtue is also on display. The righteous indignation at the thought that they could be challenged to address racism on a professional or personal level brings out emotional responses from the participants. The more abstract discussion of structural racism as a concept that exists but is not caused by or contributed to any of their actions is palatable for these participants. The fact that the two physicians who participated in the podcast were the senior editors of the Journal of the American Medical Association (the leading medical journal in the U.S.) speaks to the historic legacy of racism that is woven tightly into the fabric of America's health care infrastructure. While the AMA repeatedly apologizes for their historic and continual participation in and creation of racist policies, practices, and research, the reality is they continue to downplay the viciousness of racism, bias, and discrimination within their own organization.

> "Forgiving and being reconciled to our enemies or our loved ones is not about pretending that things are other than they are. It is not about patting one another on the back and turning a blind eye to the wrong. True reconciliation exposes the awfulness, the abuse, the hurt, the truth. It could even sometimes make things worse. It is a risky undertaking but, in the end,

> it is worthwhile, because in the end only an honest confrontation with reality can bring real healing. Superficial reconciliation can bring only superficial healing."
>
> —Bishop Desmond Tutu

With this symposium, we open the door to transparency and truth about the awful underbelly of the American health care system. We invite all who read the courageous words of our narrative authors to suspend judgment and allow empathy to guide you through this learning. We salute the courage of the new leaders of the AMA, galvanizing through Chief Health Equity Officer Dr. Maybank to right wrongs and operate in full transparency. Dr. Maybank's commentary—one of three included in this symposium—shines light on dark places. This moment is a reckoning with who we are to each other and an aspiration of who we want to be.

The authors of these narratives show us the lingering impact of continually being unheard and unvalued—many describe experiences with racism as children or describe witnessing racism toward their minority patients. We know that Adverse Childhood Experiences (ACES) have long tentacles within many people's lives. Childhood trauma lingers and sometimes grows. The reinforcement of this trauma through microaggressions, bias, and racism, masked as jokes or marginalized as insignificant only re-triggers the anxiety and negative impact.

These narratives help us explore the consequences of a system of care built on an academic model of evidence rooted in racism, bias and generational privilege. As the JAMA example shows us control of evidence by a limited group of elite "scholars" results in a suppression of knowledge and oppression of racial minorities. In the book, "Ebony & ivy: Race, slavery, and the troubled history of America's universities," MIT Professor Craig Steven Wilder explores how race based culture and slavery were foundational in the development and growth of leading American Universities and Colleges (2013). In this symposium, we raise the question of the impact of slavery, racism and bias in historic institutions that lead our health care system. Is evidence-based medicine one size fits all? What happens, is a stratified system of academic appointments resulting in a limited few, very powerful, racially anemic men serving as the primary gatekeepers of care. When the definition of "evidence" is built on a reference population that is not like the population you come from you may find that the care you seek is unavailable or leaves you in a disparate state. If I am judged by the wrong measuring stick, I will always measure insufficient. We have seen the emergence of negative terms to describe patients who challenge evidence-based care. The use of terms like "poor historian" and "noncompliant" are weaponized against patients of color who express differing views or challenge treatment plans. The concept of compliance as a requirement of care ignores the core framework of patient autonomy and reinforces a paternalistic view of medical decision making. "Poor historian" can be accurate, or it can reflect a provider's deficiency. The patient could be having trouble telling their story, or the provider could be having trouble hearing or accepting the patient's story. The history a patient gives is often the most challenging part of the provider-patient interaction. It requires the provider to suspend judgment, be conscious of their bias, listen, and then act out of empathy, not sympathy. Providers do not need to agree with the patient's lifestyle, experiences, or decisions to act on their behalf. By acknowledging the limitations of evidence-based medicine, we push ourselves to look at the value of diversity in all its forms and to promote the use of culturally appropriate reference populations in clinical trials, the advancement of diverse leaders in health care organizations and the evaluation of public health policy through an equity lens.

This symposium aims to broaden the dialogue, raise awareness and understanding about racism in healthcare, and encourage individuals to take action in promoting lasting change in eliminating it. We aimed to collect stories from health care providers who have experienced racism in the workplace or in training. The stories highlight subtle ways racism appears, along with more blatant forms of racism.

We sought commentaries from authors with expertise in bioethics, health equity, medical sociology, and institutionalized racism. We collected 17 stories from minority health care workers. Twelve of those stories are included in this symposium and the other 5 are available in the online supplement for this issue.

The Call for Stories

The call for stories sought stories from health care workers who have experienced racism in the workplace or during training.

Authors were asked to consider the following questions:

- What racially biased behavior, event, or policy did you experience? Tell us what happened. You may describe more than one experience.
- How did the experience affect you? How did you feel? Did the experience change you in any way, and if so, how?
- How did you respond to the experience?
- Has the experience of racism as a professional affected your care of patients in any way?
- Have you experienced racism as a patient receiving care, and if so, how has this affected your work as a health care professional?
- How would you advise someone faced with a similar situation?

The editors of *Narrative Inquiry in Bioethics* published the Call for Stories in the NIB newsletter and on the NIB website. Additionally, the call was posted on several social media platforms, including LinkedIn, Facebook, and Twitter. Thank you to Physician Just Equity founder and President Pringl Miller, MD, FACS, who helped us advertise the call by sharing it on Twitter with hundreds of followers. It was distributed through the American Society for Bioethics (ASBH), the Medical College of Wisconsin (MCW), the Sickle Cell Info Center, and the UNC Center for Health Equity Research. We also distributed the call through numerous private social media groups, colleagues and friends, and national minority nursing associations.

The Narratives

The stories included in this issue reflect both conscious bias (also known as explicit bias) and unconscious bias (or implicit bias) and are written by individuals from diverse professional backgrounds. The authors provide valuable insights into microaggressions, cultural invisibility, and nullifying differences and discuss the consequences of these actions, including one of the most serious: suicide. The closer you are to "Whiteness," the more access you have to privilege. The authors reflect upon the dogged denial of privilege and the resulting consequences of maintaining the status quo. Several themes emerged in the stories.

The go along to get along assault: The danger of tokenism.

This is what occurs when diversity is addressed by bringing one of each to the table. The majority rule is often an assault on those who are outliers. Difference can be silenced when majority members become uncomfortable. This happens at all levels. You probably know of instances—some call them "Karen" moments—when members of the majority community sound an alarm when minority persons act in a way that is different from the majority's comfort level. "Driving while Black, walking a dog while Black, crossing a border while Hispanic" . . . these stories have been highlighted in the media. Demonstrating times when White people become uncomfortable with Black people because the Black people won't do things the way the White person is used to. This discomfort is then weaponized against the Black person and words like disruptive, noncompliant, aggressive, angry, and other trigger words are used to alienate or punish the Black person so that the White person retains power and control. This same dynamic appears in professional health settings, often at the hands of those who declare an allegiance to the minority community. The silencing of professional differences marginalizes the minority and ensures majority preference, nullifying any actions, dialogue, or evidence outside of the evidence supported by the majority. Majority power is used to decide whose voice is heard and what conversations are valued. There is passive agreement that pain has occurred with a continued requirement that minority positions are subjugated by majority interpretation. This 'yes, but' moment in health often occurs when tokenism is applied as a solution to inequity. This contributes to the lack of diversity on hospital and corporate industry boards, admissions to medical and dental schools, and other egregious forms of biases. What looks like protocols and rules of engagement may be masking exclusionary punitive practices that promote tokenism over true diversity and inclusion.

One of the most insidious acts is putting the victim of racism on the defensive, creating an environment where the minority view is constantly being challenged and requires continual validation to be expressed. The process of invalidating different views, actions, and responses is used to marginalize, and can be seen in actions like:

- Creating criteria for promotion that do not give credit for diverse achievements,
- Devaluing community-based scholarship,
- Giving preferential recognition of specialties and procedure-based care,
- Allowing social interactions and networking to influence advancement,
- Creating dress codes that are narrow or purposely limit diverse cultures, and
- Using prescriptive policies to impede the progress of marginalized groups.

We must learn the importance of diversity, inclusion, and acceptance of change as key elements to achieving equity. By disrupting the "one of each" tokenism culture of political correctness and embracing diversity in all its forms, we lay the foundation for equitable achievement.

Passing

U.S. history is rich with the reality of cultures who can pass for White getting advantages over those that cannot. In slavery, the ability to pass was lifesaving. The light, nearly white-skinned slave's ability to get into the master's house and out of the field could save them from the worst beatings and brutality. Passing would evolve into metrics like "the paper bag test," in which opportunities would be afforded to those lighter than a paper bag but not to those who were darker. Other cultures also have ways of passing. Upon arrival to the U.S., Hispanic immigrants would often pretend to be White (e.g., Italian or other nationalities) to avoid the impact of racism. Changing ethnically identifiable names in exchange for names that the majority community embraced was another attempt at passing. Passing is a tool many have used to achieve acceptance, promotion, and advantage. Another equally disturbing form of passing is the act of going along to get along that occurs within healthcare. "Don't rock the boat," "Something is better than nothing," "Baby steps" are all phrases of the professional passer. Think of the colleague who privately decries the injustices endured by their co-workers but publicly takes a neutral or self-promoting stance. The self-promotor adopts the cause as their own to garner recognition that results in their advancement at the cost of the impacted group.

A recent article in STAT describes the Health Equity Tourist. "Opportunistic scientific carpet baggers parachuting in to "discover" a field that dates back more than a century" (McFarling, 2021). We weigh the risks vs. benefits of passing. For many passers, the consequences are mostly positive: funding, promotion, leadership, and power. The rest of us endure the negative consequences of being marginalized by having our work stolen while struggling to provide care to fragile populations who are perpetually impacted by actions taken in their interest—funds raised for them but never given to them—and living within the indentured servitude of a health care system that gets stronger as the disease burden of those we care for increases.

No opting out of bias

Affirmative action of the 70s evolved as a result of entrenched White superiority and the resistance of White leaders to diversify employment, education, healthcare, housing, and other key areas of social justice. At least one author in this symposium who is of mixed race, is confronted with one of the relics of racism: a quota for a committee. When confronted by this rule, the author is forced to confront her own reality when she is challenged for "not identifying" as any single race and instead identifying as mixed race. The mixed-race designation is not accepted in the author's institution that uses race to classify. As the author explores her own history, she begins to reveal that she too has used race to classify. She aligns her life with the "White" part of her mixed identity—growing up in a White community, going to White schools, thinking of herself in terms of White equality. In this writing, she chooses not to reveal the other parts of her ethnicity. We see the author struggle, be confronted, and then impacted by race and racism.

The Commentaries

This symposium also includes three expert commentaries on the narratives. The commentary authors Nathalie Égalité, Aletha Maybank and Fernando De Maio, and Elena Rios provide unique perspectives.

Nathalie Égalité is a PhD candidate in the medical humanities at the University of Texas Medical Branch. She holds an Honours Bachelor in Bioethics from the University of Toronto and a Master in Bioethics from the University of Montreal. Her dissertation examines moral challenges arising from the writing and publication of patient stories by physicians.

Aletha Maybank, MD MPH and Fernando De Maio, PhD, co-authored a commentary for the symposium. Dr. Maybank is Chief Equity Officer and Senior Vice President at the American Medical Association where she focuses on advancing health equity across the work of the AMA and its Center for Health Equity.

Dr. De Maio is Director of Research and Data Use at the Center for Health Equity at the American Medical Association. His work focuses on the structural and social determinants of health and the health effects of income inequality, immigration, and racism and discrimination.

Elena Rios, MD, MSPH, MACP is the President & CEO of the National Hispanic Medical Association. Rios serves on the board of the National Hispanic Leadership Agenda, the New York Academy of Medicine, and the Natural Resources Defense Council. She is a member of the Centene Health Equity and Wellness Council, the Advisory Committee for the NIH Office on Research of Women, the VA National Academic Affiliate Council, and the Rockefeller Foundation COVID-19 Advisory Committee.

Conclusion

By 2050, people of color will represent the majority of the country's population, workforce, and consumers (Turner, 2018). In the "Business Case for Racial Equity: A Strategy for Growth," Ani Turner writes, "Furthering the success of populations of color will not only serve an important social justice goal, it will be a major driver of our collective social and economic well-being" (2018). There's a potential economic gain of $135 billion per year if racial disparities in health are eliminated, including $93 billion in excess medical care costs and $42 billion in untapped productivity (Turner, 2018). One strategy for realizing a racial equitable society is to create an equitable work environment. Recruiting a diverse applicant pool and ensuring that the interview process is fair to all applicants are two strategies. Creating an atmosphere that is welcoming to all within the organization, where staff are trained in cultural sensitivities, and where there is equal opportunity for advancement are others (Turner, 2018). Advancing health equity and addressing racism in all its forms is not only a health care business imperative but with our current disease care system absorbing ~20% of the GDP it is inextricably linked to the advancement of our nation.

With the narratives in this issue of NIB, we hope to broaden the dialogue, attract attention to this important topic, and encourage individuals to take action in promoting lasting change in eliminating racial bias. What starts with a focus on race exposes one of many inequities that keep minority, rural and other populations chronically impoverished and disenfranchised. There are five keys to social justice: Access to quality healthcare, education (7,000 children drop out of school per day), economic (the federal minimum wage of $7.25 is a poverty wage), environmental (e.g., community violence, lead in our water, brown fields, pollution), and civil and criminal justice (e.g., the killings of George Floyd, Brianna Taylor, and Trayvon Martin.) Inequity in any of the key areas of social justice compromises the other four. Challenge us, challenge yourselves, and each other. We hope to create a rippling impact through our industry that results in a tsunami of change ushering a true health care system focused on primary prevention, wellness, population health and equitable inclusion that supports all contributions with a new broadened definition of the best and brightest.

All who tell their stories due so with the same reverence they give their patients— respect the pain and struggle of their journey. Open your heart to embrace difference, accept opposing views, and empathize. Remember if you do not see race you do not see *us*. Our racial differences are to be embraced not erased.

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Personal Narratives

I Can Work With Patients Too

Zaiba Jetpuri, DO, MBA, FAAFP

I was 18 years old, enthusiastic, and naïve. I had just decided that I was going to go the premed route and the thought of seeing patients and helping others made me giddy. I had always volunteered throughout high school and found that my calling came in health-related environments, being there for others when they were at their most vulnerable. Up until that time, everyone had welcomed my presence, appreciated my time, and encouraged me to continue on this path. In trying to plan what the next year would look like and making sure I did all the prerequisite work before applying to medical school, I knew I wanted to work with a physician—but I didn't want to just shadow. I wanted to feel like I was contributing and helping. Several of my peers had told me working as a scribe would give me a closer look at what being a doctor was like and would allow me to learn medical terminology. I saw it as a way of being able to help in a patient's care since I would make the doctor more efficient, and I eagerly applied to several positions until I finally got the call.

I still remember feeling my heart fluttering in my chest as she said she wanted to interview me, but she couldn't pronounce my name. I pronounced it for her, and she immediately asked where I was from. I didn't hesitate. I said Texas. I am always from Texas since I was born here. Nothing else registers when anyone asks. Her comment that followed was that my name seemed foreign, and she was surprised I spoke good English. She admitted that this is why she wanted to do a phone interview to ensure that I would be able to communicate with her patients. We spoke on the phone for some time for what I thought was a good conversation. We spoke about the expectations of the job and her need for a scribe. She told me she wanted to hire me, so she asked me to come for an office tour and sign some papers so I could get started.

I got off the phone, excited and happy—feeling one step closer to my dream of being a physician. I probably went through 8 or 9 different outfit renditions, not ever having a formal job before, not ever having worked as a scribe before, but wanting to make sure I gave a good first impression. When I arrived at the office to meet her, I could sense something was "off." She seemed a little awkward and told me to go through some side door in a hallway to get into the back offices. She immediately went into a conversation about rules and policies. It seemed like an odd way to begin the conversation but being my first job, I didn't think anything of it at the time. She discussed HIPAA, patient privacy, and the need to cater to her patients, who she stated were mostly elderly. None of the rules seemed out of the ordinary—except for one. She said I couldn't wear my headscarf (hijab) to work.

Having been raised in the suburbs of Dallas, I thought I had been lucky to have been a part of a culturally diverse upbringing. I had spent some years in a private Islamic school and some years studying in a public high school, which I felt made me confident in being able to talk to all sorts of people. From time to time, I would come across some people who may not have been familiar with why I wore a headscarf but usually, after explaining its background, most people seemed to understand. Thinking this was the same, I proceeded to explain what my headscarf was and how I wear it out of a religious obligation and for modesty. Her justification for why it wasn't allowed just didn't make sense. "We don't allow any accessories here—no hats, no jewelry, no religious affiliations here. People aren't allowed to wear necklaces with crosses." But she also said, "Wearing your headscarf here would make my patients scared."

To be perfectly honest, I don't remember much of the rest of the conversation that day. She didn't offer me an office tour and had told me to think about it and that if I wanted to work with patients, I could not wear a headscarf. I had sent several follow up emails explaining my headscarf to her, even going to the point of asking our Islamic clergy (Imam) to write an email to explain it to her, but the answer was still the same—if I chose to work in the clinic, I would not be permitted to wear my headscarf. She would make an exception and allow me to put it on during my lunch break if I sat in the breakroom, away from others who could see, but that was the only concession she was willing to make. This broke me.

> *I would make patients scared? Is it just what I am wearing, or is it my "foreign sounding name" or is it because of how I look and the color of my skin? How is it that I could volunteer at a hospital wearing a headscarf but at a private practice clinic, I would make patients scared? Are private practice patients different from hospital patients? Is this what all private practices are like? Is this what it will be like working in medicine? Will I always encounter this? Do I want to go into medicine?*

After, I started to feel angry, hurt, and confused. And I had more questions.

> *Is this discrimination or was this just a uniform? Are all jobs like this? Was it okay that she asked me where I was from? Why did she even ask that? What does where I am from have to do with my abilities to be a scribe? Why was my name "foreign" to her? What does "foreign" mean? Is she saying I don't belong? Where do I not belong? In her office? In any office? In Medicine? What does my wearing a headscarf have to do with being a scribe? Will I ever become a doctor if this is what people see? If this is what people think?*

I sat and debated these questions on end with my parents, my teachers, and my volunteer director and I realized I had always been in a safe bubble, protected from ever feeling discriminated against at school and in my experiences thus far. I had been naïve and realized that discrimination, unfortunately, was ever-so-present even in the professional world. In my what-I-previously-thought-diverse city, discrimination does exist, and I was at a crossroads of what to do about it. I thought maybe bringing attention to the matter was the way to go. My father sat with me for hours at the Equal Opportunity Office so I could plead my case. It turns out since this employer had only a few employees, equal opportunity laws are not applicable, and the only way to pursue this further was to start a legal suit. I tried writing to the local news stations, but no one ever took heed. Finally, I told myself I didn't want this job bad enough to compromise my own integrity, and if this is what doctors' offices are like, then it is not for me; and I let the dream go for a while. Medicine always kept calling to me, and I eventually found other experiences to help my resume when I applied to med school.

It has been over 15 years since this happened. Now, I am blessed to be a part of an institution where we actively promote diversity, equity, and inclusion (DEI) and try to prevent any discrimination from happening. Diversity is celebrated. We try to take the same steps when it comes to recruitment and teaching as well. Training medical professionals that it can happen and being open is the first step in bringing culture shifts and changes.

A few months ago, I had a new patient who was expressing her frustrations with being racially discriminated against. She looked at me and said, "You know I chose you specifically to be my primary care physician because I thought you may have had your share of discrimination and would understand what I am going through." It was then that my 18-year-old-self felt validated. I thanked her, and I remembered the lesson I carry from walking away from the job that I thought I wanted but didn't need. And I told her the same: "Don't let anyone stop you from pursuing your dreams because of what you look like or who you are."

And the doctor's office? It is still there. I don't know if they have changed their hiring practices and policies, but I know *she* is still there. A part of me wants to offer DEI training to them so that other people do not have to go through what I did. A larger part of me knows that I have learned what I needed from this unfortunate experience and can use it to be the force of change where I am. But, if I am being honest, there is still a tiny part of me who wants to walk back into those doors to show her that I can work with patients and wear a headscarf too.

◆

Asian Americans in Medicine: The Race That Nobody Sees

Kimbell Kornu, MD, PhD

The son of a physician, I was born and raised in Greenville, Texas. My parents are immigrants from Thailand and ethnically Chinese. We were the first Asian family in town. I proudly call myself Texan-Thai-Chinese (in that order). While growing up, I was the target of racial slurs. I remember waiting in the lunch line in fifth grade when another student asked me, "Do you know kung fu? Do you know Bruce Lee?" When I was in high school, a new girl had moved into town. Immediately after we first met, she blurted out with a fake Japanese accent, "Ohhh, sexy girlfriend," quoting the character Long Duk Dong from the 1984 movie *Sixteen Candles*. Such ignorant remarks stung with a realization: I was a foreigner in my own hometown. Ignoring little comments becomes difficult because these racial slurs build up over time. I learned that I was different from everyone else and didn't fit in.

The purpose of telling my story is to begin a conversation about how Asian Americans are invisible in medicine. One may balk at such a charge—aren't Asian Americans disproportionately overrepresented in medicine already? Asians comprise 5.6% of the US population yet make up 20% of all US medical school graduates, according to the Association of American Medical Colleges (AAMC) data. Or, one may point out that Asian Americans have been in the cultural spotlight. In the US, since the beginning of the COVID-19 pandemic in March 2020, Asian Americans have persistently been targets of racial discrimination and racially motivated violence, most recently in the shooting deaths of multiple women in Atlanta. But the very fact that racially motivated killings are required to thrust Asian Americans into the spotlight about race issues shows their invisibility. Since this racial group is neither White nor Black, they are invisible and irrelevant to race issues in America. Despite the overrepresentation of Asian Americans in medicine, to my knowledge, there is nothing published about the Asian American physician experience in the medical literature. I hope to remedy this massive lacuna by sharing my experience as an Asian American physician.

Feeling like a foreigner was not confined to my hometown—I also felt like a foreigner in my own skin. As a second-generation Asian American, I feel my identity is split between two cultures to which I don't fully belong. The racial slurs affirmed that I was different than everyone else because I looked foreign. When I visit my extended family in Thailand, everyone looked like me, but I didn't feel like I fit in because I couldn't speak the Thai language. If my body was not American enough, and my culture was not Asian enough, then what was I?

I did well in school. I internalized my parents' expectations: with academic success you can live a good life. When I was growing up, my parents identified three viable career options: medicine, law, or engineering. No other possibilities entered my imagination. If you go to an elite school and get a good job, then you can provide for your family, so the cultural logic goes. Following my father's example, I wanted to become a physician. I dreamed of going to an Ivy League caliber school, having internalized the dream from my parents who equated success with the Ivy League. If I couldn't be a full Asian culturally or a full American bodily, then my identity would be rooted in academic success. Those dreams died when I was rejected by all of the Ivy League caliber schools. Since I didn't meet the internalized family expectations nor the standards of my own self-identification, I felt like a failure and was ashamed.

One might think that becoming a physician alleviates Asian American racial dynamics, but the culture of medicine is not immune to microaggressions. As a medical student, I enjoyed rotating at the VA hospital because of the veteran population. However, immediately after I walked into a patient's room, a veteran told me, "Go away. I don't want a Jap doctor." Despite my gratitude for this veteran's service to America, I was not considered American enough to be involved in his care. My older brother, also a physician, was told by a patient at the VA, "I don't want a doctor from the Viet Cong."

Medical culture and Asian American culture share remarkably similar values that work to exacerbate the invisibility of Asian American experience in medicine. Asian American cultural values in academia and the workplace can be stereotypically summarized as: *work hard, don't rock the boat, don't trouble other people*. Out of respect for and obedience to one's parents, these values are internalized. The expectation is that all problems are solved with hard work and self-reliance. In the culture of medicine, a similar work ethic reigns. In the face of tiredness and fatigue, medical students and residents are encouraged to suck it up, work harder, and "be more efficient." Medical trainees are not taught to ask for help but rather are held to the ideal that a good physician is self-sufficient, efficient, and resilient. When Asian American culture meets the culture of medicine, the shared values mutually reinforce each culture. The Asian American/medical cultural synthesis teaches trainees and physicians in the midst of struggle to *keep your head down, work hard, don't seek help, and don't bother anyone*.

This cultural synthesis can be toxic for Asian Americans in medicine in light of data on mental health in physicians and the Asian American population. Results from the National Latino and Asian American Study published in the *American Journal of Public Health* found that Asian Americans use mental health services less than the general population (8.6% vs. 17.9%). Suicide is the ninth leading cause of death among Asian Americans, compared to tenth among Caucasians. A high level of identification with one's ethnic group is associated with lower rates of suicide attempts, according to Janice Ka Yan Cheng in an article titled, "Lifetime suicidal ideation and suicide attempts in Asian Americans" published in the Asian American Journal of Psychology. From my own experience, being a second-generation Asian American can lead to lower identification with one's ethnic group, feeling neither fully Asian nor fully American. Unfortunately, this dynamic has not been explored among Asian American physicians.

It is a well-known fact that the rate of suicide is higher in physicians than the general public. But the cause for the increased rate is unknown. Being Asian American has not been considered a risk factor for physician suicide in the medical literature. However, I would like to highlight a study on suicide among US physicians, using data from the National Violent Death Reporting System. When looking at various factors associated with the likelihood of the suicide victim being a physician, researchers Katherine Gold, Ananda Sen and Thomas Schwenk found that race was statistically significant. Physicians in the "Other/Missing" race were three times more likely than Caucasian physicians to commit suicide. It is true that the racial category of "Other/Missing" cannot delineate whether the higher likelihood is due to being Asian, Hispanic, etc. Yet, the most telling thing is what Gold et al. do *not* say in the discussion section. The study authors do not even entertain the question that race could be an important factor in physician suicide. They do not explore the possibility of breaking down the racial category "Other/Missing" to investigate whether, perhaps, Asian American cultural dynamics could be a factor in physician suicide. This is a gross oversight.

It is my hypothesis that the Gold study is a symptom of a larger problem that Asian American physicians are an invisible group in medicine. If Asian Americans feel pressure to become a physician (presumably resulting in many Asian Americans becoming physicians who don't really want to), if Asian Americans on the whole underutilize mental health services, and if physicians in general have a higher rate of suicide, then such a significant finding about race and physician suicide should be investigated. Asian American mental health in medicine is not understudied; rather, the issue is not studied at all. It is not studied because discussion about the Asian American physician experience does not exist. This is the fundamental problem. While Asian Americans face no racial disparities in terms of admissions and representation in academia, there are ocular disparities of racial invisibility due to unconscious bias. Wesley Yang says it well: Asian Americans occupy a liminal place as "an 'honorary White' person who will always be denied the full perquisites of Whiteness . . . a nominal minority whose claim to be a 'person of color' deserving of the special regard reserved for victims is taken seriously by no one."

I hope that my own story as an Asian American physician—which reflects a common experience—will start a conversation about a significant part of the medical culture and bring visibility to a group that has been invisible for too long.

* * *

The Subtle Struggle as the Minority

Cecilia Igwe-Kalu, RN, BSN

Despite the endless battle for racial equality in the United States, justice still does not seem palpable. One would believe all is fair and equal between differing ethnicities after the Civil Rights Movement, which ended in 1954 followed by the Civil Rights Act of 1964, but after living through the year 2020, so much has transpired, showing otherwise. The COVID-19 pandemic forced the entire country to "stay still," limiting activity and TV entertainment. So, when the tragic deaths of George Floyd, Ahmad Arbery, and Breonna Taylor happened, an uproar ensued, bringing most attention to news stations and news outlets about the continuous racial divide that has been neglected for years. People from all ethnicities, especially those of the Black and African American communities, were—and still are—angry and tired of the blatant disrespect and broken systems dictating how minorities are treated.

No matter the level of education or socioeconomic status, racism is deeply felt by all, evolving from generation to generation. The topic of racism is discussed commonly amongst others, but one would never think he or she would experience racism or be targeted for one's ethnic background. As an inpatient nurse working in a predominantly White population, I'm constantly reminded of my differences and have had to deal with hardships as well. I'm unapologetically going to talk about what it is like to be a Black nurse in 2021, and how my past experiences fuel my anxiety and discomfort in situations today. I hope you all truly listen and are able to learn from me; together is the only way any of this will change.

Never did I ever expect the start of 2020 to trigger feelings that had been subconsciously suppressed for several years. While at work, I unintentionally overheard a conversation that referred to Blacks negatively, specifically Nigerians. The skin color of Nigerians was compared to the darkness outside on that weeknight, and the comment was followed by endless laughter. I was immediately taken aback by the statement—why? Because I am of Nigerian descent, raised by immigrant parents born in Nigeria, who are of darker skin. In that moment, I was then pointed out as being a young Nigerian woman, which only made the situation worse. Shock and embarrassment were all I felt working the rest of that shift. It was not until when I got home from work early that next morning that I could no longer control my emotions. Lying in bed, tears fell from my eyes—two hours went by and I could not stop the never-ending replay of the trauma I had faced since childhood.

