

Conference on Addressing Medical Mistrust in Black Communities: Implications for HIV and Other Conditions: Suggested Bibliography

I. Reviews, Definitions, and Context and Origins of General Medical Mistrust

A. Peer-Reviewed Journal Articles

Alsan M, Wanamaker M. Tuskegee and the health of black men. *Q J Econ.* 2017;133(1):407-55.

<https://academic.oup.com/qje/article/133/1/407/4060075>

Arnett, M. J., Thorpe, R. J., Gaskin, D. J., Bowie, J. V., & LaVeist, T. A. (2016). Race, medical mistrust, and segregation in primary care as usual source of care: findings from the exploring health disparities in integrated communities study.

Journal of Urban Health, 93(3), 456-467. <https://link.springer.com/content/pdf/10.1007/s11524-016-0054-9.pdf>

Cuevas, A. G., O'Brien, K., & Saha, S. (2016). African American experiences in healthcare: "I always feel like I'm getting skipped over". *Health Psychology*, 35(9), 987.

<https://search.proquest.com/docview/1788232375/fulltextPDF/4F47E5C4F8FA4C44PQ/1?accountid=14512>

Hammond, W. P. (2010). Psychosocial correlates of medical mistrust among African American men. *American journal of community psychology*, 45(1-2), 87-106. <https://link.springer.com/article/10.1007/s10464-009-9280-6>

LaVeist TA, Nickerson KJ, Bowie JV. Attitudes about racism, medical mistrust, and satisfaction with care among African American and White cardiac patients. *Med Care Res Rev.* 2000;57(1_suppl):146-61.

<https://journals.sagepub.com/doi/10.1177/1077558700057001S07> (abstract only).

Northington Gamble V. Under The Shadow Of Tuskegee: African Americans and Healthcare. *American Journal of Public Health* 1997;87(11):1773-1778. <https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.87.11.1773>

Prather, C., Fuller, T. R., Jeffries IV, W. L., Marshall, K. J., Howell, A. V., Belyue-Umole, A., & King, W. (2018). Racism, African American women, and their sexual and reproductive health: a review of historical and contemporary evidence and implications for health equity. *Health equity*, 2(1), 249-259. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6167003/>

Scharff, D. P., Mathews, K. J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). More than Tuskegee: understanding mistrust about research participation. *Journal of health care for the poor and underserved*, 21(3), 879.

https://digitalcommons.wustl.edu/cgi/viewcontent.cgi?referer=&httpsredir=1&article=3708&context=open_access_pubs

Thomas SB, Curran JW. Tuskegee: From Science to Conspiracy to Metaphor, *American Journal of the Medical Sciences*. 1993;317(1):1-4. https://drum.lib.umd.edu/bitstream/handle/1903/22401/Tuskegee-From_Science_to_Conspiracy_to_Metaphor.txt?sequence=1&isAllowed=y

Thomas, S. B., & Quinn, S. C. (1991). The Tuskegee Syphilis Study, 1932 to 1972: implications for HIV education and AIDS risk education programs in the black community. *American journal of public health*, 81(11), 1498-1505.

<https://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.81.11.1498>

Williamson, L.D. and Bigman, C.A., 2018. A systematic review of medical mistrust measures. Patient education and counseling, 101(10), pp.1786-1794. <https://www.sciencedirect.com/science/article/pii/S0738399118302040>

B. Books

Blindspot: Hidden Biases Of Good People - Mahzarin R. Banajai & Anthony R. Greenwald

<https://read.amazon.com/kp/embed?asin=B004J4WJUC&tag=bing08-20&linkCode=kpp&reshareId=NVSTMB5FW1HX0VKYS7T2&reshareChannel=system>

Health Disparities In The U.S.: Social Class, Race, Ethnicity & Health Disparities - D. Barr

<https://read.amazon.com/kp/embed?asin=B07PX3QWJF&tag=bing08-20&linkCode=kpp&reshareId=4YFTF5HKCFR38BTMPFQB&reshareChannel=system>

