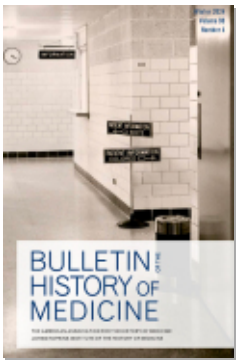
"Just Listen to Us": The Role of Oral Histories in Decolonizing Academic Medicine



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"Just Listen to Us": The Role of Oral Histories in Decolonizing Academic Medicine

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In her seminal work, *The Anti-racist Writing Workshop: How to Decolonize the Creative Classroom*, Felicia Rose Chavez argues that colonialism expresses itself in higher education not only in the ways in which white perspectives are centered and falsely universalized as "neutral," but also in a pedagogical approach based on "the ego of domination and control."[1] By this Chavez means a hierarchical pedagogical style focused on affirming the professor's authority, expertise, and power through structures that disempower students and encourage competition among them. This dynamic plays out *in extremis* in medical education in the United States. It's a field ripe for decolonization.

Biomedical researchers usually think about decolonization as it applies to microbial pathogens such as *Staphylococcus aureus*. In the humanities, colonization and decolonization refer not only to cultural rigidities in North/South socioeconomic and political communities, but also to the way knowledge is imposed on others through imperial relations, including

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1. Felicia Rose Chavez, *The Anti-racist Writing Workshop: How to Decolonize the Creative Classroom* (Chicago: Haymarket Books, 2021), 25.

interrogating why some knowledge is validated or privileged as opposed to other forms of knowledge.[2] *Decolonizing* refers to the process of recognizing how legacies of colonialism, empire, and racism (and other forms of discrimination) have shaped the knowledge systems in which we educate learners.[3] Applied to medicine, decolonization is the practice of deconstructing biomedical systems of knowledge that map intelligence, rationality, criminality, and vitality onto phenotypic hierarchies ordered primarily by skin color,[4] thereby dehumanizing racialized populations and leading to the replication of implicit and explicit discriminatory treatment in the future careers of current trainees.[5] Decolonization offers alternative ways of thinking about the world by recentering perspectives of people historically oppressed and marginalized by these legacies. In this vein, Chavez advocates for "a pedagogy of deep listening" in how we engage with one another, where we are cocreators of knowledge and content and participants in a supportive learning community:

> We invest in one another as complex individuals. We confront the voices in our heads that tell us our stories are unimportant. We honor the sidelined narratives of people of color, women, queer, differently abled, and gender-nonconforming. . . . We listen to one another . . . ever conscious of our body language. We ask questions with the intent to understand instead of retort.[6]

With these principles in mind, we undertook an oral history project to collect local stories of harm suffered by members of the Black communities in the state of Kansas when seeking health care, and to document a community-informed vision for *repair*.

Historians have long debated the utility of oral histories, which gained traction in the sixties and seventies as an alternative methodology to center the voices and perspectives of communities that were usually ignored by the Euro-American-centric white male gaze that had largely defined the field of academic history up to that time. Documentary historians maintained the critique that oral histories rest on a sandy, shifting bedrock of unreliable memories. Memories are said to be unreliable as historical

2. George J. Sefa Dei, *Anti-Racism Education: Theory and Practice* (Winnipeg: Fernwood, 1999).

3. bell hooks, *Teaching to Transgress: Education as the Practice of Freedom* (New York: Routledge, 1994).

4. Ruth Rodney, "Decolonization in Health Professions Education: Reflections on Teaching through a Transgressive Pedagogy," *Can. Med. Educ. J.* 7, no. 3 (2016): e10–18.

5. Amali U. Lokugamage, Tharanika Ahillan, and S. D. C. Pathberiya, "Decolonising Ideas of Healing in Medical Education," *J. Med. Ethics* 46, no. 4 (April 2020): 265–72, http://www.doi.org/10.1136/medethics-2019-105866.