The bullying started the very first day I stepped into my first-grade classroom. I was one of many students chosen to be in the METCO program, allowing inner-city Boston students access to better education in the surrounding schools of the suburbs. Many of the students in METCO are Black as well. Immediately upon entering the classroom, a few of the girls pointed at me and started laughing. This moment started my lifelong insecurity. From elementary school through college, I dealt with the teasing—from the color of my skin, to the texture of my hair, to the size of my lips, to my ethnicity. I was called an "African booty scratcher" while others made fun of the African dialect. It was not until college, after meeting others like me, that I finally was proud of who I was—Black, American, and African.

The incident at work did not just upset me for the time being. It affected me for months. Many do not understand the impact of a "simple" joke—words and actions that affect others remain in one's memory for years; it is never forgotten. My emotions and insecurities were at an all-time high, so much so that I was no longer comfortable coming into work. Do my coworkers also joke about my culture, my skin tone? Do my patients and families feel uncomfortable with me being their nurse? These were the questions I frequently asked myself as I anxiously braced myself for my next shift. I could no longer walk the streets, sidewalks, or even the hospital lobby without believing someone was looking at me because of the color of my skin. I lost trust in my coworkers, my friends, and they did not even know it. Coming into work my first day of a long stretch was nerve-wracking because I did not know what assignment I was going to have. Will I know the patients? Will the patients and families be okay with having a Black nurse? I spiraled and had to rebuild my self-esteem and self-confidence with the help of friends, books, and a therapist. I needed to bring my emotions back to serenity, though many of these insecurities I still battle today.

People are finally starting to see how major a problem racism still is in this country. What people may not realize is that racism is not an experience only faced in the south, but by everyone everywhere. Something as small as microaggressions can negatively affect one's belief in oneself and way of living. Racism in healthcare can negatively affect the care given to patients, the trust of patients, and unity amongst healthcare teams. With the help of public platforms and social media, the display of such racism is overt, apparent, and is the hopeful catalyst for change.

The constant reminder of being one of many few Black nurses in my institution led to my desire to become an advanced practice nurse (APN) in the near future. From experience, the more diverse there are healthcare professionals, the more comfort a minority patient may feel receiving care. I hope as an APN to be *that* face or source of comfort for those seeking a face so familiar. I hope to extend my knowledge and care to patients and families with little faith in the healthcare system and dismantle the fear of racism in the field. Having dealt with racism myself, my goal is to use my experience as motivation for greater transformation.

* * *

On Being the Only Brown Face in the Room

Anonymous One, MD

When I first began practicing as an attending, I was tasked with restructuring some hospital-based practices and procedures. As part of this work, I frequently asked for feedback from other attendings. One attending was consistently silent, so I decided to reach out personally; by the time I had done so, however, it was after the bulk of my project was completed. I later learned that after I tried to contact him and failed, he approached the department chairperson about my inquiry. He then went looking for me. One day, my secretary greeted me in my office, stating ominously, "Dr . . . is looking for you and wants to talk to you—he was very angry and said that when he sees you, he will cut your head off!" My secretary explained that he was just walking the halls looking for me; when he was unable to find me in person, he uttered loudly his desire to "cut" my head off in the presence of many of my colleagues and stormed off.

I thought this was all a bizarre joke, but saw in my secretary's face that she was not joking at all—he really did say this. I asked the chairperson for advice, and he informed me that this particular attending had been the former department chair for decades; despite the fact that he stepped down to phase into retirement, there was an implicit understanding that no major changes were to be made in the department without his knowledge and consent. As the new attending, I did not know this. I was concerned, but reasoned it was a simple misunderstanding. Secretly wishing my secretary was exaggerating, I made arrangements to talk to this attending, prepared with a smile and an apology.

We later met face to face in his office. To my surprise, I walked into a barrage of heavy cursing from the physician disparaging me for implementing changes without his knowledge and consent. His colleague was also present to support him and added to the loud, harsh rhetoric. They both openly questioned my education and what my class rank was, repeatedly asking, "where did she come from?" and the department chair should "look into" my background. They strongly suggested that I was not qualified, or may have even lied to get my new position. Both of these physicians were White and I am Black. I felt that their manner of speaking and the gist of their questioning would not have occurred had I not been Black.

I was so shocked, I froze in my chair, but did my best to use my words to defend myself. They were unmoved. Eventually, I gathered the courage to stand up and walk away. I shuffled back to my office, confused, frustrated, and in tears. I felt so disrespected and so devalued, and I could not figure out what I did wrong. I considered walking away right then and there and never returning to my job. But after reconsidering, I returned to work the following day and approached my chair about what happened. My chair stated that this attending is known for his uncivil behaviors, and that nothing could be done except to ignore it, don't take it seriously, and just move on. I felt alone. Still, I went on to tell other colleagues in the department about what happened and was told the same thing. I said that I felt I was treated inferiorly due to my race and gender, but was corrected by colleagues that no one is racist in our department. I was made to feel like I was overreacting.

But I wondered—how would anyone in this department really be capable of understanding this experience from a race lens if I was—and still am—the only Black female attending in the entire department (the only other being a semi-retired Black male)? Why wasn't anyone at least curious enough to consider the possibility?

I spent years after that event paranoid over what these physicians might say or even do to me if we unexpectedly ran into each other. When I did see one of them, I would panic. My heart would race, my skin would sweat, and sometimes I would get lightheaded. Once I even ran into one of the physicians in a supermarket—of all places! I had completed my shopping and was waiting in line to pay for my full cart of food. But I felt as if I was going to pass out just from the sight of this physician, so I abruptly left my entire cart of food in an aisle and left the market with nothing but my baby in my arms. I felt huge relief when I learned that one of the physicians moved away and the other finally retired.

I still work in the same department and still wonder why I never did walk away. I was young, new in my career, and just had a baby. I desperately wanted to prove my strength and value to my colleagues. I never went to human resources because after talking to my chair, I lost faith that anyone would ever protect me. Attitudes have improved, but despite the hiring of dozens of physicians since my first day, not a single person has been one of African descent, even though they were interviewed.

After the two physicians left, I gained the courage to out the department's shortcomings many times. For example, I have asked that more residents and attendings of color be brought on board, that chosen mentors be more diverse, and that physician wellness initiatives include space to talk about race and gender. No one disagrees, but then nothing is done, even when I bring forth working solutions. I get tired of being the only Brown face in the room, the first and the last to iterate on anything related to diversity and allied support. Sometimes I just do what is needed to simply keep my job and for my own mental self-preservation. I am learning that that is OK. With time, therapy, and support of friends and family, I am slowly understanding why it all happened, and how to avoid burning out.

I have never had the chance to mentor any colleague of color in my position since none have been hired. Would I be daring enough to speak frankly on my experiences? I don't know. I have always worked hard to never let any of these events affect my role as a medical provider, however. I always try to be a compassionate advocate for my patients. But I do wonder if I could be better had I received the support I needed when this incident occurred years ago.

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A Family That Looks Like Mine: Confronting the "Hidden Curriculum" as a Black Medical Student

Juliete Castillo-Anderson, 4th year med student

"Go ahead and interview the patient's family first and then we'll go in together." I'm excited to do my first patient interview of third year by myself, and when I walk into "Alex's" room in the ED, I immediately feel comfortable talking to his family—a family that looks like it could be my family. The patient, a cute three-year-old boy, is asleep after what sounds like a stressful and scary morning for everyone involved. His mom is lying next to him in bed, comforting him, while his grandmother holds his younger sister in the chair next to them. My job is to ask Alex's family about one of the most nerve-wracking mornings in their lives, seeing their child become unconscious and have what appears to be a seizure. After we go through all of the events that morning and I ask all of the specific seizure history questions I wrote down, I move on to my next task.

Alex has a history of staring episodes that his mom describes as seizures, and she says that this has been going on since he was one year old. When I ask her about them, she tells me that they have happened more and more frequently and are now happening every day. When I discussed this part of the history with the resident and attending before I entered Alex's room, they told me that these episodes didn't sound like seizures—that it wouldn't make sense for Alex to have absence seizures at his age, and that "his mother wasn't a very good historian anyway."

I had been told to find out more about his past "seizures" and how they were different from what happened today. But as I start asking Alex's mom about his episodes, it becomes clear to me how frustrated she is with the medical system and how they have disregarded her concerns about her son: "If they had found out what was happening, we could have prevented this big seizure. The little ones I can handle, they happen every day now, but this I can't handle." When she says this, I don't know what to say. I stand there and look for words to try to comfort this mother who is scared for her son, who feels like doctors have let her down and failed to prevent this from happening to him now. I recognize my role as a student doctor, someone who is trying to learn how to become a part of this system that has made this mom feel alienated and unheard. I also feel a twinge as I recall the conversation I had with the resident and attending and the way they had tossed this mother's concerns aside and labeled her as someone who couldn't accurately describe what was happening to her own son. "We're going to do our best to try to find out what's wrong with Alex today." That's the best that I can come up with in that moment, but it feels insufficient.

I let the patient's family tell me everything they want us to know, and then I leave the room to talk with the resident. After I've told them Alex's history and recounted the events that happened that morning, I go back in with the resident as Alex's mom tells her story again, completely unchanged from when I spoke to her. After we leave the room, I'm caught off guard when the resident says, "I would be surprised if he actually had a seizure." The story his mom had told didn't fit with the description of a seizure in the resident's mind. After we talk to the attending, the plan is made to get an EEG to evaluate Alex just in case. Through that objective test, we all learn that Alex has had a significant focal seizure and will have to take anti-seizure medication for the foreseeable future. When we tell Alex's mom, she still seems concerned, but, to me, she also seems like she feels somewhat vindicated. Finally, it seems, she feels heard.

I've thought about Alex and his family many times since I met them and about all of the reasons their story was disregarded. Was it their education level? The color of their skin? Was it the mother's young age? Could it be all of the above? I think of the times in my life that I have felt unheard and unseen as a Black patient—the times when my mother's concerns fell on deaf ears, the time that a doctor's weekend plans seemed more important than my pain and my possible surgery. I only made it through those moments due to the fierce advocacy that my mother provided for me in those situations. She never failed to amplify my voice when faced with systemic barriers or biases. During my interactions with Alex and his family, I saw that same unwavering support and advocacy in his mother—the same insistence that something was wrong, even after countless medical providers and staff had dismissed her. I know the feeling of watching my mother feel like she has to fight to get taken seriously, and I know how exhausting it can feel to repeat your concerns for what feels like a million times without seeing anything change.

Looking back, I wonder how things could have transpired differently and how I could have been more active in trying to help Alex and his mother through a system that isn't set up to help them. I tried to offer them my words of comfort and support, and I tried to convey all of their concerns to the rest of the team so that they could be heard. I made it clear that the mother had been able to provide all of the details of what happened that morning and relayed what she went through with her son with different medical providers. I did so in a way that I hoped would combat the idea that she was a "poor historian," a label I often see applied to Black and minority patients. At the end of the day, Alex and his mother got the answer they had been searching for, but I can imagine how this case could have played out differently and how powerless I would have felt to help them go against this system.

As I have continued through medical school, I have had to find ways of trying to expose biased thinking in a way that allows those teaching me to reexamine their biases without feeling like I am overstepping. I have also been confronted with the "hidden curriculum" of medicine that so many of us are exposed to as we go through our training. As students, we get messages about the types of patients who are "poor historians," the stories that deserve time and attention, and the voices that deserve to be listened to. These messages are shaped by the racism that is interwoven into the foundation of our medical system and medical knowledge. We are all vulnerable to allow these messages to influence how we practice in our future careers unless we actively pay attention to and invalidate these biases. In a way, I am grateful for some of the negative experiences that I have had as a Black patient because they allow me to recognize similar experiences in my encounters with patients, and they inoculate me against the biases that are handed down to us throughout our education. As I move toward becoming a physician, I hope that my life experiences and the patients who leave an impact on my life and education will continue to empower me. I will continue to slowly chip away at the systematic racism and biases in medicine through my interactions with patients, colleagues, and, perhaps most importantly, with the students who will be looking to me as an example to learn (or unlearn) this "hidden curriculum."

I wrote a fifty-five-word story that highlights the impact of racism and biases on undergraduate medical training and the use of race in medical decision-making. I wrote it while thinking about Alex and his family, my own experiences both as a patient and as a future provider of medicine, and the shift to try to illuminate and reduce "implicit biases" in medicine and our culture at large. I hope that those who practice medicine will continue to actively go against our inherited medical biases, attempt to uplift and empower black patients, and address the racism within the medical system and within medical practices that use race as a poor shortcut for genetics and social factors.

> Recognizing implicit biases is an important first step.
>
> But it is just that, a first step.
>
> How can we begin to tackle the biases we came into medicine with if we're leaving our medical education with a whole new set?
>
> When will we improve the evidence from which we base our care?
>
> For *all* patients.

* * *

Chronicles of a Culturally Grounded Chaplain

Calvin Bradley Jr., MDiv, CFLE, BCC, HEC-C

Owning My Space and "Knowing My Place"

When I first began my career in healthcare chaplaincy, I was invited to have a seat at several "tables." From leadership councils to special committees, I was constantly being invited to serve. I did not know very much back then, or so people thought. I was young, new, and needed to take my time learning my new environment. The truth is, by the time I began my chaplaincy career, I had earned two master's degrees, had begun working on my doctorate, and had a decade of experience in education and youth development. I was anything but a rookie. I may have been new to the neighborhood, but I was definitely not new to complex organizational dynamics or providing programs and services to the public.

Nonetheless, I showed up at the meetings and for the most part, did not say a whole lot, or challenge much of anything at all. However, as I became more comfortable in the space, and grew in my knowledge of my new space, my voice consequently became stronger. I began using my voice and pastoral authority to advocate more for my patients, bring awareness to inequities within the systems I served, and challenge the status quo. Inclusivity of persons from all walks of life, especially the marginalized and disenfranchised, has always been at the center of my work. As my passion and influence grew, I was quietly and conveniently uninvited to the next meeting. In some cases, whole projects and committees were completely dismantled, some reestablished under new facades. Ideas I had previously shared that were once downplayed as unreasonable or impossible suddenly became action items and were attributed to being the brilliant ideas of others. I experienced this behavior not only on a local institutional level of engagement but also with some national-level professional organizations with which I was a part.

Within the scope of pediatrics as a specialty population, there is a significant shortage of African American representation across all healthcare professions. I was the only African American, or racial minority representative period on many of the committees and councils I previously mentioned. It did not take long for me to realize my role was one of tokenism and that as long as I followed the path others laid out for me, I would be fine. The problem with this arrangement is that I have never worked quite so simply. As I grounded myself in the profession, I identified my own strengths and passions, and aligned myself with people and groups who were doing like-minded work on the local, regional, and national levels. As my passions and confidence grew, the magnitude and impact of the work also grew, and so did my challenges. I was suddenly labeled "unapproachable" and "distant," along with implications that my passion for certain areas by default made me neglectful and insufficient in others. The problem was not my level of competence but my ability to discover my own lane and navigate it without the permission of others. When individuals outside of my reporting line could no longer micromanage and manipulate not only how I function, but how others perceived my function, I became the problem.

Why All the Black Workers Congregate, and What Are They Talking About

In response to the racial trauma and repeated tragedies that have escalated across the country over the recent years, I have experienced a higher demand from staff and patients, primarily African Americans, seeking a space to unpack and process the various events. Sometimes this takes place in a casual one-on-one interaction, and other times it becomes an informal group interaction. As a spiritual care provider, it is well within my clinical scope and expertise to facilitate such conversations and provide the necessary space to perform very needed "Soul-care" in response to these traumatic social experiences.

The passive attempts to interrupt or intercept these opportunities are visibly noticed by myself, as well as by the staff and patients I support. For example, trivial tasks and needs suddenly become emergent, demanding the attention and response of the person with whom I may be speaking. If a group is gathered and privately discoursing, an interruption or announcement of no relevancy or real urgency is often inserted as a distractor. It is clear that some individuals do not wish to engage in these difficult conversations, but also do not feel we should be allowed to have such sacred space in which to process the social happenings that impact us. The mindset is one of "deal with that on your own time." For many African Americans healthcare professionals, I have worked with, it has been difficult to own their identity in a time where the world hails them a "hero" in light of a global pandemic, while simultaneously feeling and being treated as a threat or problem within their own institutions and communities. While many organizations have made public statements and perhaps even edited some of their policies, few have taken the time to candidly listen to the experiences people have had within their own institutions.

Ditch the Dashiki

Several months ago, I began wearing a daishiki to work at least once a week. Initially, it was one of the things I decided to do to embrace and express my cultural identity and pride more fully. It was a small gesture, but something I hoped would be a visual cue to both myself and others of the pride that I possess in my cultural heritage and identity. I got many wonderful and sincere compliments about my dashikis from people from all walks of like. Many would ask where I acquired my daishikis, wondering if they were part of my international travel experiences, which I often share. Others would often admire and comment on the vibrant and varied colors. Many African American colleagues whose professional roles restrict them to wearing a particular uniform to work, often expressed admiration and appreciation for me "representing the culture."

There was one colleague who never said anything particularly about my attire but could often be observed staring from a distance. Despite me having been wearing the daishikis for more than a couple of months at this particular time, it was the last week in February—Black History Month—when this individual finally expressed what they were feeling and thinking, disguised in what I assume they thought was either humor or sarcasm.

"Wow, this month flew by. I guess this is the last week for you to wear your "festive shirts, huh?" they said

"Why, I'm still going to be Black the remaining 10 months of the year," I quickly responded.

They quietly walked away.

Many times in healthcare, I have been reminded through the actions of others that my expected role is to be seen, but not heard; patronized but not validated; and present but not influential. I am a scholar and clinical professional who has put in the hard work, navigated the social and racial challenges set before me, and I make no apologies for my passion, my drive, or my success. It is not my size or skin color that most threatens or offends, but it is the ability to think freely and to be creative, to challenge and cultivate change, and most of all, to love people genuinely without return. It is that I both give respect, and demand respect from those around me. But most critically, it is that I have the ability to do all of this while being a Black man in healthcare.

* * *

Fear of Being Discovered

Pablo Cuartas, MBE, HEC-C, MD candidate

I never thought much about the times I was asked to "quit joking" when I introduced myself by my first name. I have been informed quite a few times that my phenotype does not resemble that of someone from Colombia but from the United States. When my introduction is met with casual disbelief, I offer reassurance that my name is, in fact, "Pablo" and laugh along. When I dig deeper into that kind of comment though, it leaves me wondering. What does someone from these United States look like? What does someone from Colombia look like? The answers to those questions and their relative proportions have changed a great deal between the pre-Columbian era and now, but here I deal with more recent events.

Before medical school, I worked as an emergency room scribe in the Midwestern United States. Once on an overnight shift, my attending and I saw a middle-aged gentleman who, while involved in a brief intoxicated altercation, made his way through a glass window, producing a dozen or so lacerations that would require some help with closure. It was when this gentleman realized we would be together for a while, as 10 minutes passed and we were only 1/8th of the way through, that in addition to being alert and oriented x3, he became conversational. I admit I operate on assumptions here, but I believe that whatever he enjoyed earlier that evening served a dual purpose: analgesia and disinhibition. He mentioned to us how happy he was to be in the company of two other men with a complexion that matched his. It seems he misinterpreted the doctor's forced smile because then he treated us like a couple of sympathizers. We listened as he described other ethnicities one by one, as though making sure to communicate each of his beliefs about this group or that before moving on to the next one. Occasionally he would backtrack, perhaps out of misplaced concern that if the doctor or I did not hear that particular racial slur, we would be left yearning for it. Some groups he favored less than others, and while he was at times difficult to follow, with each stroke of his broad brush, he painted an increasingly vivid picture of his worldview for us: Skin color matters most, and the fairer the better.

My attending and I took solace in the fact that this man seemed to prefer didactic pedagogy to the Socratic Method. However, he occasionally would ask a question. When it was not rhetorical, my attending took the lead in responding with gentle disagreement followed by a "hold still now; we're almost done here."

Throughout that encounter, I could feel the air in that breezeless room settle over my arms. It did not go anywhere or cool things down; agitated only by the occasional movement of my hands as I typed on my laptop or shifted how I was sitting. Several times I looked up to see a nurse come in and look around the room with a subtle look of amazement at what they had overheard. If I caught their eye, I tried to convey a look that said, "I know. Crazy, right? I don't agree with him either, but please don't say anything too true because we're in here in the city of sharps for at least another 30 with the guy." This was, of course, in the pre-COVID era, so I was not afforded a mask to don and cover my facial expressions. A lot of thoughts crossed my mind; chief among them was equanimity—or at least the control to feign it. Also among them churned a reluctance I had never experienced. I am proud of my culture, of being born in the United States to two immigrants, and though I try not to flaunt it, I am not one to obscure it. But when this man, despite getting stabbed a hundred times by a tiny sewing needle to stop blood from oozing from his several open wounds, gestured angrily at the prospect of encountering the groups he was discussing, I didn't say my name was Pablo. That whole time I neglected to introduce myself. I would have been made. Instead, I met my attending's occasional tired glances, shrugged, and click-clacked away about which thread had been attached to the needle and how much local anesthetic was injected just before. Eventually, this gentleman tired himself, falling asleep with a soft smile shortly after. The three of us would get some rest. The doctor finished, and we went to see the next patient. I sat through most of that encounter as a bystander. After all, the man's comments were not directed at me. My skin is not the color he seemed to take issue with.

I did not dwell for too long. There were other people to see. On the drive home that morning though, the man's words lingered, and the fact that I said nothing left me uneasy. It was not a painful or stinging sensation; I just felt more tired than usual. Though this happened years ago, I still wonder what experiences led to those beliefs and feel sad at the hate that man harbored. That tired sensation intermittently reappears. It rears its head when I meet someone that reminds me of that man. I am reminded of him too often.

* * *

"Bless Your Heart"

Sarah M. Temkin, MD

"This would be much easier if you would just say you're not White," she said into the phone. I was speaking with the administrative assistant to the department chair to whom I reported. She and I were arranging a meeting of the search committee for a faculty member that I was hoping to recruit.

I waited, then reminded myself that feigning confusion was often digested better than my innate direct style when talking to other women in this environment.

"Patty, could you explain what you're talking about?" I said, using my best bewildered voice. "I must not be understanding what's needed."

She sighed before explaining that the University had rules about search committees. One member of a 'minority' needed to be included in this group for the hire to be approved by the institution.

"Does the University keep a list somewhere of minority physicians who might allow us to meet this requirement?" I asked.

She said no.

To continue this conversation seemed to be a little like willfully entering a minefield.

"Were there instructions from the University about how to recognize physicians from underrepresented communities?" was the next question that I posed. But there were so many other questions that bubbled through my brain. "Would my assessment that the physician is 'non-White count, or would I have to ask them to self-identify?" "Which minorities 'count'?" "Would a gay physician satisfy this requirement? If so, who could provide the sexual orientation of the faculty?" "Who made this dumb rule?"

Patty didn't have an answer. She only had frustration for what she viewed as a check box but I saw it as an absurd policy. She hadn't made the rules. She was just trying to help. But she was in the unfortunate position of being the messenger of this particularly ridiculous message. Finally, exasperated, she blurted out, "either you can say that you're not White or we can invite Dr. James to this committee. She is Black."

There was a long pause.

"I chose members of this committee who had the knowledge and expertise to judge how well new faculty will fit onto my team. I'm pretty sure another person who's already on the search committee can fulfill this requirement. Dr. James' practice and research don't overlap with those of this new hire at all. Please find out more about the process by which we can qualify this committee as adequate per institutional rules." The conversation ended more abruptly than was congenial.

I had not spent a lot of time thinking about being perceived as White before moving to the South of the United States to act as the director of a surgical service. As a child with mixed race and ethnicity, I grew up knowing that I wasn't Black. But beyond that, my identity was complicated. I knew I could pass or blend in the White communities where I had grown up, gone to school and worked. But at the same time when, during my fellowship, an administrative assistant in my department looked at me from behind and said, "you have a nice booty for a White girl" I was more caught off guard by being referred to as White than by the fact that she was actively surveying and judging my body. That had not felt right.

In the hospital, I definitely fielded unending questions about my "tan." Are you Italian? Greek? Lebanese? I'd even been asked if I was Armenian by a well-meaning administrative assistant with an Armenian in-law in her family. These questions were not only common but exhausting as they peppered my communication with patients, staff, and colleagues. I fielded these questions and grew capable and competent in the art of deflection as an adult and a physician. After all, I had grown up in the suburbs, surrounded by White children, gone to an elite private college and attended medical school, surrounded by White peers and so I continued my professional life as a privileged, White-adjacent, first-generation American. Aside from the ethnicity questions from patients and that booty incident, the issue of my own race or ethnicity hadn't seemed particularly relevant to my day-to-day ability to perform my job.

But now in this new environment, I seemed to be perceived differently. White women like Patty looked at me a little too long or with a slightly raised eyebrow or a sideways glance. They knew I wasn't Black but also thought I wasn't White and then there was confusion.

When I went to get my ID and badge before starting this job, the security guard questioned me about race. In the demographic section of the form that I filled out, I had left the "race" question blank.

"What are you?" she said.

"What do you mean," I asked.

"Are you Black or White? You left the question blank."

"I'd prefer not to answer."

"This is the state hospital. You have to answer."

"I don't have to answer."

"You do have to answer."

"What happens if I don't answer?"

"I won't give you a badge."

"Why don't you fill in whatever you want. I don't feel comfortable answering."

This back and forth continued until I finally filled in the bubble next to "White" on my form. My husband had gone to get his badge later in the day and that evening, I asked him if he had filled out the race question on the form.

"No," he said.

"Did the security guard get mad at you?"

"No."

"Did she ask you what your race was?"

"No," he said.

"She just filled your form out for you and made you White," I said. "She gave me a hard time, for nothing."

This felt annoying.

A few days later another administrative assistant sat down in my office. Patty had called her and told her that she was afraid to talk to me. Patty had shed a tear during their conversation. I was scolded by this administrative assistant sitting in a chair across from me— "You could be nicer when you talk to other people. I know you're a nice person, but not everyone understands that."

"Ok." I replied calmly. "I'll try."

In my head, though, I raged. For crying out loud, I was a cancer surgeon. What was it with people telling me to be 'nice?' This institutional search committee policy didn't seem nice at all. I imagine that the policy had been created as some well-meaning attempt by the University to encourage diversity in hiring. But now, it had become what felt like an inquisition on my identity. And it hit me how unfair this was to Dr. James and every other Black physician who was expected to assume the burden of ensuring diversity for what was a decidedly un-diverse community of physicians. Acquiescing this call for tokenism must be exhausting. She was the only Black physician in a department. There were almost no Black physicians that I interacted with in this hospital, even though we cared for a large population of Black patients. And there was the how, what, and why of feeling as though I was being punished for questioning whether this policy made sense. My White-adjacent identity no longer felt authentic or useful.

I swallowed my pride and apologized to Patty. I hand wrote a note thanking her for her assistance with the search committee with an "I'm sorry if I came across as intense" on the phone the other day. "I have strong opinions about this topic." There was a box of cookies with the note.

But it was too late. Patty had worked in the institution for three decades. Like a good Southern woman, Patty knew how to get revenge through gossip. Her boss, my boss, heard about how "intimidating," "unhelpful," and "difficult" I had been in this interaction with Patty. There were other women who told other women that I was "bitchy" and "different." The women told other women, some of whom told me to watch my back. I can't help but think this misinformation might have been easier to dispel if I had been White. Or that the misperceptions might never have been formed in the first place if I had been White.

In the end, the whisper campaign did me in. I left my position before that new hire started her position. While I cleaned out my office, the last thing I packed was a "Bless Your Heart" sign that the staff in my office had bought me when I first arrived at my new office. In the South, the tone and volume with which this phrase is uttered can be used, particularly among women, to convey a thousand different meanings. The gift had been delivered as a joke. The staff in the office knew I was a Northerner and had wanted to help acclimate me to the culture of the new hospital. This had been a kind gesture. On my way out of the building, though, I tossed the sign in the trash. This was not a lesson I wanted to carry with me to my next chapter.

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An Unexpected Lesson

Henriette Mathis, MD

When I was a little girl, I wanted nothing more than to grow up and help people. I felt like when you help people that you could see them for who they truly are, just human. I decided to be a doctor. I would be able to wear this white coat that says I am here to help. So, I studied hard to make this dream a reality. The day finally came that I graduated from medical school and I would start my journey. Little did I know, the world of just being able to help still had color in it.

When I started my post-graduate education, I remember introducing myself to other staff like everyone else did. However, I was greeted regularly with you are so well-spoken. You are not like those other Black people. I was shocked and insulted. I was trying to figure out how did my ability to speak and my race correlate? Was I supposed to be speaking backward or a strange language? I went to school and received education just like my peers. Who are the *other* Black people? People they may have met? People they may have seen on television, news, or heard their music? Who are these mysterious people? How am I different? You just met me today?

I asked, "What people?"