Cultural Fault Lines In Healthcare: Reflections On Cultural Competency - Michael C. Branningan

<https://read.amazon.com/kp/embed?asin=B007IVG5C6&tag=bing08-20&linkCode=kpp&reshareId=XFTBEN78P29SBKQD15TM&reshareChannel=system>

Black feminist thought: Knowledge, consciousness, and the politics of empowerment - Patricia Hill Collins

<https://www.barnesandnoble.com/w/black-feminist-thought-patricia-hill-collins/1113960349?ean=9780415964722>

Collins PH. Black sexual politics: African Americans, gender, and the new racism - Patricia Hill Collins

<https://www.barnesandnoble.com/w/black-sexual-politics-patricia-hill-collins/1112044112?ean=9780415951500>

Body and soul: The Black Panther Party and the fight against medical discrimination – Alondra Nelson

<https://www.barnesandnoble.com/w/body-and-soul-alondra-nelson/1111008846?ean=9780816676491>

Killing the black body: Race, reproduction, and the meaning of liberty – Dorothy E. Roberts

<https://www.barnesandnoble.com/w/killing-the-black-body-dorothy-roberts/1114288328?ean=9780679758693>

White fragility: Why It's So Hard For White People To Talk About Racism - Robin DiAngelo & Michael E. Dyson

<https://read.amazon.com/kp/embed?asin=B07638ZFN1&tag=bing08-20&linkCode=kpp&reshareId=8KQNC0RTY6VFCTX5DKTS&reshareChannel=system>

Bad Blood - James Jones. <https://www.simonandschuster.com/books/Bad-Blood/James-H-Jones/9780029166765>

Overcoming Bias: Building Authentic Relationships Across Differences - Tiffany Jana & Matthew Freeman.

<https://read.amazon.com/kp/embed?asin=B01F6B0R7S&tag=bing08-20&linkCode=kpp&reshareId=JMR40YGE5SQF1QCEDD6A&reshareChannel=system>

Uprooting Racism - Paul Kivel. <http://paulkivel.com/books/uprooting-racism-4th-edition/>

Additional reading:

<https://read.amazon.com/kp/embed?asin=B0722DNVYT&tag=bing08-20&linkCode=kpp&reshareId=PD7524AP7WWZSF24PRAD&reshareChannel=system>

Just Medicine: A Cure For Racial Inequality - Dayna B. Matthews.

<https://read.amazon.com/kp/embed?asin=B010VIKPXC&tag=bing08-20&linkCode=kpp&reshareId=B7QS8KXRWBWVQA85ZMD0&reshareChannel=system>

Immortal Life Of Henrietta Lacks - Rebeccak Skloot. <https://www.shmoop.com/the-immortal-life-of-henrietta-lacks/chapter-1-summary.html>

Unequal Treatment: Confronting Racial & Ethical Disparities In Healthcare - Smedley & Stith.

http://www.precaution.org/lib/iom_on_health_disparities.020601.pdf

40 Years of Medical Racism: The Tuskegee Experiment - M. Uschan. <https://www.amazon.com/Forty-Years-Medical-Racism-Experiments/dp/1590184866>. Small summary of the book*

Medical Apartheid - Henrietta A Washington <http://originalpeople.org/medical-apartheid-dark-history-medical-experimentation-black-americans-colonial-times-present/>

Additional Discussion Link: https://www.democracynow.org/2007/1/19/medical_apartheid_the_dark_history_of

C. Popular Press

This Is How The American Healthcare System Is Failing Black Women - E. Stallings, 2017 - O Magazine August 1st, 2018: <https://www.oprahmag.com/life/health/a23100351/racial-bias-in-healthcare-black-women/>

A New California Law Seeks To Prevent Black Maternal Mortality In The State - Tomas Kassahun, 2019. Blavity Online Multicultural News and Politics Magazine, October 9th, 2019: <https://blavity.com/a-new-california-law-seeks-to-prevent-black-maternal-mortality-in-the-state?category1=news>