6. Chavez, *Anti-racist Writing Workshop* (n. 1), 17–18.

sources because they can be distorted by deterioration and nostalgia as we age, infused with personal biases that renarrate them over time, and further distorted by collective and retrospective versions of the past.[7] Undergirding many of these critiques has been less-than-subtle racism, sexism, and classism that have stemmed from a resentment that oral historians tended to center the voices of communities of color, women, and laborers. So wedded was the field of oral history to activist causes that famed Yale historian, Marxist, and outspoken Vietnam War opponent Staughton Lynd once referred to the oral history of working-class communities as "guerrilla history."[8]

Despite such critiques, oral historians developed a rigorous methodology that is interdisciplinary in its approach, borrowing from cultural anthropology, sociology, and social psychology. Oral history uses representative sampling to find consistent themes and does not eschew documentary evidence but instead employs mixed methods to combine both. Given this foundation, we find oral history perfectly suited to the work of decolonization.

In May 2020, the murder of George Floyd by Minneapolis police proved a tipping point for motivating academic institutions to support antiracism scholarship and pedagogic interventions. A string of police and vigilante murders of Black Americans, dating back to the killing of Trayvon Martin in 2012, led many universities and professional societies to issue statements committing to racial justice. In response, in 2021 the University of Kansas Medical Center (KUMC) adopted the REPAIR Project (REPAiring Institutional Racism)—an initiative born at the University of California, San Francisco[9]—as a unifying theoretical framework for coordinating institutional trainings, continuing education, community collaboration, and antiracism curriculum throughout the university.

The REPAIR framework is grounded in one question: How can academic health centers (AHCs) *repair* the harms caused by centuries of neglect, exploitation, and abuse in clinical encounters, and by biomedical systems of knowledge that have justified this mistreatment of persons of color by propagating and upholding theories of race, racial difference, and racial inferiority? The REPAIR framework explicitly recognizes that European and American doctors played a central role in giving *race*—which began as a religious-cum-natural philosophical concept in the sixteenth

7. Alistair Thomson, Michael Frisch, and Paula Hamilton, "The Memory and History Debates: Some International Perspectives," *Oral Hist.* 22, no. 2 (1994): 33–43.

8. Peter Novick, *That Noble Dream: The "Objectivity Question" and the American Historical Profession* (Chicago: University of Chicago Press, 1988), 432.

9. See https://repair.ucsf.edu/home.

century—a *veneer* of biology, thus helping to naturalize the social hierarchies and health inequities that arose due to colonialism, by placing them in a discourse of biogenetic determinism.

We undertook the challenge of "repair" with the acknowledgment of new and emerging social theory in Indigenous studies that troubles the concept of repair in contexts where the material conditions for returning to a preharm status may no longer exist,[10] especially in situations in which the harms committed led to losses of life. This acknowledgment also includes insights from critical disability studies scholars who have long critiqued distinct but interrelated concepts such as repair, rehabilitation, and cure in biomedical contexts.[11] Each activity, training, and learning module developed under the REPAIR framework is structured to meet one or more of four pillars within the theoretical framework. These pillars are used to guide the development of new research, inform institutional policies and practices, and enhance community engagement:

1. The **history** of the role of biomedicine in perpetuating racism and reinforcing theories of racial difference and racial inferiority
2. **Decolonizing the health sciences** from bench to bedside, including deconstructing the use of race as a proxy in medical decision making
3. **Action**: developing strategies to address structural racism and other isms from a socioecological perspective
4. **Accountability**: envisioning how the field of biomedicine can **repair** these harms

REPAIR Project antiracism efforts at KUMC fall into four categories, each linked to one of the above pillars of understanding: curriculum development, faculty/staff educational development and training, clinical interventions to eliminate local health inequities, and community accountability. To work toward full community accountability, we are engaged in an oral history initiative called Envisioning Racism and REPAIR—An Oral History and Photovoice Project. The aim of this component of REPAIR is to gather local stories to better understand the individual, family, and community harms caused by racism in health care and identify what AHCs can do to repair those harms.[12] The project employs community-based

10. Federico Lenzerini, ed., *Reparations for Indigenous Peoples: International and Comparative Perspectives* (Oxford: Oxford University Press, 2008).