The person stammered and had no response for me. It was like no one had ever asked them the question back.

The person went on to state, "You know the other Black people."

So, I thought to myself and realized this person means the poor and uneducated. You know the stereotypes that are displayed on television. I realized that this person was talking about my grandparents, aunts, and uncles. I knew I was on display because I knew the King's English and made it through school. It felt like I was in a museum exhibit just for receiving an education.

The only response I could give was to smile and say, "Well, we are not a monolith." However, internally I was astonished that "educated" people could have this level of thought process. I thought this might be an isolated incident on my journey, but it was not, to my dismay.

I started my first job out of residency and was excited. Not long afterward, I had a relative that was admitted to the same hospital. I went to visit him during an off day. I had my work badge on my chest. I waited patiently for the team to round on him. When they came to see him, I began to ask questions about his care and condition. The attending completely blew me off. He told me, "I do not have an answer for you because I have not even looked at his chart."

All answers were very curt in reply to anything I tried to ask. After all, my relative was a poor Black man with addiction issues, which is common in the patient population of this facility. I was just another person asking questions about another patient. A member of the team recognized me from working with me a few months prior. This person did not say anything at that moment, but I am sure that they did later. I had to work the next day, so I returned with my white coat on and the same badge on display. I was greeted with "doctor" and "hello." I was told that the chart was thoroughly reviewed, and all questions were answered. The only difference between one day and the next was my white coat. My skin did not magically change and neither did my face. I had my badge on both days. This colleague then asked me to stay and explain things to my family. This person was sure that they would not understand the complexity of the conversation. I was never asked about educational status or what my family knew about the patient's condition. It was just assumed that they knew nothing and did not have the ability to understand. The patient's sister is an educator with over 30 years of experience. There was no effort to get to know them at all. We went in for a more formal family update. My family could sense the condescension and paternalism. This person spoke to them as if they were little children with no understanding. After the team left, they said this person thinks we are stupid and ignorant. They lost all trust in the care team at that moment and were not sure if this doctor had their best interest at heart. This took me back to the situation where I was told, "You are not like those other Black people." I was the exception and had to explain to the "regular Black people" what was happening. I was angry, sad, and silent.

Is this how you treat your other patients who look like me but do not have the luxury of having a doctor relative? How have you been treating my relative prior to finding out we were related? I felt why Black people do not trust the health care system. How can one trust a system in which your doctor does not even see you as an equal? I see this colleague at work still from time to time. We have never talked about it. Honestly, I do not even believe this person remembers treating my relative.

After these incidents and others like it, I saw how prevalent microaggressions are in medicine. I saw how antiquated biases affect how patients are treated. I saw disparities in the manner of how patients were spoken to based on race. I saw assumptions on what their lives outside of their hospital admission must be like. The crazy part is that this form of racism is not loud like someone calling another person a racial epithet. It is quiet and subtle with an air of professionalism. I learned that my white coat did not exclude me from the presence of my Blackness.

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Coming Home

Ebony R. Hoskins, MD

During my last year of clinical fellowship, I contemplated where I wanted to land my first job. I considered what I thought were critical decision-making factors such as salary and proximity to family. Ten years later, I think of more important considerations when choosing where to establish and develop one's career, such as availability of career sponsors, an ethnically and racially diverse organization, and receptiveness to assorted thoughts and ideas that are brought to the organization.

I accepted my first job approximately 30 minutes from my hometown in Michigan. I worked within a cancer center in a large healthcare system. I would describe my first year "back home" as a honeymoon phase: kind staff and patients; voiced appreciation of my presence by hospital administration, staff, and patients; and the apparent ability to practice medicine with independent thought. Almost immediately, as year two hit, I found myself under a microscope for my surgical decision-making by a thoracic surgeon and not a fellow gynecologist or gynecologic oncologist. I had no idea that sharing my honest thoughts with this physician on his attempt to oversee my surgical judgment would result in false narratives about me. Further, I learned that this surgeon was a "person of influence" within the organization, which should have predicted what would follow after our one-on-one chat.

My vocalization of thoughts in this "just culture" environment was not welcomed by him or the institution. Like a domino effect, this influential physician initiated a never-ending attack on my character. Almost immediately, I had anonymous complaints in which I was described as throwing instruments at the OR staff, to an anonymous complaint on my sterile technique in the operating room. The most appalling and disappointing experience was when my gynecologic oncology clinic nurse contacted me via cell phone as I was leaving for vacation. She stated that I should urgently contact the Vice President of Medical Affairs (VPMA) by pager. The gynecologic oncology clinic nurse explained that I was on vacation and I would return the following week. He insisted that I contact him immediately regardless of my absence from the institution. I paged the VPMA without delay, unaware of the issue or the urgency. He notified me that an anonymous surgery scheduler reported me. I asked him specifically about the complaint; he stated that it was reported that I had used expletive language to a scheduler, and he wanted to address my behavior. I was then mandated to schedule a meeting in his office upon return from vacation to discuss "how I would not do this again." Upon my return from vacation, I met with the VPMA. I invited my presumed advocate, the clinical service director of the cancer center, to join the meeting since she frequently vocalized her appreciation of me. He stated the meeting was called because physician behavior could cause error and subsequently affect patient care. During his monologue, I was never offered the opportunity to voice my opinion of the incident reported nor offered the opportunity to review the alleged complaint. When I did attempt to establish common ground for our discussion and provide my personal insights, he voiced that he felt I was "intimidating," "aggressive," and "defensive" about the topic of discussion. Those three words, intimidating, aggressive, and defensive, are the antithesis of how my friends, family, or colleagues would describe me. I never use expletive language nor yell at staff. I found this complaint and the handling of the complaint offensive as a medical professional and a contradiction of my character. In all the years of my training and brief time as an attending, I never "yelled" at staff nor was told I demonstrate anger. Further, the clinical service director, who I brought to the meeting as an advocate and witness, never spoke during the meeting at all. She had said many words of appreciation for me previously, but her voice was silent during the meeting.

The VPMA demonstrated what is called implicit bias or simply prejudice. He used words that when eyes are closed, describe the "stereotypical" Black woman. A few moments later, in the same meeting, the VPMA suggested that I go to anger management classes. I reflected on how I got to this point. I went through four years of obstetrics and gynecology residency, two years of research fellowship, followed by three years of gynecologic oncology fellowship with no professional or behavioral complaints, ever. Now, I was fighting to save my reputation and my career in an organization that knew how to push people out if they did not align with being submissive and unvoiced.

Thankfully, I was confident in who I was and what I brought to the organization, but I knew I had to protect myself and my career. I sought out an employment lawyer for guidance. One of the first questions he asked during our introductory meeting was, "Why are you in this city?". I began to explain that I was from the area, I lived close to family, and the hospital offered a contract with salary and benefits I could not refuse as a new graduate from fellowship. As I was speaking to him, I realized the question was meant to be more thought-provoking. He went on to tell me story after story of the culture of the city and the organizations within it. The city was growing in visibility nationally, and many companies and organizations were looking to diversify their workforce. Diversity to me meant diversity in age, sex, race, religion, political beliefs, or thought, to name a few. As I began to consult my attorney for an exit strategy to leave the organization and city on my own accord with an unblemished record, I learned that the city and the organizations in the city were able to recruit a diverse workforce but had a difficult time retaining this workforce. I learned more about the culture of the organizations in the area. It is my opinion that my hospital employer meant diversity in appearance.

When it came to speaking with the VPMA about the thoracic surgeon's one-sided complaints and overreaching oversight of my gynecologic oncology practice, I really learned that they were not interested in what I had to say, nor were they interested in retaining me in the organization. I spoke up for myself when I was not asked, and that was against the grain of the city's culture and the organizations within it. While it may look good in print to bring diversity to an organization with a young, Black, female surgeon, the organization did not want actual change in culture.

Incidents after the sentinel events described prompted me to reconsider if home was the best place for me. Ultimately, I learned that career decisions should not be looked at with the narrow lens of money and family. Young accomplished people of color should consider other factors when making a career decision. Young doctors should consider supportive work and community environments that provide mentorship and advocacy, room for independent growth and thought, and a racially diverse environment. Home is where you lay your head and not necessarily where you originated; an experienced school of thought.

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Confronting Racism from Patients

Amin Bemanian, MD, PhD

As physicians and health care workers, we are expected to see patients of all different backgrounds and walks of life with the expectation to treat them with the utmost respect and provide them with the highest level of care possible. However, physicians of color face a unique challenge when encountering patients who voice racist views or refuse care on the basis of their practitioner's race. We can find our oath to provide care for all patients to suddenly be in opposition with concern for our mental and even physical safety. Unfortunately, due to the longstanding structural racism of medicine as an institution, physicians of color are rarely, if ever, taught what to do in these situations. Furthermore, they often have little to no support structures to turn to when these events occur.

My first exposure to this challenge came during my internal medicine rotation as a third-year medical student. A patient had been transferred to our team after he refused to be interviewed or examined by his previous doctor for being non-White. Ironically, while our attending was White, the senior resident, intern, and medical student were all non-White. Our attending was gone for a meeting until later in the afternoon, and the patient needed to be assessed after having transferred services. The intern and I went to introduce ourselves to our new patient. Instantly as we walked in, the patient gave an angry and exasperated cry.

"Where the hell is my doctor? I was promised a White doctor, and I am not talking to anyone who isn't White."

The directness of his demand caught me off-guard. I had anticipated pushback, but this was beyond what I had prepared myself for. I took a deep breath and reminded myself that he was still my patient. It was my duty to examine him. After all, I reasoned that he might be mentally altered from his illness, or the stress of hospitalization might have been making him more anxious. So I re-introduced myself again and tried taking his history. He immediately cut me off and grabbed the ID on my lanyard.

"Amin, eh? That some kind of Arab name? Why are you, a fucking dirty Muslim, here taking care of me?"

As an Iranian-American, this was not my first time dealing with racist slurs. Nevertheless, it was a new experience to be judged unworthy to treat someone based on my name. The rejection stung, and I could not help but internalize his hatred towards me. I cleared my throat and tried to redirect him, but then he quickly began ranting about his theory of racial relations.

"All you foreign doctors are ruining this hospital. Why don't you stay in your home countries and not ruin our cities? I want a real doctor. A White doctor!" He refused to let go of my lanyard and continued to ramble about the inferiority of all non-White races until my intern managed to help pull me away. We left shortly after, feeling defeated with nothing to present to our attending. The attending told us not to worry about the patient and that he would personally take care of the patient. Still, I fundamentally felt that I had failed as a medical student.

Disappointed by the events that had transpired, I shared the experience with several of my professors. I explained how I felt regret that I was not able to provide care for this patient even though he was directly racist towards me. The most common response I received was that I should simply avoid racist patients. It would be a fact of life that I needed to accept, and the easiest solution was to remove myself if a patient was being aggressive or discriminatory. Their answers seemed cold and distant. I felt they did little to help equip me with strategies for future situations. Similarly, when I mentioned the case to several of my classmates, they appeared to be uncomfortable even acknowledging that such a situation could even occur, that a patient may refuse care based on their provider's race. After turning to my teachers and peers for support, I ultimately felt more alone and isolated and regretted telling them about what had happened.

My experience is not a unique one. There are few studies capturing exactly how many physicians and healthcare workers of color have experienced discrimination from their patients, but it is not a secret that it continues to be an issue. Racism permeates every layer of our society, and physicians of color are acutely aware that they may encounter patients who have bigoted views. Our challenge as physicians of color is to fulfill our obligation to treat all patients, even in these scenarios. In my case, simply suppressing my emotions and powering through was not a practical or even safe course of action. Furthermore, there are many situations where we cannot simply avoid treating racist patients, despite what some may recommend. We may be the only provider on call or work in specialties where there are no other available providers. It is imperative that healthcare institutions establish policies to help their employees of color when they are confronted by a patient who is being racist towards them.

There is a growing recognition that antiracist policies by institutions are necessary. However, the inherent structural racism of medicine makes the implementation of these policies challenging. American medicine spent decades preserving the status quo of segregation and actively keeping Black physicians from receiving training or practicing. Still, we need to demand that these structures undergo a radical reformation now. Physicians of color do not expect hospitals and universities to be able to prevent patients from having discriminatory thoughts. But, it should be uncontroversial for us to expect our institutions to support us if a patient makes discriminatory comments or requests. In the absence of such policies, the burden often unduly falls upon the worker or trainee who is the target of the racist comments or behaviors. This results in a double trauma: first, the direct trauma from the patient's actions and words and second, the trauma of feeling unsupported in an environment that they must return to every day for work. Therefore, all healthcare institutions need to establish an antiracism policy that includes protections for their healthcare workers of color. Codifying these expectations as formal rules and mandating antiracism training can be important tools in helping to facilitate antiracist environments. Similar to having practice guidelines and clinical simulations, these tools allow both healthcare workers of color and their White counterparts to be mentally prepared in the context of facing racism by a patient. While implementing these policies may require a significant investment of time and require uncomfortable introspection by staff members, it is a necessary step to support our healthcare workers of color.

* * *

Working as the "Only"

Lisa Proctor, MSN, RN, ACNP

> "Language can never "pin down" slavery, genocide, war. Nor should it yearn for the arrogance to be able to do so. Its force, its felicity is in its reach toward the ineffable." Toni Morrison, Nobel lecture 1993

Working as the "Only"

For a teenager in the 1970s, nursing seemed like a job for women who lacked other choices. Looking at life as a vast plain of possibility, I planned on something that would be grand. The reality of adult life interrupted my exalted plans. Eighteen and desperate for employment, I took a job as a Personal Care Attendant at a center for the well elderly. What I learned there began to define who I was. The depth of conversation with clients, meshing care and interaction, drew me in. Confidence taught me that I could provide for people who were scared of the decline of aging. I narrowed my possibilities into a nursing career that I would invest my identity in.

One autumn day a Black father and White mother brought their latte-hued baby home. They carried a bundle cocooned in a creamy white and yellow newborn set embroidered with tiny flowers on the stiff polyester fabric of the 1950s. That day I met the world. I was Black in a city pulsing with skin colors. Out in the streets, my ears echoed with the chatter of vocalizations sometimes familiar, at other times including words made of unfamiliar lilts and dips. Behind the apartment doors of my building lived a conglomeration of language and culture. I grew in this world. A Black girl in the city.

My love of nature drove me to places less crowded, where green and open space allowed for unencumbered thought. The long summer days and the crisp snowy winters were expected with this move.

But the jolting change was in how this world was peopled. Northern rural life was nearly exclusively White.

The close-by small city housed Brown people in small Brown neighborhoods. So I was surprised that, in the late 1970s, I was the only Black student in my community college nursing school class. My limited experience with city hospitals was a reflection of the city, and this rural hospital provided an image of its small city and the surrounding area. The first presented a cacophony of culture to the second's homogeneous whole.

Hospitalization is an experience that chooses rather than is chosen. People have much of their identity stripped from them in the gown, the white sheets, the unending questions, all of which result in depersonalization. Being hospitalized is dependency, whether for a pneumonia that requires a little oxygen and antibiotics, or has progressed to mechanical ventilation and intensive care. Relationships with nurses tend to be that of reliance at a most vulnerable time. Intimate tasks now require help. Knowing who these helping people are brings some level of normalcy.

To be human is to categorize. Thoughts and people filed in boxes calm us and order our world. At twenty, I did not yet know this. I would come to understand this later, but never sit comfortably with the way it pulled me into people's ordering of their reality. It was the question.

"What are you?"

That question followed me around the hospital and jumped out at me from patients. At first, I struggled. I had not been around people who had never met anyone Black and who were unaware that skin hue could blend all of the tans and browns in the crayon box.

In the beginning there was an explanation, a story which included the Black and White parents and the small latte-colored baby. It was a riveting story for the listener. But it was too personal, too long, and invited too much conversation—the kind of conversation that I had reserved for friends.

Among strangers, it felt as if my shirt buttons had popped open to reveal a glimpse of my bra. One woman said, "Just like in the movie 'Imitation of Life'."

The disturbing character Peola (1934 version) jumped from the movie into my mind. I recalled the meat of her. The privilege of the White world apparent; her driving forces were "passing," and her hatred for her Black mother's presence blocking flight to a perfect imagined White life. My patient in her bed, now content in her view, her categorization of me, relaxed into her pillow. The communication had closed but had not yet claimed that moment where understanding had flowed. I felt the air too chokingly tight in the room.

At that time, the references that people harbored in this rural hospital lacked experience in real life. They were based on the flickering images of unreliable television signals. There was no "hello" at the grocery store, no sharing experience while waiting for children at school. Perceptions came not from a peopled world of reality but from the imaginations of media writers and producers.

"What are you?"

My answer changed to the simple "Black." This choice could either make other people uncomfortable or make me uncomfortable. When followed by comments about "the colored lady my aunt knew," even my toes curled while I cringed. Or my patient could be discomfited, and what had been a pleasant conversation could halt there, hitting a nerve that could hinder further interaction.

These seem simple answers, but for me were leaden with decision. Not answering was not a choice for me. That would be considered passing, and felt like a betrayal of who I was. I viewed passing in literature as one would an exotic animal in a zoo. I was always outside that cage.

I worked on and off at the same hospital and community for almost 40 years. I saw the cranks on the beds raising and lowering people's heads replaced by push-button controls. Glass IV bottles became plastic. Handwritten notes in paper charts evolved into the computer's presence in patient care. I witnessed the utility of some medications fading with the invention of new ones as science and discovery exploded. Things changed quickly, and the changes of people crawled alongside. The community became more diverse. The hospital had a few more Black faces in the building and started to be more of a presence in the community. I became a nurse practitioner. The questions that I got changed, although the answer did not. But I was no longer 20 and was more comfortable with saying "I'm Black" without engaging with other people's discomfort.

In the summer: "Are you very outdoorsy?" "Do you do a lot of gardening?"

In the winter: "Just got back from vacation?"

Over the years, my coworkers felt safe to query me about Black culture. Since nursing remains a mainly female profession, most questions centered on hair. And because my hairstyles varied, I received many questions, including the request, "Can I touch your hair?".

What is the right answer here? I wondered that every time and was always amazed that the questioner did not realize what an awkward position it placed me in. The expected answer was yes. And because of my own propensity for making people comfortable, the actual answer was almost always yes. I tried to brush it off as "no big deal," but I could not shake the feeling of now being the animal in the cage at the zoo. Occasionally, they would just touch it without asking, a personal invasion of space and always unwelcome, yet uncriticized as I internally cringed. I was, and still am, astounded by White women's lack of recognition that they move through the world unencumbered by this difficult discourse. They are not called on as representatives of all things White.

Black people knew I was Black. There were no questions. No one had any need to more closely examine the nuances of family history, to ask questions that crossed some line of polite dialog to satisfy a need to categorize. My color was not something unfamiliar. And no one asked to touch my hair.

During my shift at a less rural hospital where I worked, I was called into rooms for difficult situations involving Black people and their families. If a patient died and the family was thought to be loud and Black, my coworkers would usher me into the room to take care of people that they found too different. Hearing emotions expressed at an unfamiliar pitch, my coworkers shrank back, glad to see me and be relieved of "handling" grieving that might be communicated in a way too strong for them. The required yearly online cultural literacy could not teach tolerance in the real world. In the allotted half hour, it could not introduce the connection that comes with being with someone navigating the world differently than you. We all know loss in our bones. Shared humanity in those moments that howl with pain and grief and love can present nurses with an opportunity out of the tendency for category.

To some people, these observations may seem small. It is likely because they have moved through the world not having to figure out a way to describe themselves so that all people in the conversation are not inconvenienced by discomfort, and so the relationship of nurse and patient or coworkers can continue unsullied by embarrassment. In an ideal world, all of the words transition seamlessly, with an unemotional lightness. I see White people in a White environment moving through their world without having to think about their color as an issue, a conversation, a decision, and envy the lack of self-consciousness.

I am also aware that there is a bright facet to being an unintended instructor in the course of All Things Black–101. For my coworkers and patients, being involved with someone outside of their world helps broaden what the media presents if this was their only view. It is my hope that it shifts their categorization of Black nurses and of Black people.

I hid on the night shift for many years. At some point, however, the administration noticed me. I began to receive requests to appear in hospital publications. I appreciate even the appearance of diversity because it allows the Black community—especially the young people—to see opportunities in the health care profession. If I hadn't grown up in a world where people of all colors were represented in nursing, I might not have viewed it as a possibility. Health care disparity is a huge problem in this country, and I kept this in mind when I volunteered to represent the hospital at community events. I volunteered to have a table at the African-style market at the community center. Alongside the acupuncturist, the street minister, I wanted to be a whisper, a beckoning finger to come and see what nursing had to offer. Hoping that, after a while, no one will need to ask, "What are you?"

Web Only Content

Holly Vo, Maya Scott, Alicia Adiele Tieder, Courtney Gilliam & Arika Patneaude, Kara Simpson, Rev. Moneka A. Thompson, and Pringl Miller

“Ba Khỏe Không?” Medical Interpretation as an Ethical Imperative

Holly Vo, MD, MPH, MSc

My parents are low-income, Medicaid-dependent Vietnamese refugees with limited English proficiency. Regardless of the situation, when asked, “how are you doing?” in English, their inevitable response is a tight-lipped smile, slightly downcast eyes, and a polite, affirmative nod of the head. This is always a perfunctory response, never an actual description of their emotional or physical wellbeing.

When my father was taken to the ED a couple of years ago for worsening chest pain and difficulty breathing, his answer to the physician’s question of “how are you doing?” was a tight-lipped smile, slightly downcast eyes, and a polite, affirmative nod of the head. Though Vietnamese is a top-5 spoken language in Southern California and interpretation was indicated in his chart, my father knew from his prior interactions with the healthcare system that this request often caused delays in his care and seemed to frustrate his providers. My father had my brother accompany him to the ED to help him navigate his care. To their surprise, they were told that my father would need to be admitted. Prior to transfer out of the ED, my brother left to go to work and called my mother to update her.

My mom called me the next morning to tell me that my father went to the ED overnight and was admitted to the cardiac intensive care unit (CICU). When I spoke to my father, he said he wasn’t sure why he was admitted since they were speaking to him in English, but he thought it was to observe his chest pain. He was near certain he would be discharged later that day. I told him that he needed to request a Vietnamese interpreter and to call me immediately when a member of his medical team entered the room so I could get an update.

Despite the medical team checking in multiple times throughout the day, my father said that no one was providing him with any updates. After numerous attempts, I was finally able to get connected to the resident on-call. I found out that there was never a plan for my father to be discharged, but rather, they were waiting on a bed for him to be transferred to the university hospital. The resident disclosed that my father had suffered a severe myocardial infarction and required an evaluation by a cardiothoracic surgeon and an interventional cardiologist. The resident told me that this information was shared with my father. I immediately informed the resident that my father was not aware of this information and requested that a Vietnamese interpreter explain this information to him as soon as possible.

It was quite obvious my father was unaware of the seriousness of his condition. It fell to me to break the news. After I told him over the phone, there was a prolonged silence. My father prided himself on his health, intelligence, and independence. My father experienced many challenges in his life, including being jailed following South Vietnam’s loss in the Vietnam War and two additional incarcerations after being caught trying to flee post-war Vietnam. He finally escaped political persecution with my mother and two-year-old brother as stowaways on a fishing boat. After escaping, they resided in a refugee camp in Indonesia for years before coming to the United States. Despite the frightening stories I heard about his life, this was the first time I ever heard fear in his voice. My father was a take-charge person and the head of our family. His reliance on others to keep him informed about his care and interact with his medical team on his behalf left him feeling powerless and ignorant, two states he loathed.

Despite my request for a Vietnamese interpreter, he was transferred to the university hospital the next evening without ever hearing his diagnosis or prognosis from his medical team in a language he understood. Frustrated by the lack of communication from his team, I told my father that I was going to find coverage for my upcoming shifts and planned to fly home. He adamantly refused. The following morning, I was finally able to get a hold of a member of his medical team by phone. The cardiothoracic surgeon updated me that, in addition to the myocardial infarction a few days ago, his imaging showed severe (70%-90%) occlusions of all his major coronary arteries. The plan was to continue observing him since he was "eyeballing" well, and when the surgeon asked, "how are you doing?" my father responded with a tight-lipped smile, slightly downcast eyes, and a polite, affirmative nod of the head.

I had the surgeon pass the phone to my father, and then I asked him, "Ba Khỏe Không?" (*Dad, how are you doing?*). My father instead replied that he had been having severe chest pain, dizziness, and fatigue that had been worsening since admission. He has not been able to sleep the past couple of nights because of difficulty breathing when lying down and has been having discomfort in his extremities. I relayed this information back to the surgeon and added that my father has a past medical history significant for diabetes and high cholesterol. At this point, the surgeon stopped me mid-sentence and asked whether I was in the healthcare field. I told him that I was a pediatric resident at the University of California, San Francisco. He was either unable to or didn't attempt to mask the surprise in his response, "Oh, really?! Wow." He then proceeded to boast about his decade of surgical experience and the university hospital's accolades. Diverting the conversation back to my father, I told the surgeon that I was concerned that with his worsening symptoms and significant medical history, my father's vitals might not be reflective of how he was actually feeling. The surgeon acknowledged he didn't know this history and immediately offered to schedule him for surgery the next morning. I informed him that I would be flying down this afternoon and asked to have an interpreter explain the plan to my father in the interim. The surgeon was amenable and provided me with his personal cell phone number should I have any additional questions. He ended the call by saying, "someone should have told me that he has a physician in the family because you are the biggest asset in his life."

I arrived at my father's bedside a few hours later. Unsurprisingly, he had not yet received an update with a Vietnamese interpreter. Soon after, a senior surgical resident came by with a consent form for triple bypass cardiac surgery. I told the surgical resident that I was not a certified interpreter and the medical chart indicated my father required a Vietnamese interpreter for any medical updates, especially for informed consent to a surgical procedure. He left. Fifteen minutes passed and he came back with an iPad. We were told that an in-person interpreter could only be accommodated for Spanish-speaking patients. He fumbled with the iPad for another ten minutes - trying to turn it on and guessing out loud at the password. He asked a bedside nurse who then asked the charge nurse about how to utilize the iPad interpreter system. It took an additional twenty minutes of trial and error until we were connected with an interpreter. For the first time during his three-day hospitalization, my father was told the reason for his admission by a member of his medical team in a language he understood.

He consented to the surgery. The operation was scheduled to take place the following afternoon. My parents and I spent the next few hours joking about how bad the hospital food was and how uncomfortable the bed was. Eventually, my dad confided that he was very scared going into the surgery. He shared that he has always tried to avoid going to the hospital because he hated feeling powerless and ignorant. Both feelings had been exacerbated by the lack of proper interpretation. I assured him that I would be there to help him with his recovery and that he did not have to worry about being uninformed about his medical care moving forward. I offered to sleep at his bedside, but he urged me to take my mother home and return the following day prior to his surgery.

I arrived at his room at 6:00 a.m. the next morning to find it empty. His nurse informed me that he was taken down to the OR overnight for an emergent surgery because he was having runs of cardiac arrhythmias throughout the night.

We were updated six hours later in the waiting room that on the way to the OR, my father went into cardiac arrest requiring 5-10 minutes of chest compressions before regaining circulation. They immediately induced his anesthesia and began the operation. The cardiothoracic surgeon informed us following the surgery that my father was post-operatively recovering well, but there was a clot left in his heart due to the rushed nature of the emergency surgery.

Back in the CICU, several hours following his surgery, he failed one of his bedside neurology checks. It was quickly determined that he had suffered a postoperative stroke, likely from the aforementioned clot. He was rushed into interventional radiology for another emergent procedure to remove the clot in his brain. As my father woke from the anesthesia from his second emergent procedure of the day, I explained to him everything that happened. Since he still had the breathing tube in place, he was only able to nod or shake his head but was not able to speak. Instead of hearing the fear in his voice, I could see it in his eyes. Somehow, this was much more heartbreaking.

Over the next several days, he slowly decompensated into multi-organ failure and sepsis, requiring continuous dialysis and maximal vasoactive medications until his body finally gave out. During the final days of his life, my proud, head-of-the-family father was left deferring completely life-altering decisions to his youngest daughter . . . not because of any medical knowledge I possessed, but solely because he didn't speak fluent English.

Over the last day of my father's life and for months following his death, I couldn't get the surgeon's words out of my head. "Someone should have told me that he has a physician in the family because you are the biggest asset in his life." This experience left me feeling not like an asset but ashamed of the medical field. Had my father had a different appearance, spoke fluent English, or had higher social standing, he could have received more timely and appropriate care that could have saved his life. Instead, he died with his worst fears realized: being made to feel powerless and ignorant, like a second-class citizen.

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Leaving Our Blackness at the Door

Maya Scott, MSW, LICSW; Alicia Adiele Tieder, LICSW; Courtney Gilliam, MD &
Arika Patneaude, LICSW

Experiencing the reckoning regarding racial injustice in the past year and a half has been bewildering. Witnessing the shock of White people in our communities, learning for what seems like the first time that racism is embedded in every part of our society, has been a rollercoaster ride of emotions. There is an odd combination of gratitude that finally people are recognizing and acknowledging a long-known history and experience. In the same breath, there is deep frustration with privileged people who can look away from an experience that we have lived for our entire lives and have known in our bones through generations of our ancestors since before we had words to explain what we knew.

As each of us have looked around our institution for faces that looked like ours, there were few to be found. When we did find other Black individuals, the knowing way we each navigated our workspaces was as if someone wrote a guidebook that we all received copies of. The hushed conversations, the knowing looks, the way we navigate the world to speak out and stand up, and hold back and accommodate have long been a part of our professional experiences. There is a phrase that we have begun to use, coined by one of our co-authors Arika Patneaude: "leaving my Blackness at the door". It describes the way we are silently or loudly asked to shed parts of our identities as easily as taking off a raincoat and hanging it on a coat hanger, to move through this world safely and unobtrusively, to not take up too much space and upset the tender balance that exists.

But as the United States and the world have experienced, this silencing of our shared experiences, the requirement to check our Blackness into a locker and tuck it away for safekeeping, and then step into a world where we are routinely told we don't belong, is untenable, especially as our institution has made national headlines as it reckons with its own racist and inequitable actions, policies, and outcomes. Now, instead of quieting our voices and looking at the downcast eyes of individuals shifting uncomfortably in their seats, we are thrust into the spotlight of leading from each of our respective roles, responding to various scenarios where the racism of our system can no longer be ignored. This collective piece showcases how Black people have survived systemic racism through culture, community, and connections. These vignettes are glimpses into the experiences of a bioethicist, two directors, and a physician, all Black women.

Maya

When I entered the medical world advocating for equitable care, one of the first conversations I had was met with a telling warning. I was told that I should mind my manners because, as a clinical staff person who was not a physician, I was a guest in their house, and if I made too many waves, I could easily wear out my welcome. They reminded me that "these types of conversations" make people uncomfortable and I would burn myself out if I decided to go to battle every time I saw a broken system. The person told me this as if they were doing me a favor, orienting me to a culture that I was somehow unaware of.

As I continued to carve out my professional pathway, saying yes to far too many things, submitting my work to conferences, and attempting to speak the truths that I understood into the clinical and academic worlds, as a clinician, a parent, and a Black woman, a curious and familiar thing happened. Once I got accepted to the conference or work towards publishing my words, there were colleagues that found this newfound voice to be upsetting, threatening, and even angering. I found myself navigating a conversation with Human Resources around "preferential treatment," "favoritism," and how unfair it was that I was being handed opportunities, questioning both the how and the why.

My initial response was to question my contributions, beg my mentors to stop celebrating these professional triumphs publicly, to seek more education and certification to meet the definition of "qualified" that would allow me to skip this confidence crushing experience of the subtext, heard in my experienced ears, as questioning my belonging in a space that isn't meant for people like me. Even the comments disguised as questions asking me, *"What did you do to get so lucky?"* acted as a glaring reminder of my Blackness. The shrinking of myself in order to escape the internal and external voices that allude to being a "diversity hire" with no other strengths was an unsustainable response to the first conversations, and the many since that have told me that I was a guest and I don't belong.

Arika

I have always been a leader personally and professionally, formally, and informally. As my career has progressed and I have officially taken on leadership roles, my Blackness, while the same to me, appears to be received differently by others. Like Maya, early on in my career, I had been advised to make myself small, unobtrusive as a social worker in a medical setting, not wear out my welcome, and behave like a good guest. As my White supervisor told me these "facts," I also wondered if they were telling me not to be "too" Black. I learned quickly that yes, whether they intended to or not, that is also what was implicitly meant. I learned to navigate the professional space by balancing the joy, the beauty, the gift, and yes, the pain and trauma of being a Black woman in the world by making myself smaller, by modulating my tone, by being quieter, by not calling out microaggressions and blatant racism too abruptly; "*have you considered,*" "*I wonder if . . .* ," "*the parents are not able to be at bedside as they both have to work in order to meet their basic needs*."

I have had to explicitly name the humanity of patients and families who, through no fault of their own, are historically marginalized and surviving social determinants that impact the way that we as a healthcare system treat them, whether it be race, ethnicity, gender, socioeconomic class, immigration status and so forth. Oftentimes, these patients and families look like me. In seeing how they are treated by our system, I know that is too how I am treated within the system. "*Wow, you have a Master's degree!*" said in shock, "*Are you the interpreter? I'm waiting for the Amharic interpreter, I thought you might be them,*" said a nurse when I checked in at the nurse's station to support a family, a White family, whose child was at the end of life. It's wearing my badge when I bring my own children to my institution for care, hoping to shield them from what I see other families who look like ours experience.

Now that I am a 'Big L' leader and am further along in my career, I have changed how I show up in my Blackness. I have the privilege of having a platform where I can advocate differently, at a policy level, for historically marginalized patients, families and staff. I can be more present in my Blackness, which is a privilege that comes with longevity, experience, and age. I can choose how my Blackness shows up, whether it is necessary to leave it on the hook at the door for this one meeting in order to make greater change, or if I can show up, fully, authentically as myself, and always with humanity.

Alicia

You look so young. I love what you've done with your hair. Are you a student? You are so articulate. These are familiar phrases to subtly remind me that I am not welcome and that I am an outlier in the workforce and in leadership. I have spent my career and life striving to identify and define my values in a White-dominant society. I have silenced parts of my identity, culture, beliefs, and tone of voice in order to assimilate and keep the White judgments at bay.

As I slowly reveal my Blackness, my brilliance, and vibration, I am reminded that I can be a simmering and active volcano. This version of myself is determined, hot, outspoken, transformative, offended, and as long as I release my fire, the world will know me. I have purpose through change, movement, truth, power, strength, and heart. My Blackness can also be a coastal ocean wave. Powerful, peaceful, strong, steady, and active, transforming cliffs and coastlines over time, healing, and infinite.

I do not want to blend in. I want to be recognized and celebrated for my Blackness. I deserve power and peace. I deserve wellbeing, spiritual connection, and rest. As long as I trust and honor my Blackness, I am connected to my higher purpose, and I am well.

Courtney

My Blackness and everything people perceived with it caused numerous roadblocks on my journey into medicine. I learned at a very young age that education is deeply rooted in White supremacy culture. From as early as middle school, through high school and college, I was constantly being told, "*you aren't smart enough for this,*" "*maybe you should try a different career path, people like you don't go into medicine*." So, when I finally arrived, with the MD behind my name and entered training to be a pediatrician, it was no surprise that I was hyper-aware of my Blackness and how I was existing, attempting to thrive, in a system not built for people like me.

What I didn't realize until early in my residency training, was despite the leader I had become; I constantly felt the need to make myself small for others. I made statements like "*does that make* *sense*?" to smooth over my thoughts, feedback, and lived experience. Constantly apologizing prior to speaking up on rounds when I could hear bias and discrimination seep through. I wondered how I could bring my whole self to work, feel confident in that space without living in a place of fear. I started to wonder about all the time diverted away from my professional learning and clinical skills that went into responding, coping, and educating about racism, microaggressions, and equity. And yet, despite that, I lived by the words of my parents, who reminded me constantly, "*you will have to work twice as hard, to get half as much*." This is the cycle of being a Black woman in medicine; push through, educate and produce, silently process and cope. During residency, chief residency, and now fellowship, I grew into my own voice. I found the people who encouraged and lifted me and tirelessly looked up to the woman in my institution who looked like me. I learned that my Blackness can shape policies, save lives and provide mentorship and support. I remember the words of Maya, who when I asked, "how do you do it and feel confident that you are enough to do it?" She told me, "*bring your accomplishments into the room . . . every single time.*"

Conclusion

The questions that each of us has asked ourselves as we continue to walk through and claim space within systems that we are continuously reminded we are not entitled to take, despite our academic and professional roles, successes and accolades, are the same: *If it feels like this for us, what must it feel like to be a patient or a family walking into our institution for the very first time? If we don't show up and see these families like we see each other, who will? How can we clear the path so that others may join us?* To continue to show up fully, with all the magic embedded into our identities as Black women, is an act of revolution. Our Blackness will not be a garment hidden away to convenience others. It is a declaration of surviving, thriving, and a constant reminder that I am here, that you are here, that we are here.

* * *

Advocacy: How the Murder of George Floyd Led Me to Bioethics

Kara Simpson, LCSW-R

"All these protesters are going to spread COVID more," explained the Chair of the department during the morning clinical rounds. "They shouldn't be in the streets; they are destroying their own neighborhoods," remarked a White male attending just one week shy of the murder of George Floyd. The attendees of the virtual huddle, maybe four to five of them people of color, were stifled as the feelings of anger and frustration permeated the call but remained unspoken.

Fueled by anger and pain, I wrote an email to my organization and departmental leadership about the current political environment and how other Black and Brown staff may feel "unsupported" and "unseen," just as I did during morning rounds and days after. I encouraged them to support their staff during this difficult time and to research how best to do so with articles that I attached to the email. The responses I received from mostly White colleagues varied from "sorry you feel that way" to "I'm not a racist" and the most expected "you need to watch your back." Two people of color in leadership roles that are equivalent to my own responded. One labeling themselves as a "bystander," and the other believing that my statement was "strong" but necessary to wake people up.

From March to July 2020, my hospital was one of the epicenters for COVID cases in New York City. Our staff and patients were gravely affected by either contracting the illness, caring for others, or actively protecting themselves from contracting COVID. As all the news stories and articles conveyed, most of the ground healthcare staff are Black and Brown people, and most people that died from COVID are as well. "It's like watching a war zone of Black and Brown bodies," one colleague described.

Though we are an urban hospital, the executive leadership is all White and mostly female, and there is *no* discussion of diversity, inclusion, racism, or bias. At the time, there was no diversity or inclusion committee nor any public attempts at creating one. One would think with a mostly Black and Brown staff and patient population, that healthcare disparities would be on the agenda of every clinical department and the focus of creating treatment plans designed to suit our needs. Unfortunately, at the time, there was no change in the operation. The dual pandemic of COVID and racism via police brutality still has not affected the leadership enough to have more meaningful, productive, and healing conversations about the healthcare plight of Black and Brown people.

I started out in health care sixteen years ago as a front-line social worker. Today I am the Director of Social Work for Behavioral Health Services. The inspiration for entering my profession was largely due to my family's extensive history of working in the advocacy and healing professions. We are social injustice activists that have chosen professions in which racism impacts oppressed populations, as well as within the professions we practice. In fact, my family members chose the professions of medicine, social work, ministry, education, and the arts to empower Black, Brown, and poor people to combat oppression. We are committed to the liberation of Black and Brown people and want to make the world equal and just.

When hearing their statements about the protests, the lack of acknowledgment of racial injustice, and disregard for the Black and Brown staff members, I was flooded with so many emotions. As stated before, I was angry that the leadership did not acknowledge the current social climate and did not offer any support, especially when there was a great deal of attention and support provided to the staff about coping with the traumas of COVID. These interventions included having peer supporters come to the units for "check-ins," bringing lunches, designating "calm rooms," and referrals to mental health counseling if necessary. This support was not offered to staff during the racial injustice crisis.

I was also disappointed with the healthcare leadership for their lack of courage to have the hard conversations about racism. It felt like the topic was purposefully avoided and without consideration to the Black and Brown staff or the patients we treat. If they weren't bold enough to speak on it, how would the staff approach this issue daily? Would the patient feel comfortable talking about their experiences?

True to the nature of my family, I began my advocacy work. I emailed the corporate office, the executive leadership of my facility, and anyone in a position of power who would listen to my concerns about the lack of discussion about racism and oppression in the facility. I informed everyone that it was necessary to have larger discussions with the staff about the personal and professional impact of racism in the workplace and in health care. With very little support from leadership, a White colleague and I facilitated an open forum to discuss racism in the care setting, the community's feelings about the death of George Floyd, and personal experiences with racism within the hospital setting. This was a semi-sanctioned forum as we did not ask permission to openly discuss these very charged topics. However, once the leadership learned about the need for this meeting, they provided a COVID safe space.

Initially, we planned for one forum only. However, the staff were very emotionally charged, shared their personal experiences, and demanded more time and space to express their feelings. The most powerful takeaway from these forums was that members of the leadership were present and heard firsthand the accounts of racist experiences from the frontline and supervisory staff. The last forum was held on Juneteenth 2020, which nicely captured the spirit and the purpose of the holiday, to have the freedom to be ourselves.

Though I received little response from my corporate office, the first invitation to have a formal discussion about racism with other professionals was with my facilities bioethics committee. Traditionally, my department had not encountered the bioethics committee to discuss cases or organizational ethical issues. However, in the bioethics community, there were growing concerns about the lack of diversity in committees and consultations, as well as how implicit bias and distrust of the medical profession influenced bioethics consultations and health care in general. I was invited into this profession because of my message about racism. I participated in spirited discussions about racism, poverty, and marginalization frequently with professionals that are predominantly White.

Justice is a key principle in the practice of bioethics. In my short time participating in the hospital's Ethics Committee and Consultation Service, there has been more discussion on the practice and integration of justice into our daily work. However, there is still a struggle to answer questions such as "What would the dialogue about racism look like?" Policy Changes, open discussions on institutional racism and implicit bias, training? Does the practice of bioethics inform institutional reform?

Within the past three months, my CEO asked me to co-chair the first equity, diversity, and inclusion committee for the facility. Though I was very honored to be asked to carry out this task, I suspect the committee's formation resulted from mounting racial tensions incidents with the staff, persistent advocacy from various stakeholders, and the pressure to have a structure to influence racial issues in health care. Our 3 strategic pillars are: Creating Safe Spaces," "Communications with staff and community," and "Equity in Health Care." This is very exciting work and I feel validated and vindicated in having a hand in creating and influencing this work.

Though changes are occurring in response to the conversation on racism, there is still much more work to be done. The year 2020 was merciless in all the loss, trauma, and uncertainty experienced. However, the true blessing is that we now have the opportunity to continue important dialogue, make changes for the future, and bring equity into the healthcare profession and healthcare practice.

* * *

Who Owned More Slaves?

Rev. Moneka A. Thompson, M.Div., BCC

I am an African American, cisgender female who is a minister and hospital chaplain in the state of Alabama. The intersection of my identity and my profession in the Deep South have been problematic for many persons I have encountered through my work. The vast majority of the patients I serve are Southern Baptist and Caucasian. The minute I introduce myself as the chaplain, I am met with incredulous and skeptical looks and frequently asked, "Are you a Christian?" or, "Do you believe in Jesus?" I am uncertain what aspects of my appearance lead them to question my Christianity; perhaps it is my gender or the fact that I am African American. However, I willingly submit myself to their inquiry to appease their concerns or curiosity, and then I redirect the conversation to the actual point of my visit. I have been a chaplain since 2007 and I am sadly accustomed to bias at this point in my career. Unfortunately, the most difficult encounters have been with my colleagues.

I recall an incident from several years ago; I was seeing patients in one of the many clinics affiliated with the organization I work for. On this particular day, a Caucasian nurse was also present. I had encountered this person many times before, and we would usually exchange small talk or pleasantries. This particular day, the individual walked up, sat next to me, and began to launch into a troubling diatribe. "Blacks owned more slaves than Whites ever did! Whites never owned slaves like that! There were more Black slave owners than anything." I sat there bewildered and uncertain as to what had prompted this. Had my appearance triggered him? Was he projecting a previous discussion onto me? I remember feeling anger rising in my chest and my blood boiling over. How was one to respond to such comments? Why on earth had this person chosen to say this? What could the motivation behind the comments have been? What evidence was this person citing and why?

While this colleague and I were certainly not best friends, we had enjoyed a pleasant working relationship that was dedicated to the care of our patients and their families and caregivers. How would this incident impact the future of our working relationship?

I sat there in a pregnant pause vacillating between the professional and non-professional responses I had crafted. The former would calmly ask, "Can you help me understand what you are talking about?" and the latter would have been very crass, "What the f*%k is wrong with you?" If I had chosen the latter, I am certain I would have been labeled as an "angry Black woman" who had taken things out of context or one who was "too sensitive." Neither response reached my breath.

A door to one of the clinic rooms opened and out walked a patient who was a PhD professor in African American History. This patient is a tenured, erudite scholar in the field who just so happened to be a dear family friend. (How fortuitous for me!) It had escaped my mind that this patient would be in the clinic that day. Because of HIPPA, I intentionally had not reviewed the patient's chart and had not attempted to provide pastoral care. The patient warmly embraced me and began to inquire about the well-being of my family. After I responded to the inquiry, I turned to my colleague with incredible pride and shared the patient's profession. Quite naturally, I boasted of the patient's accomplishments and recently published book while the patient, a naturally humble individual, dismissed my high praise. At this point, my colleague began to turn beet red and the tall, heavyset frame of my colleague appeared to deflate. I watched as the redness, which I assumed to be from embarrassment, began to seep from ear lobe to collarbone on my colleague, who intentionally remained silent after my introduction. The topic of my colleague's conversation mysteriously vanished with the same urgency in which it had come.

Following this encounter, I intentionally began to engage in avoidant behaviors in an attempt to protect myself from the stinging pain, rage, and humiliation of racism. I felt awkward and uncomfortable being around the colleague following this incident. I would avoid charting on terminals near this person; I would force myself to respond to the folksy, "Hey there" greeting I typically received, and I refused to be alone with this person. Racist encounters create a maelstrom of emotions in the offended person, and I did not want this individual to have this level of power or control over me ever again. Thankfully, the colleague eventually sought another position with more agreeable working hours that would better accommodate their family, and I haven't missed this colleague since!

* * *

Racism Unplugged

Pringl Miller, MD, FACS

My destiny as it relates to race and experiencing racism in healthcare was predetermined. Born a biracial daughter to a Black father and German mother in 1964, how could it not be?

My parents were courageous, independent, and in love. They came together in New York City as an interracial couple in the 1950s. Their bohemian interracial lifestyle was supported in their immediate environs but certainly not everywhere in the United States. In November of 1964, Anthony Lewis wrote an article that was published in the New York Times Magazine entitled "Race, Sex and the Supreme Court." In his article, Mr. Lewis reminded us that 22 of the 54 United States still had anti-miscegenation laws. Had my parents' lives not intersected in New York City, I too might have been born a crime. Accompanying Mr. Lewis's article, there was a photo of an interracial couple—the couple were my parents. The caption next to their photo read, "A Negro painter and his wife at home in New York." I was three months old.

At three months old, I was already caught in the crossfire of race relations in the United States, whether I knew it or not and whether I wanted to be or not. The fight for civil rights would become my birthright. If it weren't for seeing my father referred to as a Negro in print, I never would have thought of myself as the daughter of a Negro. As I gained more understanding of the ways in which racism plays out in society, I recognized how the labels and the laws were discriminatory. Even though the labels and the laws would change over time, the underlying precedence to uphold historically discriminatory practices in society and the medical profession would not. Life's experiences would repeatedly reveal to me that my brown skin and intersectional identity would override any White ancestry I claimed by inflicting upon me stereotypes, double-standards, and the pain of being treated differently due to racism and sexism.

Over the years I struggled with my relationship to racial and ethnic identity because the systems in which I operated ignored that I was an amalgamation. American society would insist that I choose one racial or ethnic identity, making no provision for my preference to claim two. Imagine living and working in a society where the paperwork and processes deny half of who you are because of convention and conservative values. These structural barriers would undermine my personhood, denying the totality of who I am and reduce me to my genitals and skin color. Living with the dehumanization of being categorized by characteristics that I had no control over without regard for the characteristics that I worked so hard to cultivate has also been demoralizing. I've learned that my biracial identity stood in opposition to the status quo within American culture and the culture of medicine and surgery. The paternalistic nature of medicine decided that I don't belong whether I earned the right of passage or not. The unwelcoming and oppressive environments of medicine and surgery, even during the age of Diversity, Equity, and Inclusion (DEI), would fail due to the power of the status quo. No one told me early on that a meritocracy was a myth. I thought that if I played by the rules and excelled, I would be entitled to the same rights and privileges as anyone else. It was a rude awakening to realize that the game was rigged and that there was very little I could do to change that.

Breaking barriers became a condition of my very existence, first as an infant and then as an adult who was destined to follow in her parent's footsteps. In retrospect, after watching my father become the first Black art professor at the University of Washington, it's not surprising that I would also experience a series of firsts. I was the first and have been the *only* surgical resident of Black ancestry to graduate from my general surgery residency program in its 100-year history. I was the first woman to practice surgery at the hospital that recruited me out of residency. And I was the first surgeon to train as a fellow in hospice and palliative medicine at my fellowship program. Currently, I am one of a handful of women of color in the country to possess my academic and clinical credentials, which includes fellowship training in clinical medical ethics. It's hard being the first; it's also sometimes necessary and unavoidable. The penalty of being the first is undeniable because of having to combat bias, harassment, discrimination, and retaliation. Like so many other women and/or the Under-Represented in Medicine (URiM), I have endured tremendous harms in the pursuit of our dreams because of structural racism and sexism. The harms manifest by denying opportunities for growth and development, mentorship, career advancement, leadership roles, and pay equity. Microaggressions and macroaggressions often lead to a hostile work environment and situations in which you are gaslit and told you are not a good fit while doing your job with grace and excellence. Soon society will learn that it has been complicit in standing by while talented physicians and surgeons either leave the workforce due to the toxicity or because of constructive discharges. Soon society will learn that countless women and/or the URiM are underemployed or unemployed due to racism and sexism.

My intersectional identities are an excruciating irony during the age of DEI, but I would like to believe that the initiatives are more than lip service and that there would be genuine interest in my perspective. I didn't know that my race and gender would penalize me to this degree when I embarked on a career in medicine and subsequently surgery—I was naïve and optimistic. Just like racism almost held my parent's hostage in their pursuit of a marital relationship, racism has held me hostage as a professional. I don't know what I would have done if someone had sat me down and warned me—my guess is I would have pursued the same path. I just might have been more prepared for the injustices and navigated the waters differently. Medicine and surgery are challenging careers to embark on. It saddens me that after so much effort, achievement, and investment, so many talented clinicians are being lost due to racism—a factor that bears little relevance to how we take care of patients and other aspects of professionalism that should actually matter.

From the day I opened my solo-private practice in Northern California after graduating from surgical residency to the day I was forced to resign from my academic appointment at a major academic medical center in Chicago, I have faced a myriad of racist and sexist acts that have gone unchecked and unaccounted for. My work now focuses on creating a safe, equitable, and inclusive environment by advocating for clinicians who are targeted because of these very issues.

Commentary
The Epistemic Injustice of Racial Injustice

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Abstract. The treatment of essential health care providers belonging to racial and ethnic minority groups is a bioethical issue. Minority providers hold valuable knowledge of the racism they experience. However, they are continuously doubted, discredited, and disempowered as epistemic interlocutors. Such epistemic injustice has ethical repercussions for the treatment of patients. The unwillingness of colleagues to receive the authors' experiential knowledge of racism, their testimonies on its impacts, and their efforts to correct inaccurate judgments amount to a morally problematic epistemological stance. Additional moral considerations include the lack of guidance on dealing with racism in health care institutions, the marginalization of minority providers, an inflexible medical culture, the need for anti-racist frameworks, and the unique vulnerability of students and trainees. These narratives call for a sustained effort in balancing the pursuit of individual virtues and the creation of systemic conditions necessary to eliminate racial injustice.

Key Words. Racism, Ethics, Epistemic Injustice, Racial Injustice, Narratives, Health Care Professionals

Introduction

The COVID-19 pandemic has crystallized ethical issues surrounding the treatment of essential health care providers belonging to racial and ethnic minority groups. Alarmingly, the authors participating in this narrative symposium reveal a distinct occupational exposure coming from unlikely sources: although three out of twelve narratives ostensibly recount encounters with racist patients, each narrative describes racist behavior carried out by fellow health care providers. This uncomfortable truth explodes the myth of the racist as the uneducated outsider with polarizing political views. How should we proceed with the knowledge—to borrow a trope from the horror genre—that "the call is coming from inside the house"?

Bioethicists have written on the field's refusal to engage meaningfully with racism and its deleterious effects on health and well-being, arguing for the recognition of racial justice as a bioethical issue (Danis, Wilson, & White, 2016; Hoberman, 2016; King, 2004; Myser, 2003). Having interviewed minority health care providers and published findings on the contested construct of race in genomics (Égalité, Özdemir, & Godard, 2007), I bring to my analysis of these narratives an attunement to racism as undertheorized. Following the racial reckoning of 2020, along with interest in investigating racial trauma, police brutality, and mistrust of civic institutions, there has been a renewed focus on the untapped potential of a Black bioethics (Ray, 2021). However, the potential for scholars to remain outside the margins entails a re-evaluation of what kind of knowledge is produced and how social power operates to shape valuations of knowledge.

In this commentary, I will first outline the complexity of the knowledge vis-à-vis racism conveyed by the authors. I will then examine the implications of racism on knowledge practices in health care, focusing on epistemic injustice. Finally, I will identify moral wrongs and moral rights emerging from the narratives and further discuss the recommendations offered by these authors that pertain to achieving racial justice.

Knowledge of Racism

Through their use of narrative storytelling, the authors convey their intimate knowledge of racism. Mathis knows that repeated compliments of being well-spoken marking the beginning of her residency are instances of thinly veiled racism, and this long before being told in explicit terms that she is "not like those other Black people." Bradley detects the bad faith of colleagues who interrupt his facilitation of spiritual care conversations with staff to process racially traumatic events: "trivial tasks and needs suddenly become emergent" or else group conversations get derailed by "an interruption or announcement of no relevancy or real urgency." Proctor, dispatched to comfort Black families informed of the death of a family member, knows that her white colleagues' judgments of them as "too loud" are motivated by racial intolerance. "Hearing emotions expressed at an unfamiliar pitch," she writes, "my coworkers shrank back, glad to see me and be relieved of 'handling' grieving that might be communicated in a way too strong for them." Temkin has the ability to "pass or blend" in white circles. However, it offers no protection against incessant queries about her ethnicity. She deflects microaggressions but comes to learn that proximity to whiteness does not yield equally preferential treatment.

The experiences of racism in health care in this symposium invite comparisons to those vividly captured in the 1950s by psychiatrist Frantz Fanon. Theorizing on the psychic effects of dehumanizing racism, he drew from his personal experiences: he described feeling "walled in " by the prejudice towards French colonial subjects as well as troubled by the prevailing climate of suspicion surrounding the Black doctor (Fanon, 1952). Several authors' depictions of racism as embodied knowledge bring to mind Fanon's groundbreaking work on alienation, the "epidermalization" (internalization) of racism, and phenomenology. The authors share visceral reactions to racist events, notably shock, pain, fear, tension, paralysis, and numbness. Anonymous, in a paradigmatic tale of racial traumatization, dreads encountering the two doctors (one of whom threatened violence) years after their meeting. "When I did see one of them," she writes, "I would panic. My heart would race, my skin would sweat, and sometimes I would get lightheaded." Kornu's experiences of verbal assaults, objectification, and othering as a "Texan-Thai-Chinese" leave him feeling like a foreigner in his own skin. Cuartas intuitively knows that speaking his name would reveal his Hispanic heritage to a racist patient: in an act of self-preservation, he scribes quietly but this ordeal depletes his physical and mental energy. Overhearing colleagues denigrate her dark skin tone, Igwe-Kalu's anxious desolation evokes her childhood bullying—by Black schoolmates emulating white Bostonians. Crucially, the emphasis that all authors place on lingering memories and on the cumulative effect of racism suggests that their experiential knowledge has been sharpened by a lifetime of living in a racialized body.

As such, these authors have cultivated an astute knowledge of racism directed at patients. The story of Alex and his family, as told by Castillo-Anderson, highlights how prejudicial attitudes hinder care to the frustration of both patients and providers. Concerned that the resident and attending physician are dismissing the mother's report of seizure history due to her social location, she becomes a fierce advocate to get them appropriate treatment. Her knowledge is informed by her own mother's tireless efforts at overcoming bias and systemic barriers: "I think of the times in my life that I have felt unheard and unseen as a Black patient—the times when my mother's concerns fell on deaf ears, the time that a doctor's weekend plans seemed more important than my pain and my possible surgery." Jetpuri's redemption narrative similarly juxtaposes her harrowing account of religious discrimination with the development of valuable empathy that can benefit her patients. Meanwhile, others stated that their own experiences with racism allowed them to gain an increased sensitivity towards racist treatment, particularly in its more insidious forms.

Knowledge Practices

Despite demonstrating a nuanced knowledge of racism, the authors were not treated as experts vis-à-vis their experiences. The narratives further illustrate how racism manifests itself: it intervenes in knowledge practices in health care. The notion of testimonial injustice (Fricker, 2007) is especially useful in understanding the ways in which racialized individuals are often denied in their capacity as knowers. Individuals are believed (or disbelieved) based on whether their testimonies are deemed credible and trustworthy. Testimonial injustice occurs when prejudicial stereotypes about the speaker's identity distort the hearer's credibility judgments of her testimony: the knowledge that could be transmitted is not received, resulting in harms to knowledge, individuals, and society (Fricker, 2007).