11. Eli Clare, *Brilliant Imperfection: Grappling with Cure* (Durham, N.C.: Duke University Press, 2017); Eunjung Kim, *Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea* (Durham, N.C.: Duke University Press, 2017).

12. Felicia Rova-Chamroeun, "Decolonizing the Narrative: Preserving Oral History in a Diasporic Community" (master's thesis, University of Washington, 2020).

participatory, oral history, and visual ethnography (photovoice) methodologies to collect the stories and the directives for repair.

Methods

Because of the sensitive nature of the stories, because some memories can evoke painful emotions, and because of a history of racism at KUMC that has led to community mistrust, we identified six priorities for design and implementation to prevent this project from being extractive, exploitative, and replicating harm:

1. That the interview sessions be community-led. To facilitate trust and to build rapport during interviews, we committed to partnering with trusted community members to facilitate each interview session.

2. That all community members be fairly compensated for their time and expertise. We secured private philanthropical and institutional funding to pay community facilitators fifty dollars per hour for undergoing training and facilitating discussions. We also catered each group interview session and gave each participant a twenty-five-dollar gift card.

3. That the stories be community owned. Addressing expressed community fears that any honest account of past harms might be buried by the institution, we approached the Black Archives of Mid-America to be our collaborative partner for the project. The Black Archives is an independent library and archive located in Kansas City, Missouri, whose mission is to collect, preserve, and make available to the public materials documenting the social, economic, political, and cultural histories of persons of African descent in the central United States, with particular emphasis in the Kansas City region. The interview sessions launched as a collaboration between KUMC and the Black Archives and will later be curated as an exhibit. The Black Archives will retain ownership of all the stories collected during this project.

4. **That we consciously seek to sample from the wide variety of voices and perspectives in the Black diasporic community in and around Kansas City**. We made special efforts to maintain age and gender equity, including directing our outreach to include special sessions with LGBTQ+, deaf, physically challenged, and religious groups.

5. **That the interviews would be trauma-informed**. We held trauma-informed training, conducted by Alive and Well Communities, Inc., for all our community facilitators and co-PIs, prior to initiating interviews. Our facilitating guide was designed with trauma-informed principles in mind. We also partnered with a licensed clinical social worker to attend interview sessions to offer counseling

support for participants as needed. To date, no additional counseling support has been requested.

6. **That we would prioritize community dissemination**. The culmination of the oral history project will be a truth-and-reconciliation-style community event, attended by city and county leaders, in which our community partners present the findings of our research to the executive leadership of local AHCs as community directives for REPAIR.

With these priorities in design established, we recruited approximately one hundred community members with diverse lived experiences, including diversity in age, gender identity, sexual orientation, education, physical ability, and socioeconomic status, to take part in group forums throughout the Kansas City metro area. Recruitment efforts included radio commercials, church announcements, social media, community town hall meetings, and word of mouth. We used 2020 U.S. census data to identify neighborhoods in both Kansas City, Kansas, and Kansas City, Missouri, with the highest concentration of African Americans. We then asked our community partners to identify an organization or location within each of those neighborhoods to host a session. Each group interview session was cofacilitated by a community member and researcher. From these listening sessions, the research team is selecting approximately thirty individuals from the group forums who have the most salient stories to sit for two extended, one-on-one interviews conducted at the Black Archives recording studio.

The first one-on-one interview will use oral history methods to elucidate in-depth stories of racism in health care within the participant's family. The second one-on-one interview will make use of PhotoVoice methodology. We will ask participants to take between ten and fifteen photos that represent the racism they have encountered and their vision of repair of the harmful consequences of racism in their communities. After taking the photographs, participants will be asked to narrate the five most meaningful pictures and their significance.

Interviews are transcribed using temi.com, on online computer transcription service, then verified and anonymized (where necessary) by a PI in attendance. The oral histories will be analyzed using thematic analysis for themes that cross all narratives. We will compose a written report to use as a benchmark for defining repair, validate the written report with local community (both those who participated and additional community members), and create an oral and photographic history exhibit with the Black Archives.