All authors speak of being doubted, discredited, or disempowered as epistemic interlocutors. Bemanian's testimony is received with incredulity, his medical school peers "uncomfortable even acknowledging that such a situation could even occur, that a patient may refuse care based on their provider's race." Bearing witness leaves him feeling alone, isolated, and regretful. Hoskins's calm testimony is labeled as intimidating and aggressive, thereby revealing the power of racist stereotypes about Black women to tarnish her reputation. The fact that several stories emphasize the skepticism towards the epistemic statements of women echoes reports in the literature about a credibility gap caused by diminished social power (Hoffmann & Tarzian, 2001). As Anonymous writes: "I said that I felt I was treated inferiorly due to my race and gender but was corrected by colleagues that no one is racist in our department."

At the same time, lower levels of credibility afforded to patients, prejudicial attitudes about race, and systematic health care conditions that create epistemic power imbalances can magnify errors of mistaken judgment. Epistemic injustices can be identified in the unjust treatment offered to patients as detailed in two narratives. Mathis writes that epistemic trust was in short supply in a physician colleague's interactions with a patient relative— "a poor Black man with addiction issues, which is common in the patient population of this facility "—and family. His sister was denied updates about his condition because the attending judged her unsuited for a complex conversation. "I was never asked," she expands, "about educational status or what my family knew about the patient's condition. It was just assumed that they knew nothing and did not have the ability to understand. The patient's sister is an educator with over 30 years of experience. There was no effort to get to know them at all."

Along with racist stereotypes undermining testimonial exchanges is the disempowerment of ill persons as epistemic experts. Castillo-Anderson is dismayed to hear claims by the treating physicians that the patient's mother "wasn't a very good historian anyway," a label frequently applied to minorities, which skews clinical interactions. She goes on to add: "As students, we get messages about the types of patients who are "poor historians," the stories that deserve time and attention, and the voices that deserve to be listened to." Care relationship hinges on proper communication between patient and provider, yet ill persons are uniquely vulnerable to epistemic injustice (Carel & Kidd, 2014). Calling on patients to trust providers must involve a centering of perspectives of those most vulnerable to injustice, lest it increase epistemic oppression (Ho, 2011).

Epistemic injustice towards racialized individuals has additional implications in health care. If we agree with the premise that medical knowledge has a narrative structure (Hunter, 1991) and that communicative acts in clinical settings (e.g., patient complaints, diagnostic reasoning) involve testimony, then the perception of minority providers as epistemically suspect could negatively impact the delivery of care. While the authors don't say how their professional statements about patients were received, they were the subject of inaccurate assessment of their capabilities informed by racist attitudes. Tense meetings quickly devolve to colleagues questioning their credentials and legitimacy as health care professionals. Bradley was viewed as deficient in social skills crucial to his work as a chaplain because of his interest in social justice. Anonymous had her background questioned, along with her qualifications, the implication being she had used deceit to get hired. Bemanian's patient accused him of not being a "real doctor" because he was Iranian-American. Such treatment implies that minority providers are deficient knowers, with the potential to amplify insecurities about racial inferiority.

This application of epistemic injustice to health care helps explain why many authors' contributions to knowledge production were disregarded. Bradley was unceremoniously excluded from committees while his previously shared ideas "once downplayed as unreasonable or impossible suddenly became action items and were attributed to being the brilliant ideas of others." Resistance to the restructuring of procedures initiated by Anonymous, to the information on religious dress provided by Jetpuri, and to the improvement of diversity hiring practices offered by Temkin suggests a concerted effort to undermine the authority of their roles in the production of knowledge. Authors felt that their input was not solicited, most egregiously, when it came to refining the understanding of racism in their institutions.

Knowing Moral Rights and Wrongs

I contend that an unwillingness of colleagues to receive the authors' experiential knowledge of racism, their testimonies on its impacts, and their efforts to correct inaccurate judgments amount to a morally problematic epistemological stance. Epistemic ignorance, by which a socially dominant group cultivates misconceptions about social realities and inequalities, has been deployed to analyze the perpetuation of racial injustice (Alcoff, 2007). The concept of white ignorance also encompasses moral ignorance: a wrong way of seeing the world. It denotes a systematic ignorance of moral implications as well as incorrect judgments about moral rights and wrongs (Mills, 2007). In contrast, the authors offer morally defensible claims about the rightness and wrongness of their experiences of racism.

Moral wrongs and moral rights can be discerned following a reading of these narratives. From the perspective of the authors, the lack of institutional policies and training sessions on how to deal with racism perpetuates a climate of racial injustice. Guidelines have been published, for instance, on dealing with racist patient requests, yet they have not been widely implemented (Paul-Emile, Smith, Lo, & Fernández, 2016). This confusion over professional duties to provide care shortchanges patients, while when discriminatory remarks and abusive language are tolerated, staff suffer harms. Interestingly, the majority of authors focus instead on their responsibilities to minority patients. They surmise that it is wrong to neglect responsibilities to reduce bias in health care practice, increase the involvement of minority providers, and provide racially-sensitive care. The authors effectively denounce the centering of those who commit racist acts at the expense of those who bear the brunt of racism.

Another moral wrong is the marginalization of minority providers. They point out the incongruence between statements by leadership recognizing the need to address racism and the absence of concrete, impactful initiatives to bring about meaningful change. Charges of tokenism, performative allyship, superficial engagement with equity, and projecting an image of diversity for appearances' sake abound in these narratives. Hoskins describes the indifferent silence of a clinical service director, who frequently voiced appreciation of her professional conduct when she was brought in "as an advocate and witness." Minority providers are overly solicited to represent their organizations. Their visibility serves to deflect from accusations of discrimination; they are pressured to defy expectations in their work performances yet must remain subordinated and show gratitude. The narratives make clear the harsh penalties resulting from perceived transgressions of this workplace order. Several authors believed they were exploited, manipulated, and treated as a means to an end.

Arguably the most troubling aspect for these authors was dealing with the promotion of a medical culture they perceived as unresponsive to anti-racism. Racial mistreatment was minimized, excused as an unfortunate fact of life. Several authors mention the virtue of self-reliance exalted by superiors impressing upon them the importance of moving on. Lessons were hard-learned about how racism is condoned along with subtle messages that it should be dealt with off-the-clock. Desirable traits for providers transmitted in the hidden curriculum included incivility, obsequiousness, and feigned equanimity. The reinforcement of racism as individual responsibility ought to be viewed as an occupational stressor that has the potential to exacerbate moral distress and burnout for minority providers. Racism is framed as an outside problem when a long history of racism in medicine (Byrd & Clayton, 2001) and more than 400 years of abuses in America (Washington, 2006) point to the existence of systemic racism in the medical establishment. These narratives thus challenge the stories medicine tells about itself.

In response, the authors identify the adoption of anti-racist frameworks as morally preferable to the status quo. Aligned with social justice, anti-racism is conceptualized as an active process of identifying and opposing racism through changes (to systems, organizations, policies, practices, and attitudes) with the goal of achieving a more equitable redistribution of power (Center for the Study of Social Policy, 2019). More recently, it has been heralded as a way to redress racial injustices in medicine. The authors identify actions consistent with anti-racism efforts, such as highlighting inequalities, advocating for disenfranchised patients, and improving the evidence base underlying the treatment of racialized populations. Several authors stressed the need for institutional policies. "All healthcare institutions," proposes Bemaniam, "need to establish an anti-racism policy that includes protections for their healthcare workers of color." Still, they are acutely aware of obstacles to institutional changes. In embracing anti-racism, the authors appear receptive to critical theoretical approaches informed by other academic disciplines. And experiences of racism along multiple axes of oppression (e.g., disability, sexual orientation), as well as the unique situation of members of more privileged groups (e.g., high socioeconomic status, second-generation providers), reaffirm the importance of using an intersectional lens (Crenshaw, 1989).

Consequently, attending to the vulnerabilities of students and trainees emerges as an important moral right. Many authors stress how they were confronted with racism during their first positions in new roles, from scribe to attending. Educational interventions for trainees can be found in the medical education literature, recommending notably the pedagogical use of simulated patient encounters and the use of clinical rubrics for decision making, all the while ensuring a safe learning environment to support students (Alexander et al., 2021; Eisenberg & Kieffer, 2019). At this critical juncture in their professional trajectories, experiences of racism are formative: personalizing these events, the authors were left to question their abilities and whether they belonged. The power differential made standing up to mentors and colleagues difficult. Students are a captive audience to absorb influential discourses about the reification of race as a biological category, health disparities as fixed without taking into account social determinants, the use of race in medical decision making, and most importantly, the value of minority providers. The narratives remind educators of their particular obligations to the next generation of health care providers.

Conclusion

This collection of narratives provides unparalleled insights into the lived experiences of minority health care providers. The emotional intensity conveyed by the authors captures the burdens of racism while the contextual details, too often missing from analyses in the bioethical literature, inspire a novel way of understanding what is morally at stake.

Faced with a callous lack of epistemic humility about racism, Anonymous wonders: "Why wasn't anyone at least curious enough to consider the possibility?" Through their testimonies, the authors have contributed to bridging a racial epistemic divide. These narratives likewise include thoughtful considerations on the difficult balance between the pursuit of individual virtues and the creation of systemic conditions necessary to eliminate racial injustice. The recommendations they provide on ameliorating knowledge of racism inspire readers to go beyond the ethical act of testimonial exchange towards the creation of transformative social change.

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Commentary
Confronting Racism in Medicine: Stories of Resistance

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Abstract. The national (even global) discussion about racism in medicine has evolved significantly in the past few years. Important efforts are underway in many areas of health care; efforts that center on previously marginalized voices. Yet is it clear that there is a wide range in our collective levels of understanding and awareness of the fundamental and ongoing presence of racism and white supremacy in our society, in general, and in health care, in particular. The stories in this symposium offer a valuable perspective, highlighting the lived experience of medical students and physicians as they navigate their lives and careers through systems that tolerate and often build upon racism.

Keywords. Othering, Racism, White Supremacy, Health Care Delivery, Narratives

"I get tired of being the only Brown face in the room, the first and the last to iterate on anything related to diversity and allied support. Sometimes I just do what is needed to simply keep my job and for my own mental self-preservation." One cannot but be struck by that poignant reflection offered by the anonymous physician author of "On Being the Only Brown Face in the Room," one of the stellar pieces in this collection of stories examining racism in health care. In particular, the first three words —"I get tired"—offer an opening into a perspective that is not often appreciated in many accounts of contemporary diversity, equity, and inclusion efforts, which tend to privilege institutional and bureaucratic milestones and objectives at the expense of personal reflections. These twelve first-person narratives offer insight into both the reality of racism in health care, as experienced by health care workers, and the promise of a better and more equitable future, as illustrated by the perseverance, dedication, and grace shown by the authors.

The stories in this collection cover a lot of ground, from the experiences of an 18-year-old Muslim student interviewing as a medical scribe, whose hopes and enthusiasm crashed against the discriminatory policies of the clinic that prohibited her hijab and treated her as a threat, to the trauma generated by racist patients. This is perhaps most vivid in an example in the story from Dr. Amin Bemanian, recounting the patient who angrily cried out, "Where the hell is my doctor? I was promised a white doctor, and I am not talking to anyone who isn't white." Racism manifests in different ways in "An Unexpected Lesson," when Dr. Henriette

Mathis recalls, "introducing myself to other staff like everyone else did. However, I was greeted regularly with you are so well-spoken. You are not like those other Black people," and in "Working as the 'Only,'" Lisa Proctor investigates whiteness, with the observation: "I see white people in a white environment moving through their world without having to think about their color as an issue, a conversation, a decision, and envy the lack of self-consciousness."

While these diverse stories vary significantly in their topics and even in their analysis, there are important underlying commonalities, particularly those revolving around the concept of *othering* and the experience of discrimination, as well as around the culture of medicine itself. Furthermore, the examples and presence of hope and perseverance throughout these stories inspire and serve as important anchors for the reader.

In reading these stories, one wants *more* . . . and wonders about larger, structural changes that are required to overcome the injustice described by these courageous authors. For the most part, these narratives reflect the struggles of individuals, often overcoming traumatic experiences without much-needed community or groups that would act in solidarity to acknowledge that trauma, support long-term healing, and initiate action for change. How might these experiences have been different if there had been sources of support? What if the institutions in which these scenarios played out had offered something more? What if the institutions had truly prioritized equity and justice?

In the 1950s, the American sociologist C. Wright Mills described a simple but powerful analytical frame: "personal troubles" and "public issues" (1959). For Mills, personal troubles are essentially our biography; they are the day-to-day issues that affect our lives and are described and understood as individual-level experiences. In contrast, public issues go beyond individual biography and affect groups of people; public issues are historical, political, and economic and must be described and understood as societal-level experiences. Mills advocated for a social science that could link personal troubles and public issues, grappling with and understanding lived experience (for example, through case studies and qualitative methods) and recognizing how that experience was shaped by larger structural systems. And that is precisely the opportunity offered by these twelve stories of racism in health care. On one level, they are clearly accounts of personal troubles, the experiences of individual health care workers struggling against a myriad of racist and discriminatory experiences. Yet on another level, all of these stories reflect underlying public issues, including the foundational role of racism (in all its forms—including internalized, interpersonal, institutional, and structural) in the health care system and across US society in general (Jones, 2018).

Othering: Protecting Privilege Through Discrimination

Dr. Zaiba Jetpuri begins her story recounting an experience when she was an 18-year-old student seeking a position as a medical scribe with this observation: "I still remember feeling my heart fluttering in my chest as she said she wanted to interview me, but she couldn't pronounce my name. I pronounced it for her, and she immediately asked where I was from. I didn't hesitate. I said Texas. I am always from Texas since I was born here. Nothing else registers when anyone asks. Her comment that followed was that my name seemed foreign, and she was surprised I spoke good English." Alarms began to go off that something was wrong, and soon enough, her fears were confirmed: "When I arrived at the office to meet her, I could sense something was 'off.' She seemed a little awkward and told me to go through some side door in a hallway to get into the back offices. She immediately went into a conversation about rules and policies. It seemed like an odd way to begin the conversation but being my first job, I didn't think anything of it at the time. She discussed HIPAA, patient privacy, and the need to cater to her patients, who she stated were mostly elderly. None of the rules seemed out of the ordinary—except for one. She said I couldn't wear my headscarf (hijab) to work." The doctor justified her position with the claim that "Wearing your headscarf here would make my patients scared." In those few but incredibly harmful words, the doctor branded the 18-year-old student seeking entry-level employment in health care a threat because of her religious practices. In her account of the experience, Dr. Jetpuri remembers, "This broke me."

Parallel stories of othering are offered by Dr. Kimbell Kornu in his account of "Asian Americans in Medicine: The Race That Nobody Sees." He describes the complexity of his experience, both in health care and society: "Feeling like a foreigner was not confined to my hometown—I also felt like a foreigner in my own skin. As a second-generation Asian American, I feel my identity is split between two cultures to which I don't fully belong. The racial slurs affirmed that I was different than everyone else because I looked foreign. When I visit my extended family in Thailand, everyone looked like me, but I didn't feel like I fit in because I couldn't speak the Thai language. If my body was not American enough, and my culture was not Asian enough, then what was I?" In Dr. Kornu's story, the process of othering overcame any sense of self-definition; while he proudly called himself "Texan-Thai-Chinese (in that order)," this was no protection from the harm of racial slurs and a fundamental dissonance: "I was a foreigner in my own hometown. [. . .] I learned that I was different from everyone else and didn't fit in".

In "Fear of Being Discovered," Pablo Cuartas describes another perspective on othering through his experience with a racially abusive white patient. He begins his story: "I never thought much about the times I was asked to 'quit joking' when I introduced myself by my first name. I have been informed quite a few times that my phenotype does not resemble that of someone from Colombia but from the United States. When my introduction is met with casual disbelief, I offer reassurance that my name is, in fact, 'Pablo' and laugh along. When I dig deeper into that kind of comment though, it leaves me wondering. What does someone from these United States look like? What does someone from Colombia look like?" The questions take on heightened importance when faced with a racist patient who attributes whiteness to a then-student Pablo and assumes he and the attending physician are sympathizers: "He [the patient] mentioned to us how happy he was to be in the company of two other men with a complexion that matched his. [. . .] We listened as he described other ethnicities one by one, as though making sure to communicate each of his beliefs about this group or that before moving on to the next one. Occasionally he would backtrack, perhaps out of misplaced concern that if the doctor or I did not hear that particular racial slur, we would be left yearning for it. Some groups he favored less than others, and while he was at times difficult to follow, with each stroke of his broad brush, he painted an increasingly vivid picture of his worldview for us: Skin color matters most, and the fairer the better."

In this case, neither Pablo nor the attending confronted the man or reported his racist abuse; they tended to the patient's wound and went on to the next patient. Pablo remembers: "On the drive home that morning though, the man's words lingered, and the fact that I said nothing left me uneasy. It was not a painful or stinging sensation; I just felt more tired than usual. Though this happened years ago, I still wonder what experiences led to those beliefs and feel sad at the hate that man harbored. That tired sensation intermittently reappears. It rears its head when I meet someone that reminds me of that man. I am reminded of him too often."

As noted in Dr. Bemanian's story, "On Being the Only Brown Face in the Room," there are no easy answers: "physicians of color face a unique challenge when encountering patients who voice racist views or refuse care on the basis of their practitioner's race. We can find our oath to provide care for all patients to suddenly be in opposition with concern for our mental and even physical safety. Unfortunately, due to the longstanding structural racism of medicine as an institution, physicians of color are rarely, if ever, taught what to do in these situations. Furthermore, they often have little to no support structures to turn to when these events occur." And it is here where Mills' distinction of personal troubles and public issues is perhaps most helpful. Our collective challenge is to recognize and understand the personal troubles, the individual-level trauma experienced and recounted in these stories. Yet the solutions must grapple with the underlying public issues at hand, the passive acceptance by many institutions, inside and outside of medicine, of racist practices, from "microaggressions" to large-scale acts of structural racism.

Culture of Medicine That Perpetuates Harm

Many of the stories in this collection speak directly of the harmful aspects of the culture of medicine that creates or perpetuates harm. Dr. Kornu, for example, describes this as a process that teaches students and physicians "in the midst of struggle to *keep your head down, work hard, don't seek help, and don't bother anyone*" (emphasis in the original). This is reflected in the aftermath of Dr. Bemanian'story we previously mentioned ("Where the hell is my doctor? I was promised a white doctor, and I am not talking to anyone who isn't white"). He notes: " . . . when I mentioned the case to several of my classmates, they appeared to be uncomfortable even acknowledging that such a situation could even occur, that a patient may refuse care based on their provider's race. After turning to my teachers and peers for support, I ultimately felt more alone and isolated and regretted telling them about what had happened." His conclusion: "[. . .] I fundamentally felt that I had failed."

In "An Unexpected Lesson," Dr. Henriette Mathis describes an incident of a white doctor treating her Black family member with condescension and paternalism, noting that the white male doctor "spoke to them as if they were little children with no understanding." Dr. Mathis reflected: "Is this how you treat your other patients who look like me but do not have the luxury of having a doctor relative? How have you been treating my relative prior to finding out we were related? I felt why Black people do not trust the health care system. How can one trust a system in which your doctor does not even see you as an equal? I see this colleague at work still from time to time. We have never talked about it. Honestly, I do not even believe this person remembers treating my relative." And Dr. Mathis concluded: " . . . I saw how prevalent microaggressions are in medicine. I saw how antiquated biases affect how patients are treated. I saw disparities in the manner of how patients were spoken to based on race. I saw assumptions on what their lives outside of their hospital admission must be like. The crazy part is that this form of racism is not loud like someone calling another person a racial epithet. It is quiet and subtle with an air of professionalism."

The denial of racism is also notable in the experiences recounted by Anonymous, a Black physician who writes of the hostile treatment from senior white male physicians who openly questioned her education and class rank, suggesting that she was unqualified and that they would "look into her background." Her conclusion reveals a lot about the interaction and the institutional failures that enabled and perpetuated a harmful environment: "I felt so disrespected and so devalued, and I could not figure out what I did wrong. I considered walking away right then and there and never returning to my job. [. . .] I felt alone; still, I went on to tell other colleagues in the department about what happened and was told the same thing. I said that I felt I was treated inferiorly due to my race and gender, but was corrected by colleagues that no one is racist in our department. I was made to feel like I was overreacting. But I wondered—how would anyone in this department really be capable of understanding this experience from a race lens if I was—and still am—the only Black female attending in the entire department (the only other being a semi-retired Black male)? Why wasn't anyone at least curious enough to consider the possibility?"

Consider those words: "I was made to feel like I was overreacting" since "no one is racist in our department." These words were echoed in the widely-criticized 2021 podcast and tweet from JAMA that claimed, "No physician is racist, so how can there be structural racism in health care?" In one of the most thoughtful commentaries on that case, the anthropologist Clarence Gravlee, drawing on the work of the geographer Andrea Gibbons, explores "five refusals of white supremacy" (Gravelee, 2021). These are worth recounting here, as they also manifest in the twelve narratives in this collection:

1. Refusal of the other's humanity and tolerance for perpetual violence and exploitation.
2. Refusal to listen to or acknowledge the experience of the other.
3. Refusal to confront the history of racial oppression and the ways it continues to shape the present.
4. Refusal to share space.
5. Refusal to face structural causes.

And it is that last element, *the refusal to face structural causes*, that is most pronounced in these stories.

Structural Change

Collectively, these narratives point us towards root causes of health inequities. Yes, they are written primarily as first-person accounts, as personal reflections. Their power lies not only in vivid details but in deep diagnosis, pointing to structural problems that require structural solutions. Along these lines, Calvin Bradley Jr., in "Chronicles of a Culturally Grounded Chaplain," notes, "While many organizations have made public statements and perhaps even edited some of their policies, few have taken the time to candidly listen to the experiences people have had within their own institutions." He goes on to describe the *tokenism* of many efforts: "I was the only African American or racial minority representative period on many of the committees and councils . . . It did not take long for me to realize my role was one of tokenism and that as long as I followed the path others laid out for me, I would be fine." And there was a price to be paid when he went beyond that role: " . . . I identified my own strengths and passions and aligned myself with people and groups who were doing like-minded work on the local, regional, and national levels. As my passions and confidence grew, the magnitude and impact of the work also grew, and so did my challenges. I was suddenly labeled 'unapproachable' and 'distant,' along with implications that my passion for certain areas by default made me neglectful and insufficient in others."

Tokenism is also a focal point in the narrative offered by Dr. Sarah M. Temkin: " . . . it hit me how unfair this was to Dr. James and every other Black physician who was expected to assume the burden of ensuring diversity for what was a decidedly undiverse community of physicians. Acquiescing this call for tokenism must be exhausting. She was the only Black physician in a department. There were almost no Black physicians that I interacted with in this hospital, even though we cared for a large population of Black patients." Notably, here again we have an author writing of the exhausting nature of this work. These stories are a testament to the perseverance, dedication, and grace of the authors, all of whom are engaging in the struggle against racism and for racial justice and health equity.

We conclude this reflection and review with the poignant words of Ceclie Igwe-Kalu from her story "The Subtle Struggle as the Minority."

> "I'm unapologetically going to talk about what it is like to be a Black nurse in 2021, and how my past experiences fuel my anxiety and discomfort in situations today. I hope you all truly listen and are able to learn from me; together is the only way any of this will change."

Disclaimer: The views expressed in this article are those of the authors and should not be interpreted as official AMA policy.

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Commentary
Challenges of Racism and Health Equity in Medicine

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Abstract. The racial/ethnic populations in the United States, in general, have less access to quality health care and behavioral healthcare services than the Caucasian population. They face barriers to access health care access, and experience higher rates of chronic diseases and complications with heart disease, diabetes, cancer, HIV, and obesity. Increasing the number of racial/ethnic physicians is one way to build trust, provide patient-centered and cultural quality care, and attract racial/ethnic patients to healthcare services. However, the inherent structural racism of medicine and implicit bias of physicians makes this challenging. In this collection of stories from racial/ethnic physicians, trainees, and other health care providers, authors focus on the trauma they have experienced with racist patients and colleagues during their careers, yet discuss how what they have learned is important for medical education for other healthcare providers like them.

Keywords. Racism, Justice, Institutionalized Racism, Healthcare, Health Equity

The racial/ethnic populations in the United States, in general, have less access to quality health care and behavioral healthcare services than the Caucasian population (Escarce & Goodell, 2007). Many live in poverty and face social determinants of health such as lack of nutritious food, safe spaces for physical activity, transportation, as well as substandard housing and overcrowding (Velasco-Mondragon et al., 2016). In addition, they face many barriers to accessing health care such as limited health insurance, lack of education and health literacy, limited English proficiency, and they live under toxic stress (Escarce & Goodell, 2007).

As a result, racial/ethnic populations face health disparities with chronic diseases and complications such as heart disease, diabetes, cancer, HIV, and obesity at much higher rates when compared to the White non-Hispanic population (Centers for Disease Control and Prevention, 2015, 2016, 2021a). The COVID-19 pandemic, which has resulted in African Americans and Latinos having nearly three times the hospitalizations and two times the deaths compared to Caucasians, has prompted the call for targeted policies and programs to improve access to prevention education and healthcare access for these underserved groups (Centers for Disease control and Prevention, 2021b).

Increasing the number of racial/ethnic physicians is one way to build trust, provide patient-centered and cultural quality care, and attract racial/ethnic patients to healthcare services. Thus, medical education is increasing diversity and equity training, but the inherent structural racism of medicine and implicit bias of physicians makes the implementation of these policies challenging. A common theme throughout this collection of stories from racial/ethnic physicians, trainees, and other health care providers is their recognition of racism in the health system that they face from patients and from colleagues.

Do No Harm

Some of the physician and trainee authors focused on the trauma they have experienced with racist patients during their careers, yet discussed what they have learned is important for medical education for physicians like them.

Some of the physician and trainee authors call attention to the need for cultural competence training of physicians in order to better meet the needs of patients who are from different backgrounds than the physicians. "Physicians of color are not taught what to do when encountering patients who voice racist views or refuse care on the basis of the doctor's race," so reports Amin Bemanian. Bemanian continues to discuss their attempt at calling for the need for training on anti-racist bias training to allow physicians to learn about racism and not continue to ignore it.

Kimbell Kornu reported that medicine is not immune to microaggressions. Kornu notes, "As a medical student, I enjoyed rotating at the VA hospital because of the veteran population. However, immediately after I walked into a patient's room, a veteran told me, 'Go away. I don't want a Jap doctor.'" Medical trainees are not taught to ask for help but rather are held to the ideal that a good physician is self-sufficient, efficient, and resilient.

Medical student authors share that the younger generation is continuing to experience racist attitudes from patients, but are reflective about how they can handle the encounters and not focused on how to change the culture of the healthcare system. Pablo Cuartas, MBE, HEC-C, medical student, discussed the encounters he has had about his skin color and being a son of immigrants growing up in the U.S.

Juliete Castillo-Anderson, medical student says, "In a way, I am grateful for some of the negative experiences that I have had as a Black patient because they allow me to recognize similar experiences in my encounters with patients, and they inoculate me against the biases that are handed down to us throughout our education. As I move toward becoming a physician, I hope that my life experiences and the patients who leave an impact on my life and education will continue to empower me."

The Hidden Curriculum

Some authors focus on the hidden curriculum of racism they encounter from their colleagues. Cecilia Igwe-Kalu, RN, BSN discusses her colleagues at work making fun of Nigerians that brings up her experiences with bullying back in grade school in Texas and being reminded of being made to feel that she doesn't belong.

Juliete Castillo-Anderson, medical student, discusses the "hidden curriculum" of medicine that so many of us are exposed to as we go through our training accepting that she has to be stronger as she works with her classmates and attendings since racism is part of medicine. A hidden curriculum is experienced by minority physicians from their mother's advocacy for them as children to providers with implicit bias in a racist system.

Zaiba Jetpuri discusses her experience with a biased physician who told her that her name seemed foreign, and was surprised Jetpuri spoke "good English." The hiring physician said that Jetpuri couldn't work in her medical office wearing a head scarf.

"A common response from my supervisors was to avoid racist patients." So reports Amin Bemanian, as if to convey that Bemanian was the problem attracting these patients.

Medical training shows the cover-up of racism—why does this continue? And then the minority physician is said to be overreacting.

Calvin Bradley Jr., MDiv, CFLE, BCC, HEC-C states, "As my passion and influence grew, I was quietly and conveniently uninvited to the next meeting. In some cases, whole projects and committees were completely dismantled, some reestablished under new facades." Bradley goes on to say, "Many times in healthcare, I have been reminded through the actions of others that my expected role is to be seen, but not heard; patronized but not validated; and present but not influential."

The Need for Institutions to Celebrate Diversity in a Meaningful Way

We must ask why should minority physicians, trainees, and other healthcare providers bear the burden of being a target of racist comments and behaviors from patients, and at the same time, have trauma when feeling unsupported in an environment that has inherent racism?

Some physicians who are considered foreign in the professional world have grown up in the U.S. in a bubble and look for an institution where diversity is celebrated. Zaiba Jetpuri, DO, MBA, FAAFP explains, "I had been naïve and realized that discrimination, unfortunately, was ever-so-present even in the professional world."

As others reported: Diversity is encouraged. Leadership requests more residents and attendings and mentors of color be hired and that wellness initiatives include focus discussion on race and gender, but this often leads to no action. Diversity success is valued, but then the institution uses labels put upon the minority physicians—overreacting, unapproachable, distant, tokenism. Black doctor, both seen as heroes in this pandemic and also a threat or problem at their institutions.

Racism in healthcare can negatively affect the care given to patients, the trust of patients, and unity among healthcare teams. There is a recognition of the importance of elevating anti-racist training across the medical education curriculum; however, the stories in this collection point to the leadership of a status quo that does not act on this need.

Policies Needed to Improve Health Equity

We need to recognize that there has been an increased focus on diversity in medical education by the federal government (CLAS Standards) and by the accreditation bodies of undergraduate and more recently, graduate medical education to support training of cultural competency that focuses on anti-racist bias training. This training is warranted in order to promote health equity and change the culture of medicine with the next generation of medical students and residents.

Minority physicians should be supported and heard and recruited to academic faculty and executive leadership positions in academic institutions so that a new curriculum can be developed in medical education about how to have an environment that celebrates diversity for all trainees in medicine.

There is a need for antiracism policies that are in the mission of medical education institutions and programs and a need for awareness building about implicit bias among physicians.

Training should include partnership with community minority physicians with the experience in the community and with a family to educate students to better understand how minority communities cope with living conditions in poverty and with social determinants of health.

Increased focus on diversity brings with it the challenge of changing the culture of medical delivery—you bring in more ethnic doctors to train, the medical schools must support the need for a culture shift in the institution so that patients show more respect to these doctors

The Ethics of Justice in Medicine

Beneficence, nonmaleficence, autonomy, and justice constitute the 4 principles of ethics (Beauchamp & Childress, 2013). Justice is generally interpreted as fair, equitable, and appropriate treatment of persons. Of the several categories of justice, the one that is most pertinent to clinical ethics is distributive justice. Distributive justice refers to the fair, equitable, and appropriate distribution of healthcare resources determined by justified norms that structure the terms of social cooperation. How can this be accomplished? There are different valid principles of distributive justice. These are distribution to each person (i) an equal share, (ii) according to need, (iii) according to effort, (iv) according to contribution,

(v) according to merit, and (vi) according to free-market exchanges. As Beauchamp and Childress explain, each principle is not exclusive, and can be, and are often combined in application (2013). It is easy to see the difficulty in choosing, balancing, and refining these principles to form a coherent and workable solution to distribute medical resources.

Institutional racism involves practices, procedures, patterns, and policies that operate to privileged members of particular racial groups in every aspect of society (Elias & Paradies, 2021). It is an exclusionary system where a group is denied access to rights and privileges conferred on some groups in the form of unearned advantage. Through the exclusionary "production, control and access to material, information and symbolic resources" in societies, institutional racism serves to widen power differential between racial groups (Elias & Paradies, 2021).

Three fundamental reasons—disrespect, unfairness and harm—have been proposed as the core ethical flaws of racism. Within the unfairness paradigm, the ethical question of racism broadly and institutional racism specifically can be seen in the notion of racism as a disregard for racial minorities. This locates the fundamental ethical flaw of racism in the failure of individual citizens and society to consider the conditions of racial minorities. (Elias & Paradies, 2021).

Based on a review of multidisciplinary research on racism, particularly focusing on healthcare, we can demonstrate how institutional racism leads to social and economic inequalities in society.

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“We’re Not Moving Forward”: Carers’ Demand for Novel Research and Effective Interventions for Psychotic Disorders

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Abstract. The lack of access to effective interventions for psychotic disorders places a considerable burden on informal caregivers. At the same time, the convergence of clinical neurosciences and next-generation genomics has the potential to transform psychiatric care. This article presents findings from a qualitative study. I conducted focus groups with carers of a person suffering from psychosis. I investigated how carers conceptualise the ethical issues arising from novel neurobiological approaches to psychosis. On the one hand, carers pictured a narrative of hope. They strongly demanded novel research and effective interventions that might help their ill relative to recover and lead a flourishing life. On the other hand, carers were frustrated at their present situation and feared that technological innovation might produce more harm than benefits. I argue that carers’ moral outlook can be best understood by referring to an ethics of care. This study suggests that investigating carers’ perspectives on sensitive ethical issues is vital to ensure that the needs of those who suffer from psychosis are appropriately met.

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Introduction

Psychosis is a state of the mind characterized by delusions, hallucinations, disorganized thinking, and more generally by a loss of contact with reality. Mental disorders that are primarily characterized by psychosis, such as schizophrenia, are termed psychotic disorders (American Psychiatric Association, 2013). Psychotic disorders are considered to be amongst the most severe forms of mental illness. After more than a century of confinement of people suffering from mental illness in total psychiatric institutions (Goffman, 1961/1991), in the last decades deinstitutionalization and the development of community mental health services have produced relevant social changes in Western societies. Yet, the lack of access to effective interventions for psychotic disorders and the burden on informal caregivers are still striking (Fleischhacker et al., 2014).

As a response to such hindrances to effective mental health care, the past decades have seen a tremendous increase in research into the neurobiology of schizophrenia. The development of clinical neurosciences and their application to psychiatry have helped researchers to unveil the structural and functional processes behind disrupted brain activity in psychotic disorders (Fusar-Poli et al., 2012; Howes et al., 2015). The expansion of next-generation sequencing is leading the way towards a greater understanding of the genetic basis and molecular architecture of psychotic disorders (Corvin et al., 2020). More importantly, neuroscientific and genomic approaches to psychosis are increasingly intertwined because of technological convergence (Corsico, 2020). The converge of neuroscience, next-generation genomics, and data science could soon transform the care of those who suffer from psychosis by helping to redesign diagnostic categories, by supporting the development of effective interventions, and by ameliorating risk assessment and clinical prediction (Insel, 2009; Shatte et al., 2019).

In this article, I use the word "neurobiology" to indicate the convergence of neuroscience and genomics in tackling psychosis. Potential clinical benefits to be gained from an increased understanding of the neurobiology of psychosis are easy to describe. Yet, what ethical challenges arise from this endeavour? Participant recruitment in mental health research has historically raised many ethical issues (DuBois, 2008). The issue of mental capacity in research and care is longstanding (Appelbaum, 2006). Further, complex ethico-legal concerns arise regarding the management of neurobiological information in the context of mental illness, such as return of results to research participants (Lazaro-Munoz et al., 2018), or disclosure of unsolicited findings in neuroimaging research (Racine & Illes, 2007).

At the same time, treatment in the community often means that the relatives of individuals who suffer from psychotic illness—many times their parents—take on a substantial caregiving role. Carers[1] are an essential component of the community treatment model in psychiatry (Cree et al., 2015). An increasing body of literature has started to investigate carers' experiences of caring for a person suffering from psychosis (Young et al., 2019). However, carers' perspectives on the expansion of neurobiological approaches to psychosis and the ethical issues thereof remain largely unexplored.

Study Aim

This article presents results from a qualitative study. I investigated how carers conceptualise the ethical issues that arise from the implementation of neurobiological approaches to psychosis and from technological innovation in psychiatry. More specifically, I investigated how carers perceive issues around three areas: (1) ethical issues in clinical research on the neurobiology of psychosis; (2) ethical issues in clinical translation of neurobiological findings; and (3) impact of neurobiological research and translational efforts on patient care and family dynamics.

Drawing from focus groups I conducted with carers of a person suffering from psychosis, I argue that carers provide a different outlook on the ethics of technological innovation in psychiatry. I argue that this outlook has epistemic value. Further, I argue that carers' moral outlook can be best recognised—and understood—by referring to an *ethics of care*. Care ethics was not used deductively in this study to shape qualitative data collection or data analysis. Yet, care ethics emerged as the most appropriate framework to interpret findings from the focus groups. Carers' demand for novel research and effective interventions was linked to the recognition that their cared-for's needs must be appropriately met if we wish for technological innovation to have a positive impact on their lives.

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[1] *The term 'carers' is a British synonym for 'caregivers' and was the term used throughout this study, which was conducted in the United Kingdom.*

Such an approach, I argue in this article, is grounded on carers' recognition of the moral value of care.

Methods

I conducted three focus groups as part of a larger qualitative study entitled: Ethical, Legal and Social Issues in Novel Neurobiological Approaches to Psychosis and Schizophrenia: A Qualitative Study (ELSI-NAPS). The study was reviewed and granted ethical approval by North West—Greater Manchester South Research Ethics Committee, REC reference number: 17/NW/0315. Inclusion criteria to take part in the focus groups were: (1) being aged 18 years or above; (2) acting as carer / legal guardian of a psychiatric patient or service user with a diagnosis of psychotic disorder or schizophrenia; (3) being a first or second-degree relative, spouse, or civil partner of the patient or service user. With reference to the COREQ criteria my personal characteristics as chief investigator, focus group moderator, and author of this article are: doctoral student in bioethics, male, with training in qualitative health research (Tong et al., 2007).

Recruitment and Participants

I used purposive sampling to identify potential participants via two routes (Battaglia, 2011). First, posters were placed in physical noticeboards across community mental health services in Greater Manchester Mental Health NHS Foundation Trust. Second, the study was presented at meetings of mental health carers groups in Greater Manchester. Individuals interested in the study were invited to contact me. I had no relationships with potential participants prior to recruitment. Potential participants were screened for eligibility and, if eligible, were sent a participant information sheet and were invited to take part in one focus group. When at least four participants had confirmed their availability, a date was set and a focus group organized. Fifteen participants were recruited between July 2018 and January 2019. Each participant took part in only one focus group. Three focus groups were held with four, five, and six participants respectively. Group size was kept relatively small for two reasons: (1) in order to facilitate in-depth discussion and allow all participants to talk about their personal experiences, and (2) because the resources available for recruitment were limited as the study was conducted as part of my doctoral studies.

All participants provided written informed consent and completed a short demographic questionnaire prior to the focus group (see Table 1). They were offered a £20 voucher as an incentive to their participation. Participants could have their travel expenses reimbursed if they wished so. During recruitment, potential participants were invited to take part in the study if their cared for had a diagnosis of schizophrenia or psychotic disorder understood as a mental disorder with relevant

Table 1

Participant Demographics

	Age	Gender	Education	Diagnosis of cared-for	Relationship with cared-for
Carers *n* = 15	Range = [49–76] Median = 66 Mean = 66.0	F = 14 (93.3%) M = 1 (6.7%)	Primary education = 1 GCSE = 5 A-Levels = 3 Undergrad. degree = 4 Postgrad. degree = 2	Schizophrenia = 7 Paranoid schizophrenia = 4 Psychotic disorder = 1 Bipolar disorder = 1 Borderline personality disorder = 1 Prefer not to disclose = 1	Parent = 12 Spouse = 2 Sibling = 1

psychotic features. Participants were then asked to disclose the "main diagnosis" of their cared for in the demographic questionnaire before the focus group. This explains why Table 1 reports one occurrence of bipolar disorder and one of borderline personality disorder, which are not generally considered psychotic disorders. Participants were also given the option not to disclose their cared-for's diagnosis in the questionnaire. Almost all participants were women and most were parents of the patient or service user. The most common diagnosis was (paranoid) schizophrenia. In other words, the majority of participants were mothers of a person suffering from schizophrenia. This fact may constitute gender bias in participant recruitment. However, recent literature has highlighted gender imbalance in family caregivers of individuals suffering from schizophrenia. For instance, Awad and Voruganti (2008) note how surveys in the United States show that up to 82% of carers of people suffering from schizophrenia are female, with 90% of those being mothers. Gender imbalance in family caregiving was also reported in a recent systematic review of qualitative studies (Young et al., 2019) and in qualitative research exploring the views of carers in the United Kingdom (Lloyd et al., 2017).

Data Collection

Focus groups took place in public meeting rooms that were hired ad hoc. Each focus group lasted for approximately ninety minutes. I used a focus group guide that was not amended across different sessions to comply with REC requirements. The focus group guide is presented as supplemental online material. I acted as moderator of the focus groups. A second researcher was present at the venues to assist the author in welcoming participants and in taking field notes. The focus groups were audio recorded. I transcribed the audio recordings *verbatim*. Transcripts were anonymized to ensure confidentiality and pseudonyms are used in this article. Transcripts were not returned to participants for comments and corrections.

The focus group guide presents a breakdown of the topics explored and how much time was allocated to each topic during the focus groups. The first 10 minutes (not reported in the guide) were used to welcome participants, provide information on the research, explain ground rules for the session, and answer potential questions from participants. Then, 20 minutes were allocated to warm-up questions. I explained to participants that we would discuss neurobiological approaches—that is, neuroscientific and genomic approaches and their convergence—to psychotic disorders. I asked if participants were familiar with these approaches to psychosis and we discussed how they understood psychosis and schizophrenia. Then, I asked participants what they felt could be the arguments to justify conducting neurobiological research on psychosis. After the warm-up phase, 30 minutes were dedicated to a focusing exercise: a group discussion of a case vignette.

Case Vignette: The Story of Anna, David, and Tom[2]

A printout of the vignette was given to participants approximately 30 minutes after the focus group had started. Therefore, not all themes discussed in the results emerged in response to the vignette. The quotes that refer to the vignette are clearly identified in the results. Given the relevance of the vignette to data generation, I report the vignette below.

Instructions to participants: We are going to describe a scenario to you about a family involved with mental health services and clinical research. Please, read the story and think about what you would do:

> Anna and David live in Bolton, Greater Manchester. They have been married for over 20 years. Anna works as a nurse in a local hospital. David occasionally works as a carpenter. He has a history of mental health problems, and has received a number of diagnoses in the past 10 years, including schizoaffective disorder and schizotypal personality disorder. However, he has not been relapsing for the past 18 months. Anna and David have a son, Tom, aged 17. Tom has always done very well in school. He has

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[2] *A slightly modified version of this case vignette has already been presented by the author as a case study in another article (see Corsico, 2020, p. 271).*

> friends and enjoys playing football and going to concerts. However, in the last year he has been very distressed. His school grades have worsened. He stopped seeing his friends, and he spends a lot of time alone. The family GP[3] has recommended that Tom engage with the local early intervention team. He has received an assessment at the early intervention service, and the clinical psychologist says that Tom is at risk of developing psychosis. A clinical research team approaches Tom and Anna. They offer that Tom be included in a trial, in order to monitor his possible transition to psychosis. Tom would be given a smartphone, which would monitor his activities for the next 6 months. Over the next 6 months, Tom will have to attend a hospital visit once a month for neuroimaging scans. The research team says that this would allow for a better understanding of Tom's condition. In addition, a blood test is available, should Tom decide to do it, in order to assess Tom's genetic risk to develop a psychotic disorder. What would you do if you were Tom? What would you do if you were Anna? What would you do if you were David?

The first 30 minutes of the focus group had been dedicated to discussing participants' understandings of psychosis and arguments surrounding neurobiological research. The case vignette discussion focused on an imaginary case where research and care intersect—whereby ethical challenges may occur when the boundaries between the two are blurred. After the case vignette discussion, I allocated 20 minutes to discussing ethical issues in the translation of research findings in clinical care. First, I asked participants what they thought of the possibility of assessing someone's risk of developing a psychotic disorder using neurobiological measures. Then, we discussed the impact that such measures could have on patients and service users and on how they see themselves. We then discussed stigma and labelling in relation to neurobiological approaches to psychosis. Lastly, I asked participants how they thought that the translation of neurobiological findings in clinical care might affect family dynamics.

In the last 10 minutes, I asked participants if they wished to discuss anything that had not been covered in the session. I answered participants' questions, thanked them for their participation, and closed the session. Each focus group lasted approximately 90 minutes.

Data Analysis

Transcripts were analysed in a stepped thematic analysis process to identify recurring themes and to organize the data in a structured format (Braun & Clarke, 2006). After a first reading of the transcripts, I developed initial codes that captured the arguments expressed by participants. A first coding structure was developed and transcripts were coded without the use of data analysis software. In a subsequent phase, a second researcher independently reviewed the coding structure against one of the three transcripts to ensure reliability. The coding structure was revised to incorporate the reviewer's comments and a coding manual was developed. The coding structure and manuals were then re-reviewed by the second researcher and by a third researcher and consensus was reached. The transcripts were then transferred to NVivo 11 and were coded using the revised coding structure and manual. Some codes were eventually adjusted during this process. After coding all the transcripts, I wrote the present article. The final coding structure / thematic map are presented in Table 2. The final coding manual is presented as supplemental online material.

Results

Taking care of a person suffering from a psychotic disorder, who is often a son, a daughter, or a close relative, is an intense and emotional experience (McAuliffe et al., 2014; Young et al., 2019). For this reason, conducting focus groups with carers of someone suffering from a psychotic disorder presents specific practical challenges. Carers spoke about their experiences and described the problems they face in the everyday practice of caring for their relative. They often did so while answering the questions they were asked. More precisely,

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[3] *In United Kingdom, the acronym GP stands for General Practitioner, who is the family doctor.*

Table 2

Coding structure / Thematic map

Anger

Frustration

- At medical profession
- At research
- Lack of social support
- Coercion and moral distress
- Expert role of carers

Stigma

- Blame on parents for illness
- Carers' shame / fear of social judgement
- Experiences of discrimination
- Stigma and fear related to diagnosis
- Frustration at "politically correct"
- Media as drive of social stigma
- Need for education on social stigma
- Stigma and neurobiology
    - *Research in general can reduce stigma*
    - *Neurobiology could reduce stigma by removing blame*

Understanding of illness

- Psychosis is (not) an illness
- Schizophrenia just a collection of symptoms
- Right understanding is biological / biopsychosocial
- Diagnostic system is flawed

Hopes

Need for effective intervention

- Timely and accurate diagnosis
- Effective medication
    - *Medication is currently trial and error*
    - *Neurobiology may support accurate prescription*
- Effective prevention
    - *Prediction useful only if intervention available*

Strive for knowledge / understanding of illness

- Research has vital relevance
- Fair access to research / treatment
- Peer-support groups are vital to carers

Communication

- Detailed information on research to carers
- Careful communication (on research) with participants
- Confidentiality as a barrier
- Effective communication with mental health professionals

Benefits of psychosis prediction / risk identification

- Impact on patient's life choices
- Extension of individual choices
- Increased hope towards recovery if effective intervention

Fears

Resources

- No money for new technologies
- Poor treatment has societal costs

Harms of psychosis prediction / risk identification

- Prevention (prediction) of schizophrenia is not possible
- Risk of medicalization and over-diagnosis
- Burden on (young) individuals / iatrogenic effect
- Young people difficult to engage in research

participants tackled the issues under investigation by embedding their reflections within their personal narratives. This phenomenon has been reported in other qualitative studies with similar populations (Wainwright et al., 2015, p. 107). Participants who shared similar narratives of caring for a person suffering from mental illness often directed group discussion towards their shared experiences. Rather than constituting a limitation, this fact allowed me to answer the research question by providing context-rich personal narratives.

The aim of the focus groups was to capture carers' perspectives on the ethics of novel neurobiological approaches to psychotic disorders. Carers' engagement with ethical issues was deeply embedded in their personal narratives. Their reflections were marked by a strong emotional involvement. For this reason, it seemed appropriate to organise emerging themes along different emotional axes. Organising participants' arguments along different emotional axes allowed me to capture their perspective on ethical issues whilst portraying their emotional involvement. It also allowed me to describe the data by showing how carers' reflections were rooted in their personal experiences.

The main message that emerged from the focus groups was one of ambivalence. On the one hand, carers pictured a narrative of *anger* towards their present situation. Frustration at the medical and research professions, experiences of media-fueled social stigma, and occurrences of moral distress were commonly reported. On the other hand, carers pictured a narrative of *hope* for the future. They strongly demanded novel research and effective interventions which might help their cared for to recover and to lead a flourishing life, as well as support carers in fulfilling their role without being overwhelmed by it. Participants endorsed a biopsychosocial model of psychosis and recognized the importance of neurobiological research in producing novel interventions and effective prevention. Yet, they were ambivalent in describing how technological innovation might be beneficial to patients and service users. Carers expressed *fears* of how technological innovation might exacerbate common ethical issues in mental health.

I describe the themes that emerged from the focus groups along three emotional axes: anger, hope, and fear. The themes identified are:

Anger: frustration, stigma, and understanding of illness.
Hopes: need for effective intervention, strive for knowledge, communication, and benefits of psychosis prediction / risk identification.
Fears: resources, harms of psychosis prediction / risk identification.

Anger

The most common reaction of participants upon being asked about neurobiological research and technological innovation was a sense of frustration towards the medical profession:

> P9: I know they've got the best brain scanner in, um, I mean it's Cardiff or somewhere, in the all of Europe, um but here in [omitted] we're not moving forward, we're not just standing still, we're moving backwards, we are just ticking all the boxes, and, as to diagnosis, using old medications . . .

> P13: And I think, yeah, you can look at genetics, you can look at brain scans, you can look at social, whatever, you can look at all that stuff, but basically, what we need is an effective mental health service. And I don't think you got it.

The same level of frustration was expressed with regard to research. Carers were mostly dissatisfied with the limited impact of neurobiological research on clinical practice:

> P14: . . . the money that's put into research with drugs. Incredible! But we need research into what works, what doesn't work, what is, what is wrong! What it's got, but. Just to start, just to give people drugs . . .

Carers' frustration was exacerbated by the lack of social support available to them and their relatives, and by experiences of coercion and involuntary hospitalization. In addition, carers felt that they have a specific "expertise by experience" in identifying their relatives' care needs. However, this expertise is mostly ignored by the medical profession:

> P12: . . . hum it's you know, "we're the experts, leave it to us" [referring to medical profession]. And that is the most crude. I think that's, that's not so common as it used to be. But the involvement of carers and family, that seems to be a huge resource that's lost again and again, and everybody loses [participants agree]. Not just with, you know, the caring for somebody who's got a diagnosis but even in research as well.
>
> P9: And I find, that the only thing that keeps me relatively sane, not completely, is the group, and that's because we are the only ones that know, we are all in the same boat, and we are the only ones that understand. Even the researchers, the psychiatrists, the doctors, nobody understands more than a mental health carer, what it's like to care for somebody with a severe mental illness.

Social stigma attached to psychosis and schizophrenia was mentioned as a common ethical issue. Carers described how social stigma is related to the diagnosis of their ill relative and reported experiences of discrimination, shame, and fear of social judgement. Interestingly, many participants complained that the cultural context in which they live often blames parents for their children's illness. In one occasion, participants explicitly linked this phenomenon to 1960s psychosocial theories of illness aetiology developed by scholars such as R.D. Laing:[4]

> P6: Who was this nut job who was saying that it's all the parents' fault? You know, our friend, what's his name?
> P2: Oh yeah, there's, what, after Freud it was . . .
> P6: It's a Freudian, a Freudian . . . I can't remember his name, I don't want to remember his name, cause he was so destructive, when I thought [swears] if those people are in charge of helping my son, God help him. It was shocking that someone could be so ignorant and so biased.
> P2: Is it T. Laing or R. D. Laing. Yeah. He's the guy? He's the guy [other people agree]. And it's so primitive now. It's so bloody primitive.

Carers argued that stigma is also fuelled by the media's portrayal of mental illness and of violent crimes involving individuals suffering from schizophrenia. They argued that education is the most appropriate way to deal with stigma. In addition, when asked about the role of biological approaches to mental illness in fuelling or reducing stigma, many participants argued that neurobiology has the potential to reduce stigma by removing blame towards psychotic illness:

> P1: But I think what, in answer your question, and what would feel really strongly for me, is, yes, if there was a genetic base to mental illness, I think it would massively reduce stigma. 'Cause what we're saying, this is not people's fault. [Participants agree].

This argument was closely linked to carers' understanding of psychosis. Participants were ambiguous on whether psychosis should be considered an illness. The majority of them argued that psychosis is an illness that must be treated like other physical illnesses. Yet, others were more sceptical of the medical model. At the same time, the two approaches converged around the idea that the term "schizophrenia" only identifies a collection of symptoms and *not* a discrete condition. More importantly, carers agreed that the current diagnostic system used in psychiatry is inherently flawed:

> P14: Imagine if you had diabetes and said "no, it's not diabetes actually, it's epilepsy." No no, we're not quite on that, it's like, you kidding me? So, in physical health, it would be taboo to, you know, to get it wrong, to get a diagnosis wrong, imagine getting a diagnosis wrong in physical illness and be treated for that [P12 agrees] and then six months later, yeah, it's much rare than in mental health, in mental health they're changing diagnoses all the time. Yes, it does happen in physical health.
> P13: But, I would say because there's no diagnosis in the first place, it's a, it's a . . .
> P14: It's kind of, what, what . . .
> P13: It's them, it's them imposing labels that don't necessarily fit with the mental health . . .
> P15: It's just tick boxes isn't it, really?

Whilst arguing that the diagnostic system is flawed, most participants seemed to endorse a biopsychosocial model of psychosis whereby biological factors play an important role in the development of psychotic symptoms along with psychosocial factors:

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[4] *An account of R.D. Laing's theory about the nature of mental illness in relation to the family can be found in Laing & Esterson, 1964/1986.*

> P5: What I would just like to say is, in my opinion, there is a genetic disposition to mental illness. That it doesn't necessarily follow through, but . . . So, I do think there is a fam-, a genetic disposition, but I don't think just because one member of the family has it, that it would automatically follow through.

Hopes

In sharp contrast with feelings of anger towards their present situation, carers expressed *hope* that novel research and technological innovation may bring improvements in the life of their ill relative and support carers in their caregiving role. Carers strived for knowledge and demanded that neurobiological research cast more light on the nature of psychosis:

> P2: And, just because the dopamine, um, research didn't get anywhere, doesn't mean they have to throw it out again and go back to "abuse." So, I think, [inaudible] shut up, and do what we're doing, and get in people that are doing the research, taking the time, and getting the evidence, because . . . my sons deserve that.

> P9: Because that's the only way of moving forward. If we don't do research and people get on board more than they are, and drag the old stalwarts out of the past into the future.

Carers also demanded better access to research on grounds of fairness towards people who suffer from mental illness if compared to those who suffer from physical illnesses. This argument was linked to the demand for better communication with the medical and research professions. Detailed information on research should be more easily available to carers:

> P2: There's lots of trials going on now, and some of them are really getting somewhere, and you know, we're just not told about them. And, the other thing is well, what's the blood test, for the markers, to see if your young person has got treatment resistant schizophrenia, there are trials going on, and, I know my son was just a little bit too late for the trial because we weren't told about it, or we should have been.

In addition, careful communication on research opportunities should be established with carers' ill relatives, especially when these are young. In a broader perspective, carers demanded better communication between the family and mental health professionals about research opportunities and treatment strategies. The need for effective communication was anecdotally exemplified by carers' tendency to consider confidentiality as a barrier to their caring role:

> P12: I recognise that confidentiality is a real issue nevertheless. And that, you know, somebody. My son is entitled to confidentiality . . .
> Moderator: Yeah.
> P12: . . . and handling that is very difficult. The most crude way to handle it is to fend people off and say "I can't talk to you because is confidential." Then nobody wins. Including in research and not just, you know.
> Moderator: Do people share this view about confidentiality?
> P15: Yeah.
> P13: Yeah.
> P14: Oh yeah. Absolutely.
> P15: In a big way. [laughs]
> P14: And it is a big way because I think, sorry, sorry [P15], I think, I think because we see our loved ones in the most vulnerable position, and there's nothing we can do about it because of confidentiality.

Overall, carers' strongest hope was for the development of effective interventions which might help their cared for to recover and live a flourishing life. According to carers, three elements would be necessary to achieve this: (1) timely and accurate diagnosis, (2) effective medications, and (3) effective prevention. First, diagnoses should be timely and accurate:

> P6: Now my son, my son wasn't diagnosed until things went very very bad when he was 18, that's when he really went haywire. But, in a way, his diagnosis was a blessing, because I understood why all this had been going on ever since he was a child. Lot of things happening. Where were the people to identify that?

Second, and most importantly, carers' strongest hope was that neurobiological research and technological innovation might produce interventions that are effective in treating psychotic disorders:

> Moderator: What would be the thing that is most needed?

> P14: Well, to find out what causes mental illness. [laughs, other participants agree] You find out what causes it then, you know, then we can get an action plan together about what you can do to treat it.

This includes developing better medications. Antipsychotic medications were generally perceived by carers as too burdensome for their ill relative. Carers described prescription of antipsychotics as a "trial and error" process carried out by psychiatrists at the expenses of their relatives' quality of life. They hoped that a greater understanding of the neurobiology of psychosis might improve accurate prescription in the future.