Emerging Themes

While the project is still ongoing (we've held group interviews for about ninety participants thus far over thirteen sessions), significant themes have already emerged—both in the stories we are collecting and in navigating the political landscape at the institution and more expansively because of the national Republican Party–led assault on grappling with the American history of racism. The racist injustices that our participants report fit into four broad categories: being disrespected and having their dignity insulted, providers showing a disregard of their suffering and knowledge of their bodies, being racially profiled, and not pursuing the best care for their illness. Our project is open to identifying others as or if they emerge.

"Just Listen. Listen to Us When We Tell You That Something Is Wrong with Us"

By far, the most prevalent finding is that African Americans report not being listened to when they make a medical complaint. This theme has emerged at every session. Many participants reported that when they seek medical care, health care professionals often assume that they are not intelligent enough to know what, if anything, is wrong with them. Consequently, health providers often do not conduct a thorough history and assessment or order all necessary diagnostics to make an accurate diagnosis. Instead, assumptions are made based on racial profiling, such as assuming the person is suffering from common morbidities like diabetes or hypertension, has an STI or is pregnant, or, as seems to be quite common, is merely drug seeking and not really suffering at all. As a result, participants were prescribed medications or recommended procedures based on these assumptions, which failed to address their major health concern. Consequently, participants conveyed the need to be hypervigilant during any medical encounter where the provider was not also Black.

"Don't Just Treat My Symptoms, Care Enough to Find Out What's Wrong with Me"

Many participants reported that going to the doctor is a constant struggle to be seen and treated as if their lives mattered. Consequently, they constantly have to engage in *impression management*: paying special attention to their dress, speech, and overall demeanor in order to be treated like "someone worth saving." The desire to stand up for oneself and demand competent and compassionate care is constantly balanced against the

possibility of being dismissively labeled "an angry Black patient," after which all empathic connection is severed. Many participants are haunted by memories of loved ones who they feel died too young because medical professionals did not treat their sick friends or family as if their lives were worth saving.

Violating Black Women's Rights to Reproductive Autonomy

A particularly disturbing finding was that several Black women have reported that health care providers are *overly eager* to recommend and perform hysterectomies, even for benign conditions where one is not warranted. This finding is consistent with several large investigations that have reported higher rates of hysterectomies performed on Black women, irrespective of common clinical and demographic factors that are associated with undergoing hysterectomy.[13] Black women are also half as likely to undergo minimally invasive hysterectomies,[14] a disparity that has existed for over a decade and is not eliminated when controlling for patient-level differences or insurance status. Abhorrently, one participant was subjected to a hysterectomy *when she was pregnant*, as her health care provider did not bother to give her a pregnancy test before the procedure, or ask if she might be pregnant. She was told offhand by a nurse afterward, "By the way, it turns out you were pregnant when we took your uterus out."

Directives for REPAIR: "I Believe That in a University Setting There Should Be Classes Taught on What Different Cultures Have Had to Go Through in Medical History"

This theme emerged across multiple sessions with participants voicing that KUMC specifically, and all health professions curricula in general, should include a required course for all health profession learners that explores local histories of medical mistreatment as the primary method to prevent future health care providers from replicating these harms. Participants also advocated for courses to be structured in a way that centers the voices of marginalized groups where students learned from the com-

13. Vanessa L. Jacoby, Victor Y. Fujimoto, Linda C. Giudice, Miriam Kuppermann, and A. Eugene Washington, "Racial and Ethnic Disparities in Benign Gynecologic Conditions and Associated Surgeries," *Amer. J. Obstet. Gyncol.* 202, no. 6 (2010): 514–21, https://doi.org/10.1016/j.ajog.2010.02.039.

14. Asha McClurg, Jacqueline Wong, and Michelle Louie, "The Impact of Race on Hysterectomy for Benign Indications," *Curr. Opin. Obstet. Gynecol.* 32, no. 4 (2020): 263–68, https://doi.org/10.1097/GCO.0000000000000633.

munity—flipping the classroom and challenging power differentials that perpetuate antiquated models of person-provider relationships.

Another frequent theme expressed at most sessions was a call for there to be more African American doctors trained and practicing in the United States. As one participant put it, "I breathe a sigh of relief whenever my doctor is Black," an indication that she would not have to worry about whether she was getting good care or whether her humanity was being respected. Participants also wanted to see more Black nurses. Another variant of this theme was a desire to see "more Black patient advocates" available to help navigate the clinical encounter, especially when dealing with chronic and life-threatening illness. With respect to the dire situation of maternal and fetal health outcomes, participants said they wanted to see more Black doulas and midwives. Some participants took this suggestion even further, expressing a desire to seek health care at an organization specifically dedicated to the health and well-being of African Americans. These desires are consistent with a recent study that found Black people who live in counties with more Black primary care physicians enjoy longer life expectancy and lower mortality rates.[15]

Finally, the participants expressed a desire to be empowered—to be educated on what to do when they have been wronged by the health care system in the future. They want KUMC to offer free community education that covers patients' rights, what steps to take, and with whom to file a complaint if they feel that they are the victim of mistreatment. This directive emerged during testimony of how existing hospital and health system customer service infrastructures had failed to take any corrective action when some participants made complaints about their mistreatment in the past, leaving them feeling like such efforts were useless. They wanted to know whom they should *really* talk to and how to frame the conversation to ensure true corrective action would take place.

Discussion

We are conducting this study against a national backdrop where a Republican Party–led movement is attempting to ban any research and instruction in American history that accurately grapples with the U.S. history of racism. Though institutional leadership at KUMC, guided by Vice Chancellor Dr. Jerrihlyn McGee, has been very supportive of REPAIR Project

15. John E. Snyder, Rachel D. Upton, Thomas C. Hassett, Hyunjung Lee, Zakia Nouri, and Michael Dill, "Black Representation in the Primary Care Physician Workforce and Its Association with Population Life Expectancy and Mortality Rates in the US," *JAMA Network Open* 6, no. 4 (2023): e236687, https://doi.org/10.1001/jamanetworkopen.2023.6687.

initiatives, they are nevertheless attuned to this latest front in the culture wars that has also found traction in the Republican-dominated Kansas state legislature.[16] This backdrop has, understandably, led institutional leaders to prefer that this work fly under the radar and avoid being made into a political football, resulting in light tension at times. At the very beginning, institutional leadership strongly recommended we remove the term "reparations" from the REPAIR acronym, as it originally had when we adopted the framework from UCSF. More recently, there was tension between PIs and the KUMC communications office over some of our advertising efforts to recruit for the project. When a local NBC affiliate station approached us wanting to air a special story on the project, the communications office wanted to review and approve every word spoken by every KUMC employee interviewed. They also wanted a representative present at every interview. In many ways, these efforts by the communications office to control any media messaging regarding the institution are normal, but we experienced extra attention and scrutiny because of the heightened political tensions around the history of racism in the United States currently in play.

Even with all the precautions we took in our study design to secure trust with our community collaborators, one of the persons we recruited to be a cofacilitator and who underwent the trauma-informed training with us as a group later decided to withdraw from participating because, as he described, he had been "burned" by KUMC and other health systems too many times in the past. He did not trust that institutional leadership would honor the stories we are collecting and faithfully implement community directives for repair. He therefore feared that the project risked retraumatizing community members in service of a vision of repair that would never materialize. As PIs, we found it difficult to argue with such well-earned cynicism, but it also instilled in us a commitment not to repeat this mistreatment. We are currently planning a project that will use liberatory design to cocreate with our community partners interventions to address the findings from the oral history sessions.

None of these challenges have proved insurmountable. If anything, the powerful stories we've collected, and the community's desire to tell them, have sustained and enhanced our commitment to this project. Being in conversation with the leaders guiding other projects profiled in this special issue has also helped affirm the power and necessity of local

16. Tim Carpenter, "Physician Asks Kansas Lawmakers to Ban Racial Diversity Programs at Medical Schools, Hospitals," *Kansas Reflector*, February 2, 2023, https://kansasreflector.com/2023/02/02/physician-asks-kansas-lawmakers-to-ban-racial-diversity-programs-at-medical-schools-hospitals/.

histories and their vital role in designing local interventions in the larger national reckoning with health inequities.

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