Third, particularly when discussing the case vignette, carers expressed hope that effective prevention of psychotic disorders in general and of crisis events in particular be put in place:

> P9 [discussing vignette]: So, if I was Tom, yes, I would like to think, knowing what I know now, I would grab everything that was offered to me [participants agree] with a view to stopping anything happening. . . . If I was David, I would be pressing my son, "look at me! Is this what you want for your future? Or, can we stop this happening?"

At the same time, several participants specified that prediction of psychotic illness would be useful *only* if effective intervention was available, thus subordinating accurate prediction to the availability of appropriate intervention:

> P9: If you are going, if you're going to be able to give me something that is going to, stop, schizophrenia or bipolar or whatever it's going to be, why, do you want to live with that knowledge, um, if there isn't anything positive on the horizon?

Carers recognized that some benefits might derive from psychosis prediction and risk identification when these are supported by novel technologies, as discussed in the case vignette. Such benefits were generally linked to the extension of individual choices, both for patients as for their caregivers:

> P2: Well, it could give us the choices and chances . . . [one participant agrees] I mean, at least, we would have the choice, take the blood test to see if, if you, if you can pass it on, or you've got it, to a different degree. And I mean, at least, they deny us any choices with mental illness. And it is illness, it's not just emotional problems. And, we are just denied choices.

Fears

Not only did carers voice their needs and hopes. Their reaction to future scenarios was ambivalent. Carers feared that technological innovation might exacerbate moral challenges in mental health and eventually produce more harm than benefits. First, participants argued that poor treatment of mental illness has high societal costs, which are often borne by informal caregivers. At the same time, carers were sceptical that technological innovation could be easily implemented in mental health services because of the structural lack of funding:

> P1 [discussing vignette]: But can I just tell, it feels to me cloud cuckoo land that anyone gets that level of service. [laughs] Do you know what I mean? [participants agree] And so, it would be wonderful, I mean, you've talked about things and may—when you're in the inside you know where few people get these sorts of treatments, but the sense to me is, there's millions of people banging on the door for help and get turned away, there's people [participants agree], you know what I mean?

Carers also identified a number of other hindrances to the implementation of (research on) technological innovation. Despite expressing their need for effective prevention (as described above), several participants were sceptical that prevention and prediction of psychotic disorders might be even possible. Carers also argued that young people are very difficult to engage in neurobiological research:

> P14: When I think about my son's perspective, that's a different bargain. At least, well, I think he's very wary of anybody that tries to intervene with his way of thinking, at certain times. So, I remember when he was quite young, actually, probably in his early, maybe 18, early twenties, and it was suggested that maybe he goes to some kind of brain scan, and he saw that as a, as a real intrusion. You know, how dare you? You want to pick, literally pick my brains, and examine them.

Further, carers worried about two potential sets of harms when discussing future developments as described in the case vignette. First, carers worried about the risk to medicalize adolescents' behavioural difficulties and to over diagnose psychotic illness:

> P6 [discussing vignette]: Tom being 17, um, I can't really see anything that's, what's wrong with, when you spend time alone when you're an adolescent? It's just about the time, when there's a lot going on, you know identity formation, and although I think that a lot of heavy mental constructs are going on at that time. I would actually be careful about exposing Tom to even the suggestion.

Second, carers worried about the burden of research on young people and about the iatrogenic effect that such burden could have on them:

> P3 [discussing vignette]: So, I mean, it's kind of very tricky especially at age 17. I know, when my son was 17 he didn't realise he had a problem, and "what am I talking about? You're talking about going to the hospital. Why are the early intervention team here? What you doing, are you trying to lock me up?" It's been terrible. Absolutely terrible. So, if he does do it, that's good for him. But, I find it very challenging that a 17 year old would volunteer to do it. It'd be good for him if he does but, as I said. And all these things with blood tests, and, how can they afford to do all that? Is he a guinea pig then in here? Because, I said, he's starting psychosis, he's in transition. His "possible transition to psychosis" so he's actually being treated for the possibility of having psychosis. The possibility.

> P9 [discussing vignette]: I think it would make somebody mentally ill. [Participants loudly agree] The stress trigger.

Discussion

These findings highlight carers' demand for novel research and effective interventions. Yet, what moral challenges arise from the convergence of neuroscience, next-generation genomics, and data science in tackling psychotic illness?

Interestingly, some key topics that characterise the ethics debate were absent from carers' discussion. Carers rarely, if ever, mentioned mental capacity. Individuals who suffer from psychosis do not automatically lack capacity to make decisions on research and care (Appelbaum, 2006, 2007). However, the issue of mental capacity—governed in England and Wales by the Mental Capacity Act 2005—represents the framework that regulates care decisions and access to research in this jurisdiction. Thus, one would expect capacity to play a prominent role in the discussion of ethical concerns. This did not happen. Coercion and involuntary hospitalisation were mentioned by participants, but only in relation to their experiences and to feelings of moral distress. Further, the ethics debate on clinical neurosciences and psychiatric genomics is often focused on how to handle neurobiological information: returning results to research participants (Lazaro-Munoz et al., 2018), managing unsolicited neuroimaging findings (Racine & Illes, 2007), and data sharing (Information Commissioner's Office, 2017) are amongst the most debated issues in current ethico-legal literature. Such issues were almost absent from carers' discussions in this study.

Why is that so? One possible reason could be the design of this study, which investigated carers' perceptions of moral challenges by asking carers general question and by reflecting on a case vignette. Carers were not asked directly about the issues mentioned above, and therefore they did not mention them. This is a possibility. A second explanation could be that carers are lay members of the public. They are not ethics and legal experts. Thus, they might not be aware of many complex ethico-legal issues. This is also a possibility. However, a different hypothesis can be grounded in this study's data: carers' narratives may reveal a *different outlook* on the moral challenges of technological innovation in psychiatry. Given the specific viewpoint from which carers reflect and operate, I argue that this outlook can be best understood by referring to an ethics of care.

The moral life of the carers who took part in this study was dominated by the interplay between anger, hope, and fear. Carers face many challenges in the everyday practice of caring for their ill relative. Some of these challenges and the emotional struggle carers have to endure are well documented in qualitative literature, and they are mirrored in the results presented here. Carers' relationship with mental health professionals is often conflictual, and carers' feel that their competence is not recognised (Angermeyer et al., 2003, p. 595; Cree et al., 2015, pp. 6–8). Confidentiality is perceived as a barrier to effective communication and as a tool used by the medical profession to exclude carers from treatment decisions (Askey et al., 2009, p. 312; Wainwright et al., 2015, p. 111). Carers strive for a clear diagnosis and for an increased understanding of psychosis (Wainwright et al., 2015, p. 109). They demand timely and effective interventions (Askey et al., 2009; Hickman et al., 2016).

The emotional ambivalence—anger, hope, and fear—represents the background against which carers conceptualise ethical issues in technological innovation. I argue that this emotional ambivalence towards technological innovation has epistemic value: it allows us to identify (some of) the care needs of those who suffer from psychotic illness.

Care as Practice and Value

The epistemic value of the results of this study can be best recognised within an ethics of care. More precisely, I did not use care ethics deductively as a lens to shape the focus groups or to inform theme generation during data analysis. Themes were developed inductively from the data to capture the arguments expressed by participants. However, it became apparent during data analysis that the moral outlook revealed by participants—and this outlook's epistemic value—could be best recognised by referring to care ethics.

The practice of care starts with the recognition of the other's needs. Caring implies "taking the concerns and needs of the other as the basis for action" (Tronto, 1993, p. 105). How can the convergence of neuroscience, next-generation genomics, and data science be beneficial to individuals who suffer from psychosis? Participants in this study suggested that technological innovation could be beneficial *only* if we identified the real caring needs of those who suffer from psychosis. They recognised the value of neurobiological research and biomedical innovation. Yet, they seemed to argue that any research that can produce prevention and effective interventions is important, so long as it helps to respond to the needs of their ill relatives. On the contrary, harms can derive from neglecting such needs, and from not considering the personal and social circumstances in which technological innovation takes place. Carers were angry at their present situation. They hoped for and demanded an improvement in their relatives' treatment, but also feared that technological innovation might worsen their relatives' situation.

Carers' expertise consists precisely in holding this knowledge—they know their cared for's needs—by virtue of their position and of the caring values they cultivate. In the words of Virginia Held (2006), "the central focus of the ethics of care is on the compelling moral salience of attending to and meeting the needs of particular others for whom we take responsibility" (p. 10). Carers' claimed knowledge of their relatives' needs might at times clash with what their relatives actually *want*. Carers might want better interventions while their relatives might want more independence (Noble & Douglas, 2004). Yet, this does not invalidate the epistemic value of carers' perspectives. Carers might at times not know what their relatives want, but they *care about* them and *take care of* them. In doing so, they put their relatives' needs at the centre of their reflections and demands. Carers might get their relatives' wishes wrong but they wish their relatives' needs to be met.

Adopting such an approach poses a challenge to ethics scholarship. Should we frame the ethics discourse by taking into account carers' suggestions?

Let us consider prevention and prediction. According to carers, prevention of psychotic disorders is needed. Carers seem to suggest that the real moral challenge of psychosis prevention does not consist in whether or not this might be beneficial (Appelbaum, 2015). Rather, psychosis prevention presents a different moral dilemma. Effective prevention is needed, but at what cost? Further, would psychosis prediction be truly beneficial if no appropriate intervention were available? Are the risks of over-diagnosis, medicalisation, and the burden on young people that characterise psychosis prediction and risk identification acceptable? More precisely, carers suggest that the discourse around benefits and harms might be missing something important. Structural problems in the conduct of research and in the delivery of mental health care must be addressed if we wish that technological innovation—and the increased understanding of the neurobiology of psychosis that comes with it—can really transform the lives of people who suffer from psychosis. The discourse around benefits and harms risks neglecting the social contexts where technological innovation takes place. In order to begin addressing these structural problems we ought to start adopting a *caring* perspective.

In other words, carers seem to suggest that we ought to start taking people's needs seriously. This was evident in the case vignette discussion: there is little doubt that early intervention and research that could yield more effective prevention strategies, and better prediction tools are needed and would be welcome. Yet, if we neglect (young) people's needs and their embeddedness in a social context, we risk, at best, not being able to engage these individuals and, at worst, having a negative impact on their lives. These reflections point us to what Joan Tronto (1993) has called *attentiveness*: the capacity to be attentive to the needs of others as an ethical requirement of care (p. 127).[5] Carers' position and the values they hold allow them to recognise attentiveness as an important moral challenge beyond traditional ethical issues in neurobiological approaches to psychosis. If we are *not* attentive to people's needs and to their situation, the risk is that technological innovation might do more harm than good and that it might exacerbate, rather than solve, people's problems.

Care can be understood as practice and as value (Held, 2006, p. 29). This study suggests that, whilst promoting treatment in the community, we should take into account the actors who take responsibility for such caring practices and the values they hold. Again, the issue of confidentiality can be taken as a good example of this dynamic. Confidentiality is perceived as a conflictual ethical issue because it does pose a moral conflict: respect for patient autonomy conflicts with carers' need to be involved in research and treatment decisions (Szmukler & Bloch, 1997). An uncritical focus on autonomy might not provide appropriate avenues to solve this conflict, especially in mental health care. Even when they retain their capacity, carers' ill relatives are not aloof from their carers, as their actions are embedded within a caring relationship. Not recognising this fact means, at least, disrupting the caring relationship. Care ethics poses a serious critique to liberal individualism by promoting a relational theory of the person (Held, 2006, p. 13). A relational interpretation of autonomy might help to solve the issue of confidentiality in mental health.

More precisely, carers recognise that confidentiality is an important ethical requirement of research and care; they recognise that their relatives are entitled to confidentiality. Yet, they claim that professionals' uncritical reference to autonomy in enforcing confidentiality risks disrupting their caring relationship. Carers suggest that we might have to revise our ethico-legal frameworks surrounding confidentiality. The community treatment model places substantial caring responsibilities on informal caregivers. Hence, we might have to devise strategies so that caregivers have access to essential information, whilst upholding the principle that patients ought to be able to build a trusting relationship with the medical profession. A "relational autonomy" model might give us the necessary room to allow those carers who play a substantial caregiving role to access information that is relevant to fulfilling their caring responsibilities. Carers might have to negotiate the appropriate "access level" with their cared for and with the medical profession. Yet, some room for negotiation appears to be precisely what carers in this study were requesting.

Lastly, this study suggests that carers' demands are not only ethical, but also political. Carers demand a substantial restructuring of how society deals with mental illness in recognition of the value of caring. This principle must accompany technological innovation in mental health. As Tronto (1993) has claimed, carers' anger emerges from

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[5] *"If we are not attentive to the needs of others, then we cannot possibly address those needs. By this standard, the ethic of care would treat ignoring others—ignorance—as a form of moral evil" (Tronto, 1993, p.127). See also Held, 2006, p. 39.*

their struggle to separate their own needs from the needs of those they care for, where resources are insufficient (p. 143). Carers' rage, their hopes, and their fears might help us to translate technological innovation into psychiatry so that individuals who suffer from psychosis might effectively benefit from it.

Conclusions

Technological innovation has the potential to transform the care of people who suffer from psychotic illness. Novel interventions, effective medications, and accurate prevention strategies and prediction tools are likely to result from an increased understanding of the neurobiology of psychosis, fueled by the convergence of neuroscience, genomics, and data science (Thompson & Broome, 2020). The findings of this study suggest that carers of people who suffer from psychosis can provide an interesting outlook on the moral challenges arising from this endeavour. This outlook is narratively rich and epistemically valuable. Given carers' vital role in supporting treatment in the community, their narratives are an essential source of knowledge for bioethics. This study further suggests that carers' conceptualisations of ethical challenges may not be necessarily focused on the traditional issues of capacity, coercion, and management of neurobiological information. This does not mean that such issues do not deserve the attention usually granted by bioethicists. Rather, I argue that bioethics could greatly benefit from acknowledging carers' expertise in framing the ethics debate.

According to carers, research and care ought to move forward. Because now they are not moving forward. Because their relatives' poor quality of life requires that research and care move forward. More precisely, carers *demand* that research and care move forward. A clearer understanding of the neurobiology of psychosis could help psychiatric research and mental health care to move forward. It could help to ameliorate the lives of people who suffer from psychosis, mitigate carers' frustration, and support them in their caring role. Yet, it could also result in over-diagnosis, medicalisation, and excessive burden on (young) patients and service users. According to the participants in this study, which way it goes will depend on whether the needs of those who suffer from psychosis are appropriately met.

In this sense, carers' outlook on sensitive bioethical issues can be best understood by referring to an ethics of care. Not only do the findings of this study suggest that carers' moral outlook is an essential source of knowledge on the ethics of technological innovation. This study also suggests that we must reflect on the moral value of care so that we might successfully incorporate carers' perspective into ethical theory. Care ethics appears to be an important theoretical framework to inform such understanding of care, to recognise the epistemic value of carers' perspectives—which is grounded in their particular position and in the values they cultivate—and to reaffirm carers' vital role in shaping mental health research and psychiatric care. Carers' vital role precisely consists in helping to make sure that their relatives' needs are assessed, understood, and met. As carers argue, taking people's needs seriously is essential to ensure that technological innovation can positively affect our response to severe mental illness.

Data Availability

The data supporting the findings of this study are not publicly available because they contain information that could compromise the privacy of research participants. The data may be made available by the corresponding author upon a reasonable request from a bona fide researcher in order to validate the reliability of data analysis.

Ethics Approval and Consent to Participate

The ELSI-NAPS study was granted favourable ethical opinion by North West—Greater Manchester South Research Ethics Committee, REC reference number: 17/NW/0315. All participants provided written informed consent prior to taking part in the study.

Consent for Publication

This article contains aggregated anonymised demographic data and anonymised quotations from participants in the ELSI-NAPS study. All participants provided written consent to the use of information about them in anonymous form to support other research in the future. All participants also provided written consent to the use of anonymous quotations collected for the study in scientific publications.

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Focus Group Guide

Sessions	Questions
Warm up (20 mins)	Recent years have seen the development of novel medical technologies. These include neuroimaging (brief description) and genetic techniques. Researchers are currently trying to understand the biological processes related to psychotic experiences and schizophrenia. This does not mean that psychosis or schizophrenia are just biological conditions. As we know, psychotic disorders involve at the same time biological, psychological and social factors [put emphasis]. However, a better understanding of the biological processes could help provide better diagnosis, prognosis and treatment options to patients and service users. – How many of you are familiar with what I am describing? [show of hands]. – If people raise hands, enquire: In general, what are your thoughts about this approach to psychotic disorders? ○ *Possible probes*: – How do you understand psychosis / schizophrenia? – If you were to describe psychosis and schizophrenia to someone who does not know what it is, how would you describe it? – If people do not raise hands: ○ describe a bit more in depth neuroimaging and genomics ○ promote engagement with participants – What do you feel could be the arguments for justifying conducting this kind of research? ○ *Possible probes*: – Help understand the condition? – Help patients / service users understand their experiences? – Identify an appropriate diagnosis? – Enable early detection? – Improve prognosis? – Improve clinical outcomes? – improve treatments available?
Focusing exercise: vignette (30 mins)	Now I would like us to do an exercise altogether. I will distribute a vignette, which describes an imaginary case scenario. I would like you to read the vignette, and then we will have a discussion and go through some questions together. Please, remember that there are no right or wrong answers. Also, remember that you can feel free to say whatever you want. – Distribute vignette – Allow time for people to read the vignette (approx. 5 minutes) – Open up and lead discussion (approx. 25 minutes) **[The vignette has been inserted in the text file so it is not reported here]**

Sessions	Questions
Exploration of common ethical issues (20 mins)	– How would you feel if there was a way to assess your risk of developing a psychotic disorder without you having any symptoms, just based on your family history and biological measures? – Would you be interested in knowing that? Why / why not? – Would you be interested in knowing for your children? Why / why not Now I would like to explore with you some common ethical issues. – What impact do you think that measures such as the ones we have described could have on the way patients / service users see themselves? – What would be your reaction if a person you take care of were to have a brain scan or a blood test performed for assessing the risk of developing a psychotic disorder? ○ *Possible prompts*: Interest? Curiosity? Fear? Anger? We know that having a psychiatric diagnosis, or even attending a mental health service can generate social stigma towards patients and service users. – Has anyone experienced social stigma towards the person you take care of? What was your reaction to that? – Do you think that a stronger focus on the biological aspects of psychotic disorders would *increase* or *decrease* stigma? Why? The implementation of neurobiological approaches to psychosis could result in improvements in formulating a diagnosis. Some people think this would result in *labelling*. – Do you think that a diagnosis based also on biological factors would be beneficial to patients / service users? Why / why not? – Do you think patients may understand this as if they have a "brain condition"? – Do you think that "giving a name" to psychotic experiences can help people cope with their conditions? Why / why not? – Do you think that this could lead to an increase in self-stigma in patients or service users? Why / why not? – Do you think that having a more accurate name for a psychiatric condition may improve engagement with mental health services? Why / why not? – What about compliance with medications? Why / why not? – If you think back about what we have discussed, how do you think this could affect family life? Can anyone give me an example? – How do you think this would affect your relationship with the person you take care of?
Questions from participants & Closing (10 mins)	That was the last topic I wanted to discuss with you. If there is anything that was not covered during the focus group, and that you would like to discuss, please feel free to tell me. Allow time to answer potential questions from FG participants Thank participants for their participation in the study and for taking the time to answer all the questions. Briefly explain what will happen to data, and provide means to re-contact the research team.

Coding Manual

ANGER:

Frustration:	*Carers' frustration towards their and their cared-for's condition*		
	At medical profession:	*Frustration towards medical profession and mental health service provision*	
	At research:	*Frustration towards the ineffectiveness of medical research on psychosis / schizophrenia*	
	Lack of social support:	*Lack of social support for carers and for individuals suffering from psychosis*	
	Coercion and moral distress:	*Experiences of coercion / involuntary hospitalisation of cared-for and link with carers' moral and psychological distress*	
	Expert role of carers:	*Carers' expertise in caring for a person with a psychotic disorder is essential and should be valued by medical profession*	
Stigma:	*Carer's experiences and conceptualisations of social stigma*		
	Blame on parents for illness:	*Parents' blame and self-blame towards cared-for's mental illness*	
	Carers' shame / fear of social judgement:	*Carers' shame of their family situation and fear of social judgment*	
	Experiences of discrimination:	*Carers' and cared-for's experiences of discrimination due to mental illness*	
	Stigma and fear related to diagnosis:	*Social stigma and fear related to mental illness depend on labelling and are related to diagnosis*	
	Frustration at "politically correct":	*Carers' frustration towards "politically correct" initiatives / language to reduce stigma*	
	Media as drive of social stigma:	*Media perceived as a main drive of social stigma around mental illness*	
	Need for education on social stigma:	*It is necessary to educate the public around mental illness in order to tackle social stigma*	
	Stigma and neurobiology:	*Connections between social stigma and neurobiological understandings of mental illness*	
		Research in general can reduce stigma:	*Any improved understanding of the nature of mental illness can reduce social stigma*
		Neurobiology could reduce stigma by removing blame:	*Neuroscience and genomics could remove responsibility towards mental illness, and thus reduce stigma*

Understandings of illness:	*Carers' understandings of the nature and aetiology of psychosis*		
	Psychosis is (not) an illness:	*Carers' ambivalence on the idea that psychosis is / is not a form of illness or a medical condition*	
	Schizophrenia just a collection of symptoms:	*Schizophrenia does not exist as a discrete condition. It is only a collection of symptoms*	
	Right understanding is biological / biopsychosocial:	*The correct model of psychosis is a biological model, or a model that takes into account the biological components of illness*	
	Diagnostic system is flawed:	*The psychiatric diagnostic system does not reflect the reality of mental illness, it is a collection of arbitrary labels*	

HOPES:

Need for effective intervention:	*Carers' need for effective interventions that can cure / increase the quality of life of their cared-for*		
	Timely and accurate diagnosis:	*Timely and accurate diagnosis is essential to effective intervention and care*	
	Effective medication:	*Need for more effective medication with less severe side effects*	
		Medication is currently trial & error:	*Prescription of medication for psychosis is arbitrary and not targeted*
		Neurobiology may support accurate prescription:	*A greater understanding of the neurobiology of psychosis could support accurate prescription*
	Effective prevention:	*Effective prevention of psychosis and schizophrenia is essential*	
		Prediction useful only if intervention available	*Prediction of psychosis and schizophrenia is useful only if appropriate intervention is available*
Strive for knowledge / understanding of illness:	*Carers' demand for an increased understanding of psychosis and psychotic disorders*		
	Research has vital relevance:	*Any form of research on psychosis has vital relevance to support care*	
	Fair access to research / treatment:	*Individuals who suffer from a psychotic disorder deserve better access to research and treatment (justice requirement)*	
	Peer-support groups are vital to carers:	*Peer-support groups are vital for the well-being of carers*	
Communication:	*Need for effective communication carers / cared-for / medical profession*		
	Detailed information on research to carers:	*Carers have a right to be informed of relevant research opportunities for their cared-for*	

	Careful communication (on research) with participants:	*Careful communication with individuals with psychosis, both in research and care, is required from researchers and mental health professionals*
	Confidentiality as a barrier:	*Confidentiality is a barrier to effective communication and effective care. Confidentiality is often used by professionals as a tool to exclude carers from information / treatment decisions*
	Effective communication with mental health professionals:	*Effective communication between carers and mental health professionals is paramount to support patient care*
Benefits of psychosis prediction / risk identification:	*Psychosis prediction and psychosis risk identification may produce clinical and personal benefits*	
	Impact on patient's life choices:	*Psychosis prediction and risk identification could positively affect patients' life choices*
	Extension of individual choices:	*Psychosis prediction and risk identification could extend the spectrum of life choices of people who (may) suffer from mental illness*
	Increased hope towards recovery if effective intervention:	*Psychosis prediction and risk identification could increase hope towards recovery if effective intervention was available*

FEARS:

Resources:	*Research and interventions must face a structural lack of resources in mental health services*	
	No money for new technologies:	*There might be no money to implement new technologies in research and care*
	Poor treatment has societal costs:	*Poor treatment of individuals who suffer from mental illness has great societal costs*
Harms of psychosis prediction / risk identification:	*Psychosis prediction and psychosis risk identification may harm individuals*	
	Prevention (prediction) of schizophrenia is not possible:	*Effective prevention or prediction of schizophrenia via neuro-technology or other methods is not possible*
	Risk of medicalization and over-diagnosis:	*Psychosis prediction and risk identification could exacerbate medicalization of mental illness and result in over-diagnosis*
	Burden on (young) individuals / iatrogenic effect:	*Psychosis prediction and risk identification could be psychologically and morally burdensome to (young) individuals. At worse, it could increase the likelihood to suffer from mental illness (iatrogenic effect)*
	Young people difficult to engage in research:	*Young people are difficult to engage in research on psychosis prediction / risk, mainly for fear or incapacity to appreciate the importance of research.*

CASE STUDY

Phantom Physicians and Medical Catfishing: A Narrative Ethics Approach to Ghost Surgery

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Abstract. The concerns raised by ghost surgery, an unethical practice in which someone other than the surgeon who obtains consent performs an operative procedure without the patient's knowledge, have long been ignored by bioethics and other related disciplines. Indeed, ghost surgery is neither tracked nor studied in the United States, and the practice itself remains underreported. Ghost surgery represents a corporeal transgression as well as a relational rift: what was communicated by physicians is rendered null and void, and the surgical narrative that patients thought they knew is disrobed as a lie and revealed to be a catfish. In order to combat this practice and prevent any form of medical catfishing, physicians must guarantee effective communication and transparency and view themselves as storytellers alongside their patients. By following such a framework, physicians can ideally end the simulation and suture an ethic of accountability within a co-constructed narrative.

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Keywords. Ghost Surgery, Narrative Ethics, Accountability, Catfishing, Medical Harm

Introduction

On the afternoon of February 14, 2018, my grandfather underwent a transcatheter aortic valve replacement (TAVR), a minimally invasive procedure to resolve his gradual aortic stenosis. For the past month, my grandfather had been meeting and communicating with Dr. B., an experienced cardiothoracic surgeon in our local area who would be performing the procedure.

Dr. B. was affable and energetic, welcoming my grandfather into his office with open arms and a wide smile during every visit. He was more than optimistic about my grandfather's prognosis; with no other chronic diseases or comorbidities, my grandfather was "the perfect patient" for the TAVR. On the day of the procedure, Dr. B. was dressed in scrubs as he first met with my family and then wheeled my grandfather to the operating room, both of them jocular and at ease. As we sat in the waiting room, nothing seemed out of the ordinary.

But we were soon notified that a severe surgical complication had occurred: the artificial valve had been successfully placed but my grandfather's left ventricle had been perforated during the process. This adverse event, we were told at the time, has less than a two percent chance of occurring during the TAVR. The news came as a shock: Dr. B. had only discussed benefits and improvements related to the procedure with us, never any potential risks, complications, or even alternatives. To be fair, we had never asked him either. When we demanded to speak directly to Dr. B. after receiving the news, we were begrudgingly informed that he was not in the hospital—in fact, Dr. B. had departed once he took my grandfather to the operating room, and some other surgeon had performed the procedure without our consent and committed the surgical error.

During the ensuing chaos, Dr. B. informed us that there had been a "misunderstanding" on our part, that we as a family had "assumed" that he would be performing the TAVR. Years later, I cannot help but believe that everything before the date of the procedure—the pre-operative evaluations, the office visits, the warm conversations—was purposely deceptive. We had been catfished, lured under the guise of an intimate and trusting relationship in the clinical setting, and my grandfather paid the ultimate price as the victim of ghost surgery.

A Brief History of Ghost Surgery

Ghost surgery occurs when someone other than the surgeon who obtained consent performs an operative or invasive procedure without the patient's knowledge. Contrary to what might be expected, these bait-and-switch practices occur in institutions other than teaching hospitals and involve healthcare professionals other than residents. Indeed, the ghost surgeon in question can include other surgeons, registered nurse first assistants, surgical assistants, and physician assistants (Dunn, 2015). Ghost surgery itself engenders a host of legal implications, and in some cases can even result in billing fraud (Jones, McCullough, and Richman, 2005). First and foremost, however, the practice bypasses informed consent and infringes upon respect for patient autonomy. As Mininder S. Kocher (2002) argues, ghost surgery "flies in the face of case law and violates an individual's right to control his or her own body and violates the person's right to information needed to make an informed decision" (p. 150).

Originally, the term "ghost surgery" referred to instances in which an unqualified surgeon would invite a qualified surgeon to perform the required procedure without the patient's knowledge. The unqualified surgeon would then bill the patient and provide postoperative documentation of the procedure (Holmes, 1980). The term has since evolved to include any occurrence in which a healthcare practitioner is substituted or replaced without informing the patient. This conceptual shift and greater scrutiny were in part due to the 1978 Lifflander Report, which sought to regulate medical care in the state of New York and uncover unethical conduct in surgery (Rensberger, 1978; Holmes, 1980; Dunn, 2015). Today, ghost surgery has largely been denounced and condemned by the organized medical community. The Council on Ethical and Judicial Affairs of the American Medical Association (AMA) has stated that any "surgeon who allows a substitute to operate on his or her patient without the patient's knowledge and consent is deceitful" (2015, p. 324). Similarly, the American College of Surgeons (ACS) has previously stated that "[i]t is unethical to mislead a patient as to the identity of the doctor who performs the operation" (Kocher, 2002, p. 150). It should be noted, however, that the current ACS Statements on Principles (last updated in 2016) no longer explicitly condemn the practice of ghost surgery.

Although ghost surgery is not extensively tracked or studied in the United States (Shelton 2012), instances can still be found in medicolegal history. A 2019 editorial (Epstein) published in *Surgical Neurology International* posits a 1966 court case (*Gray v. Grunnagle*) as one of the first documented examples of the practice in the country, in which the plaintiff received an $80,000 verdict based on lack of informed consent during ghost neurosurgery that left the plaintiff paraplegic. In a 1983 case (*Perna v.*

Pirozzi), the courts ultimately determined that ghost surgery constituted battery, citing the violation of informed consent and respect for autonomy: "Even more private than the decision who may touch one's body is the decision who may cut it open and invade it with hands and instruments . . . Few decisions bespeak greater trust and confidence than the decision of a patient to proceed with surgery" (Bouknight, 2003, p. 1537).

Outside of the United States, ghost surgery has become the focus of immense controversy in South Korea following the deaths of several surgical patients. The Ministry of Health and Welfare has since announced potential legislative revisions to outlaw ghost surgery (Eun-ji, 2019). A 2018 study (Hong et al.) published by the Korean Surgical Society determined that charges of bodily harm, assault and battery, and fraud with respect to ghost surgery could be applied under South Korean law as well. If passed, a new bill submitted by the Democratic Party of Korea would require hospitals to install security camera systems inside operating theaters in order to properly monitor operations and confirm the identities of surgeons involved (Han-na, 2020). Although the Korean Medical Association has issued self-reform measures and advocated in favor of harsh punishments for surgeons and hospitals that engage in unethical practices, the organization has staunchly opposed this bill and claimed it would force physicians to adopt more defensive medical behavior (Eun-ji, 2019; Han-na, 2020). In the United States, however, ghost surgery has yet to receive the same level of attention and discussion.

Although ghost surgery can occur for a variety of reasons, one of the ostensible rationales is the professional obligation to provide residents autonomous experiences in the operating room—despite the fact that ghost surgeons can still include those other than trainees. Ghost surgery thus aligns with the deceptive practice of catfishing, in which an unsuspecting individual develops a relationship, usually over the Internet, "with someone who turns out to be completely different from the identity that they had portrayed" (Lauckner et al., 2019, p. 290). Medical catfishing creates a perceived closeness between physician and patient that is revealed to be a façade. Indeed, ghost surgery represents a corporeal transgression as well as a relational rift: what was communicated by and co-constructed with the physician is rendered null and void, the surgical narrative that the patient thought they knew disrobed as a lie.

Narrative as Immoral Work

The very term "ghost surgery" raises alarm and unease, conjuring an image "of a white-sheathed phantom-like figure sneaking into the operating suite after the patient is unconscious" (Holmes, 1980, p. 412). This description is dramatic yet fitting. Ghost surgery is predicated upon the existence of a phantom physician who cuts into the flesh of voluntarily unconscious patients. This phantom physician remains a specter throughout the clinical encounter, haunting the clinical realm of operating rooms as well as the subsequent lives of affected patients. The revelation of ghost surgery uncloaks a discrepancy between expectation and reality, an incongruency between what was told and what transpired. In addition to breaching the fiduciary patient-physician relationship, ghost surgery precipitates a crisis in regard to narrative.

The discipline of narrative ethics first emerged from within mainstream bioethics in the 1980s, paralleling the development of narrative ethics within the literary field. Unlike principlism, which is primarily used to resolve dilemmas in an applied ethics approach, narrative ethics seeks to emphasize the storytelling aspect at the core of the clinical encounter and better understand the patient's lived experience, focusing on "how that person came to be here and where the path forward might lead" (Irvine and Charon, 2016, p. 119). The patient comes to the physician with a story; the physician listens and apprehends this story; the patient and physician then co-construct the following steps of action on the shared journey of illness and health care. Ideally, such an approach will acknowledge the patient as the primary author of his or her own story while also recognizing and respecting the voices of those whose personal or professional lives are intertwined in this encounter (Jones, 1999).

According to bioethicist Hilde Lindemann (2014), stories within health care are significant since they can enact "many different kinds of moral work"—and in turn, immoral work as well. She explains, "[S]tories don't just represent situations—they can also *mis*represent them. They can distort the moral contours, provide faulty explanations for how the situation came about, feature the wrong collateral events and circumstances while papering over relevant ones, and depict ways of moving forward that would be morally disastrous" (p. S28). The same stories at the heart of the clinical encounter, Lindemann argues, can also be used to perform immoral work and violence against certain parties. This immoral work, for example, can characterize electronic health records that purportedly document medical errors, charts in which physicians must "compose and contribute to successful narratives about mistakes, when success is measured in terms of personal and institutional protection from litigation or in terms of transmitting tribal norms" (Berlinger, 2007, p. 24).

Lapses in obtaining proper informed consent, such as patients being unable to thoroughly read and sign consent forms or surgeons failing to verbally explain the role of their colleagues in the respective operation, can also constitute immoral work. In an interview with *WFAA* (Huffman & Smith, 2019), physician and public health speaker Michael Greger goes as far as to suggest that hospitals and surgeons do not want patients to read the fine print of consent forms, which can explicitly state that residents will be involved in the surgery or contain language that provides leniency for how one can interpret who will be performing the surgery. "The reason they do it that way is to railroad you in. They know you're not going to be reading anything," he argues. "And, of course, you're in no mental state to be going through it. You're being rushed through the process." According to Greger, ghost surgery occurs not because of miscommunication or misunderstanding but because of a deliberate lack of transparency—an intent to not tell the full story.

Two cases of ghost surgery, both of which occurred in 2019, have garnered significant attention from news outlets and highlight the consequences of immoral work. Kathryn Weber, who selected a double board-certified surgeon at the University of Texas Southwestern Medical Center to perform her breast reduction, claims that her ghost surgery left her "mutilated" and "disfigured" after two residents-in-training were involved in her procedure as "assistant surgeons." Weber has since insisted that she never had any verbal conversation informing her that residents may be involved in her operation or that her selected surgeon would act only as a "supervisor" (Huffman & Smith, 2019). Similarly, the Steiger family claims that their disabled son Jack was the subject of a ghost neurosurgery conducted by a second-year resident at the Mayo Clinic in Minnesota (Oliver, 2020). Their selected surgeon reportedly functioned as a "consultant" (Scott & Schmidt, 2020). Both Weber and Steiger experienced various complications after their respective surgeries and, at the time of this writing, have been unable to hold the surgeons and hospitals involved accountable.

Indeed, the relationship between storytelling and immoral work is heightened when explicitly analyzed in the context of ghost surgery. By withholding informed consent, ghost surgery erases the communicated narrative and concocts a new, doctored one in its place. Ghost surgery thus hinges upon two causally dependent narratives: the catfish that is first relayed by physicians and believed by patients, and the reality that then becomes manifest behind the scenes. The discrepancies between these two are cause for concern, as the catfish persona put forth by physicians distorts the truth via omission and obfuscation—an example of what Lindemann calls immoral work. In some instances, this immoral work can be retroactively repaired through honest and transparent communication post-surgery. As nurse Debra Dunn (2015) explains, unanticipated circumstances (such as the surgeon in question falling ill or being called to an emergency) can lead to unintended ghost surgeries in which the surgeon must identify and assign a qualified substitute. The surgeons then have a pressing responsibility to inform the patient about these events postoperatively, and in doing so, can restore a sense of narrative coherency to the patient experience. Such a framework aligns with current guidelines put forth by the ACS as well (2016). When the patient is not given this missing information, however—either before or after the surgery, depending on the case—then the patient finds themselves trapped within a story which they were never told and to which they never agreed while the phantom physician exists outside the story, unseen and unheard. Ghost surgery thus carves out a gaping hole within the patient's lived narrative, a gap that skirts accountability.

The Specter of Physician Accountability

Patients usually discover this "phantom" and become aware that they have been catfished only after something goes wrong during the operative procedure, which can include complications, adverse events, side effects, and iatrogenesis. In this way, ghost surgery and medical harm are inextricably linked: the forced disclosure of ghost surgery almost always necessitates the admission of medical error and unethical behavior (Kweon, 2016; Boodman, 2017; Huffman & Smith, 2019).

But who will be held accountable, and who will accept accountability? Lindemann (2014) proposes that narrative misrepresentation and ensuing immoral work can be avoided through the communal act of co-construction between patients and healthcare professionals. By its very phantom nature, however, ghost surgery precludes co-construction. It is a malconstruction, a clinical encounter built upon a faulty foundation in which stories are manipulated and its purported characters vanished and exchanged without proper explanation. The narrative of ghost surgery hinges upon fungibility: the physician is replaceable and the patient a moveable widget in the non-relational assembly line constructed by the medical-industrial complex. This impersonal dynamic follows the unethical clinical tradition of unsanctioned educational pelvic and rectal exams on anesthetized women and men, respectively, in which patients' bodies are reconfigured—without their knowledge—as tools available for use by medical students and doctors alike (Adashi, 2019). Such practices not only enact violence upon patients but are also a disservice to students and trainees, who may be forced to engage in these behaviors and subsequently internalize them as morally acceptable.

Stories, too, are composed of moving parts. The process of storytelling often avoids a linear arc, disrupted by new developments and unsettled by retrospective revelations. As nurse and bioethicist Christine Mitchell (2014) explains, "[S]tories leave out and may conceal as much as they reveal . . . [Storytellers] choose which aspects to include and invest with meaning on the way from a selected beginning, to a moveable middle, toward an end, inevitably transforming persons into characters and experiences into events" (p. S13). Mitchell designates patients as storytellers and healthcare practitioners as listeners, but the paradoxical reversal of these roles is at the heart of ghost surgery. Indeed, the purposeful narrative concealment on the part of healthcare professionals as storytellers portends Lindemann's greater notion of narrative misrepresentation and immoral work.

Traditional bioethics and health humanities paradigms emphasize that the patient is the primary storyteller; patient-centered care can be achieved by receiving the patient's story with active listening and nonjudgmental communication. And yet, patients are routinely blamed for being unable to fully convey the complexity of their illness, often labelled by physicians as "poor historians" (Charon, 2008, p. 31) in an attempt to compose a more palatable narrative that will be accepted by the medical system. In cases of ghost surgery, however, these diametric positions are reversed: the patient listens to the story of proposed treatment and prognosis while the physician is the unreliable narrator, noncompliant with the plan of care and misrepresenting significant details, events, and characters. Physicians who participate in this behavior not only perpetuate catfishing, but also become "simulation doctors," healthcare professionals who "act out a good relationship to their patients but have no authentic connection with them" (Hanna & Fins, 2006, p. 265). Given the skewed dynamic inherent in the patient-physician relationship, such narrative misrepresentation on the part of the physician does not constitute forgetfulness or therapeutic privilege—rather, as Greger suggests, it is a blatant abuse of power.

If ghost surgery triggers a rift in relationality, then it can only be resolved through a restoration of narrative accountability. Allan Peterkin (2011) first proposed the concept of "narrative accountability" in response to physician writing and other narrative-based practices, which can inadvertently result in "iatrogenic risks" for the patient. Per Peterkin, narrative accountability "has always meant serving the patient first and enhancing learning within the profession second" (p. 397). If "telling stories about patients has had built-in standards of accountability" for physicians (p. 396), then telling stories *to* patients and failing to fulfill communicated roles underlines the power imbalance inherent in the clinical encounter—the threat of simulation, the disconnect between *saying* and *doing*. Here, I expand the term narrative accountability to refer to not only stories written and presented by physicians, but also stories that execute the immoral work cautioned by Lindemann, narratives that implicate physicians, expose unethical behavior, and demand a recognition of wrongdoing. By entering into a relationship with a patient, the physician promises to fulfill a role in the patient's shared narrative. When ghost surgery occurs, the physician fails to uphold that role.

The sort of narrative accountability that I propose represents a synthesis of "backward-looking" and "forward-looking" accountabilities first proposed by clinical ethicist Virginia A. Sharpe (2004), a type of accountability that will exorcise the phantom simulation and construct a genuine, meaningful relationship in its place—a relationship that situates doctor and patient on the same page of lived experience. Backward-looking accountability seeks to assign blame and punishment for certain parties whereas forward-looking accountability seeks to assign goals and objectives for future improvement; narrative accountability, in turn, emphasizes the physician's responsibility to the patient before, during, and after the clinical encounter. If ghost surgery deprives the patient of consent and leaves them with an incomplete narrative, then the physician's ultimate duty is to suture an ethic of accountability by acting as a reliable narrator and carrying out their communicated role.

Conclusion

My grandfather ultimately returned home on his own two feet near the end of August 2018—a much different prognosis than either my family or the hospital care team were ever anticipating. His life and health were forever changed; after suffering a slew of complications that were accompanied by a continued lack of transparency, he was no longer "the perfect patient." My family and I served as his caregivers before he passed away less than a year later from the severe iatrogenic effects that began with the ghost surgery. But during those months that my grandfather remained in the hospital, the ghost surgeon never visited my family or grandfather. He showed his face only once, briefly, on the afternoon of February 14, and never again. During those months, no one ever uttered an apology or admitted any sort of ethical transgression. No one acknowledged the existence or actions of the phantom physician, and Dr. B. conveniently and deliberately avoided any discussion of the ghost surgery itself. To this day, my family and I have never received any proper explanation about why the ghost surgery happened and what allowed it to take place. The matter was never addressed—and yet it lives on, like a ghost.

I cannot help but wonder if the ensuing events would have unfolded differently had Dr. B. and others adopted a narrative ethics approach. As Arthur W. Frank (2014) writes, "Narrative ethics asks first what the problem might be for patients and their families, not for healthcare professionals and institutions . . . [N]arrative ethics is more interested in preventing breakdowns in mutual understanding from happening in the first place than in adjudicating conflicts over preferred courses of action. The primary focus is to prevent situations from turning into cases" (p. S16). By following such a framework, perhaps Dr. B. would have been obligated to inform my family that he would not be performing the TAVR. Perhaps the ghost surgeon would have felt compelled to meet us face-to-face after he committed the error and during the rest of our hospital stay. Or perhaps, I wonder, the ghost surgery would never have even been considered a legitimate option in the first place.

Physicians should view themselves as storytellers alongside their patients, storytellers who have a moral role and responsibility to guarantee effective transparency and "break the silence of the switch" (McAlister, 2015, p. 2479). In turn, the traditional paradigm of storytelling and listening within medicine needs to be reevaluated in order to acknowledge the power imbalance at the heart of the clinical encounter, a gap that necessitates the practice of narrative accountability among healthcare professionals. In order to put an end to ghost surgery and any sort of medical catfishing, physicians must recognize their own privileged positions as not only healthcare practitioners who perform operations on voluntarily vulnerable beings, but also as storytellers who communicate and co-construct with the patients they ostensibly serve.

Discussion Questions:

1) Have you ever witnessed or been involved in a ghost surgery? If so, how could you have prevented it?
2) How can healthcare professionals become effective, transparent, and reliable storytellers with their patients? Is this a matter of personal responsibility, institutional responsibility, or a mixture of both?
3) What can healthcare systems do to ensure greater trust with their patients, especially when patients are not privy to events that occur behind the scenes? How might factors such as race, gender, age, and socioeconomic status affect this relationship?

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CASE STUDY

It Takes Time to Let Go

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Abstract. Futile or nonbeneficial treatment is often a source of contention between care teams and family members of ICU patients. This narrative describes such a case at a cancer center. In the midst of the COVID-19 crisis, the psychosocial team had to act as a bridge between a patient's surrogate decision maker and the care team. In light of COVID-19 visitor restrictions, the psychosocial team, the surrogate/family, and the care team had to respectfully work towards what was best for the patient.

Keywords. Nonbeneficial treatment, COVID-19, Psychosocial team, Values, Goals of Care

> They say a person needs just three things to be truly happy in this world: someone to love, something to do, and something to hope for.
>
> —Tom Bodett

The COVID-19 pandemic has added additional layers of difficulty to the end of life. Many hospitals have limited visitors in order to slow and prevent the spread of the virus, leaving hospitalized patients with limited access to their loved ones. In the past, many inpatient Goals of Care meetings took place organically, but COVID-19 restrictions have eliminated opportunities to have ad hoc bedside meetings with patients and their loved ones. Loved ones permitted to shelter in place at patients' bedsides report feeling "held hostage" without the opportunity to leave the hospital building and feel fresh air and sunshine. The following account is based on key elements of various cases the authors have worked on during the past few months. Some elements were altered to protect individuals' privacy. The account reflects the ethical struggles that are exacerbated when patients' loved ones must make end-of-life decisions without the in-person support of their inner circles and the ability to come and go freely.

Mike and Jo-Anne found each other later in life—two well-educated, cerebral individuals who met at their nondenominational church. They were both searching for companionship after failed marriages. Their union was grounded in mutual respect for one another's independence, and although they were together for several years, they didn't choose to legally marry until Mike had received his initial diagnosis of cancer.

Mike's initial course of treatment included standard chemotherapy, a stem-cell transplant, and investigational chemotherapy. The road was long and hard not only for Mike and Jo-Anne, but also for Mike's medical care team. Although his initial treatment was successful, his cancer returned after two years. Suddenly, Mike was in the intensive care unit (ICU), on life support, with little to no chance of recovery.

Three days before his ICU admission, Mike and Jo-Anne embarked on an 8-hour car journey to attend a routine appointment at the cancer center; they had chosen not to fly due to the dangers of COVID-19 infection, since Mike was already immunocompromised. Little did they know that this would be the final stage of their journey together. Upon arrival at his appointment, Mike was very ill, and his doctors admitted him emergently to the ICU. Mike had febrile neutropenia (a fever and too few white blood cells to combat infections), antineoplastic chemotherapy–induced pancytopenia (too few red and white blood cells due to bone marrow suppression by chemotherapy), anemia (too few red blood cells to carry oxygen), and hypokalemia (a low level of potassium in the blood, which can cause fatigue, muscle cramps, and abnormal heart rhythms). In addition to all this, COVID-19 had to be ruled out. As events unfolded very quickly, Mike and Jo-Anne had not been prepared for his emergent admission to the ICU.

During the COVID-19 pandemic, ICUs around the globe had very strict visitation policies that were normally only relaxed in end-of-life situations, when a patient was actively dying (Strang et al., 2020). These kinds of restrictions complicated the psychosocial care patients received during hospitalization for acute events, and even more so for life-threatening events. Family members have commented on the huge emotional burden of not being permitted at their dying loved one's side, to love them and be loved, to forgive them and to be forgiven (Strang et al., 2020).

Given the novel and evolving danger of COVID-19, Jo-Anne was uncertain about whether she should return home to collect some of her personal belongings; the medical teams were saying that Mike's hospital stay could be long and drawn out. After advocacy by the psychosocial team (social workers, chaplain, and ethicist), the nursing leadership, who were the custodians of the COVID-19 visitation policy, approved a compassionate exception that would allow Jo-Anne to return to Mike's bedside after going home. But this meant that Jo-Anne would essentially agree to shelter in place indefinitely upon her return.

Before Jo-Anne left, she experienced a crisis of trust in Mike's attending physician. In an attempt to explain Mike's grave prognosis, the physician told Jo-Anne that Mike would not survive through the evening. When Mike survived the night, Jo-Anne saw this as proof that his doctors might be wrong about his long-term prognosis, reinforcing her ongoing mistrust of the opinions of the medical team. By the time she returned from her trip home, Mike had been intubated and sedated. As Mike's legal next of kin, Jo-Anne felt the weight of making his medical decisions. He had not completed advance directives and had been reluctant to discuss the possibility of his decline and death with her, stating that they should keep a positive attitude. Nevertheless, Jo-Anne felt clear that Mike valued the health of his mind over the use of his body and that as long as his mind was sound, he would still feel like he had good quality of life even if he needed help performing basic daily activities.

Although Jo-Anne was allowed to reside at Mike's bedside, she was alone and isolated due to the COVID-19 visitation policy limitations. Mike was not allowed any additional visitors, and Jo-Anne was required to stay in the hospital in order to limit her exposure to COVID-19. It became apparent to Mike's psychosocial team that Jo-Anne was struggling. Her isolation was not only a physical reality, but also a mental one. It was hard for the psychosocial team to help Jo-Anne, as she always politely refused counseling and support groups, even virtual ones, stating that her friends were present to her online.

Recognizing that Jo-Anne's support network was far away, the social work counselors tried to draw closer and offer her a shoulder to cry on. Interventions like these are within the scope of social work practice, which emphasizes core values such as the importance of human relationships, the dignity and worth of the person, integrity, competence, service, and social justice (National Association of Social Workers). Thus, the social work team felt obligated to meet with Jo-Anne and learn about her worldview in order to help her navigate this difficult situation. In light of Jo-Anne's unwillingness to open up to support, the social work counselors approached her with unconditional positive regard, an additional tenet of their profession. Unconditional positive regard has been described as the "acceptance of every momentary experience of the other. The good, the bad, and indifferent momentary experiences are accepted with equality" (Bozarth & Wilkins, 2001, p. xii). This meant that they set aside the clamor of the ICU to simply sit and be present to Jo-Anne, allowing her to process her thoughts or remain silent, depending on her needs. Meeting someone where they are is the key to compassionate patient- and family-centered care. Social workers employ empathy when they "tune in to the client's sense of urgency and use [their] senses to fully embrace all the client is feeling and experiencing" (Shulman, 1992, p. 58). After some time, Jo-Anne willingly allowed social work counselors to provide care for her. The counselors were not only instrumental in supporting Jo-Anne, but were also able to help Mike's medical team better understand Jo-Anne's motivations and beliefs. Two weeks into Mike's hospitalization, the medical teams realized that the care he was receiving was likely to be futile, or nonbeneficial from a medical perspective. Brody (1994), a renowned ethicist and physician, argued that it is difficult to define "medical futility" and that any judgment of futility "contain[s] an irreducible value component . . . [which is] not within the exclusive expertise of physicians" (p. 876). Given that medical futility is based on a value judgment (albeit one made from mostly technical perspectives), it is important for the care team to get the input of the patient, the surrogate decision maker (if the patient does not have capacity), and/or the patient's family to ascertain what other values may be at play in their decision making. A multidisciplinary team approached Jo-Anne to better understand her values and Mike's and their goals for treatment. Jo-Anne believed that Mike would regain his full mental and intellectual capacity, and shared that in their view, quality of life was centered on mental and intellectual ability, regardless of physical status. Hence, their hierarchy of values indicated that, from a cognitive perspective, there *was* meaning in the treatment; *inter alia*, it was not futile for Jo-Anne. The psychosocial team shared this with the medical care team and served as an advocate from Jo-Anne's perspective, at least until she was ready to accept that without physical life there can be no cognitive function.

It is important to mention here that the values and preferences expressed by patients and their families have come to play an important part in how care teams approach patient care. Understanding the goals of care, based on value assertions by patients and families, is important and often mandated by local or state laws. In Texas, there has been a definite shift from physician direction of decisions in futile cases, as defined by the Texas Advance Directives Act of 1999 (Fine, 2000), to a recent state law, Senate Bill 11 (85th Legislature, 2018), which supports patient and family preferences (Bruce et al., 2018).

What became concerning for the team was that throughout Mike's ICU stay, Jo-Anne was totally focused on small improvements and was unable to entertain the "big picture" of Mike's continual physical breakdown. This common coping strategy is often referred to as "medical coping" in health care settings. A patient's family member or loved one copes with the greater difficulty at hand by focusing on small measures (e.g., blood pressure, heart rate, and oxygen settings). Often, it is a long process for family members to be able to accept the decline and impending death of a loved one. To this point, despite his being intubated and sedated, Jo-Anne was convinced that Mike was communicating to her that he had no pain, wasn't suffering, and wanted to continue with treatment even though it was not effective. As they witnessed the physical breakdown of Mike's body, the care team had difficulty understanding Jo-Anne's reluctance to accept the inevitable: Mike was not going to survive.

The social work counselors recognized that Jo-Anne and the care team had different perspectives on the value of life and suspected that Jo-Anne was experiencing complicated grief. They were able to explore her complex history of loss, which had been largely unattended to over the years. Her anticipatory grief over Mike was made more difficult by the accumulation of grief over illnesses and deaths she had experienced in her lifetime. The loss of a loved one is the most common—and the most difficult—loss we face. Grief is a complex process characterized by feelings of intense pain and sorrow and by persistent thoughts or memories of the loved one. Complicated grief occurs when a person has experienced multiple losses that they are unable to process. This type of grief is accompanied by difficulties carrying out a normal routine, withdrawal from others and from social activity, signs of depression, persistent thoughts of guilt or self-blame, and feeling that life is not worth living. Unfortunately, Jo-Anne was exhibiting many symptoms of complicated grief, making it hard for her to cope with Mike's situation.

After an additional week during which Mike showed little improvement, members of Mike's medical team expressed concerns about his full-code status, stating that resuscitation would be painful and futile if his heart were to stop. In addition, the medical team worried about Mike's pressure ulcers and other breakdowns of the body that typically happen when a patient has been intubated and immobile for long periods of time. Mike's nurses and other staff members, who were concerned that Mike was suffering, experienced cognitive dissonance and moral distress. They mused that Jo-Anne's intelligence was clouding her ability to see that Mike had been left with an extremely poor quality of life in light of his grave prognosis. At this point, Jo-Anne confided in the social work counselors that she was torn: she herself would not want to live in the condition that Mike was in, but she felt he had clearly communicated to her that he was not in pain and wasn't ready to "give up."

The ICU Goals of Care team was enlisted to help Jo-Anne better understand and begin to process Mike's clinical picture and the likely outcome of his illness. The ICU Goals of Care team consists of the patient's primary medical team, ICU medical team, supportive care medical team, Social Work counselors, management, and a clinical ethicist. The aim of the intervention was to align all the different treating teams' opinions and to present a united message to the patient and/or family. This interdisciplinary team approach was invaluable for communicating to Jo-Anne the gravity of Mike's condition. Given the depth of Jo-Anne's denial, several Goals of Care meetings were held to deliver this information in the most compassionate way possible. Denial is a very common reaction upon learning of a loved one's impending death, especially when the loved one is a significant other and the main source of emotional and physical support. Eventually, Jo-Anne was able to grasp the futility of Mike's treatment, moving away from her previous emphasis on cognition and acknowledging the medical dimension playing out in front of her eyes.

In the last days of Mike's life, the psychosocial team was able to gain Jo-Anne's trust and become a system of support for her. Many hours were spent in conversation and silent reflection with Jo-Anne, remembering Mike's life, all that he had done, and all that he had taught her. In celebrating Mike's life, Jo-Anne was finally able to let Mike go and instructed the medical team to focus on comfort care rather than aggressive life-sustaining measures. After more than a month and a half by his side in the ICU, Jo-Anne agreed to change Mike's code status to do-not-resuscitate and to withdraw life support. The medical team began the process of withdrawing all support from Mike's body. Within two hours of starting the end-of-life protocol, in which life-support mechanisms are slowly weaned away, Mike quietly passed away with Jo-Anne at his bedside, holding his hand and stroking his hair.

This case example illustrates that there is no singular approach a team can take to engage with family members of patients who are, in the opinion of the care team, receiving futile or nonbeneficial treatment. Every patient and family member bring different experiences and contexts with them into the encounter. In the era of COVID-19 restrictions, it is more important than ever for psychosocial teams to provide support to isolated patients and family members in times of acute stress and urgent decision making. As described by Sotomayor and Gallagher (2019), ethicists are often "bridge builders" in difficult conversations. However, this case study illustrates that along with ethicists, the rest of the psychosocial team, including social workers and chaplains, is an integral part of the conversation. They too are bridge builders, especially when a family member has difficulty making decisions due to complicated grief. The entire psychosocial team is an essential bridge between the care team, the patient, and the caregiver, serving as a sounding board for many competing value statements and reminding the care team that different people have different sources of meaning and value in life. Living through the death of one's soulmate is traumatic, and having to do so during a pandemic is even worse. The support from the psychosocial team can never fill the void left by Mike's death, but it eased Jo-Anne's experience of her final journey with Mike by offering a bridge to hope and comfort.

Reflection Questions:

1. What strategies do your psychosocial and medical teams employ to help loved ones with "medical coping"?
2. What impact do you think that COVID-19 has had on the grieving process of loved ones?
3. Do you feel the psychosocial and medical teams' approach to Jo-Anne was effective in moving her through her denial?
4. What other ways could the teams have supported Jo-Anne?

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