The Never Ending-Mistreatment Of Black Patients - J. Zitter

The New York Times Newspaper June 29th, 2019 - Opinion Section:

<https://www.nytimes.com/2019/06/29/opinion/sunday/hospice-end-of-life-racism.html>

The New York Times Magazine: Why doesn't the United States have universal health care? The answer has one word, racism. <https://www.nytimes.com/interactive/2019/08/14/magazine/universal-health-care-racism.html>

D. Videos

Medical Apartheid - You Tube Discussion:

<https://www.bing.com/videos/search?q=medical+apartheid+you+tube&view=detail&mid=54B1FE99604B4601575E54B1FE99604B4601575E&FORM=VIRE>

Miss Ever's Boys - <https://www.fandango.com/miss-evers-boys-106579/plot-summary>

The Immortal Life Of Henrietta Lacks - HBO Movie:

<https://www.bing.com/videos/search?q=immortal+life+of+henrietta+lacks+video&view=detail&mid=EBBD21330C6928D5D2A7EBBD21330C6928D5D2A7&FORM=VIRE0&mmscn=tpvh&ru=%2fsearch%3fq%3dimmortal%2520life%2520of%2520henrietta%2520lacks%2520video%26qs%3dn%26form%3dQBRE%26sp%3d-1%26pq%3dimmortal%2520life%2520of%2520henrietta%2520lacks%2520video%26sc%3d2-38%26sk%3d%26cvid%3d681DF0AFC95B49BAAA957AB9E65C9A57>

TED Talk: The Problem With Race-Based Medicine <https://www.youtube.com/watch?v=KxLMjn4WPBY>

Unnatural Causes: Is Inequality Making Us Sick: Episode #1 In Sickness & In Wealth - <https://www.youtube.com/watch?v=hX0WgJOZZTU>

I

I. General Medical Mistrust: Implications for HIV Prevention and Treatment

A. Peer-reviewed Journal Articles

Dale SK, Bogart LM, Wagner GJ, Galvan FH, Klein DJ. Medical mistrust is related to lower longitudinal medication adherence among African-American males with HIV. *J Health Psychol.* 2016;21(7):1311-21. <https://journals.sagepub.com/doi/full/10.1177/1359105314551950>

Earnshaw VA, Bogart LM, Dovidio JF, Williams DR. Stigma and racial/ethnic HIV disparities: moving toward resilience. *Am Psychol.* 2015;68(4):225-36. <https://psycnet.apa.org/record/2015-27522-005> (abstract only).

Eaton LA, Driffin DD, Kegler C, Smith H, Conway-Washington C, White D, et al. The role of stigma and medical mistrust in the routine health care engagement of Black men who have sex with men. *Am J Public Health.* 2015;105(2):e75-e82. <https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2014.302322>

Gaston GB, Alleyne-Green B. The impact of African Americans' beliefs about HIV medical care on treatment adherence: a systematic review and recommendations for interventions. *AIDS Behav.* 2013;17(1):31-40. <https://www.ncbi.nlm.nih.gov/pubmed/23010941> <https://link.springer.com/article/10.1007%2Fs10461-012-0323-x>

Jaiswal J. Whose responsibility is it to dismantle medical mistrust? Future directions for researchers and health care providers. *Behav Med.* 2019;45(2):188-96. <https://www.tandfonline.com/doi/full/10.1080/08964289.2019.1630357>

Kalichman, S. C., Eaton, L., Kalichman, M. O., & Cherry, C. (2017). Medication beliefs mediate the association between medical mistrust and antiretroviral adherence among African Americans living with HIV/AIDS. *Journal of health psychology*, 22(3), 269-279.

https://journals.sagepub.com/doi/full/10.1177/1359105315600239?casa_token=L_R3aFrNsKKkAAAAA%3AUWsWBHWeFL-Tqaiifi8PaeuxReqq0TxYSz5ESalZQPMXaD5PXHJV81h2tg1a1YdlzdSQ85XImGm3

Quinn, K., Dickson-Gomez, J., Zarwell, M., Pearson, B., & Lewis, M. (2019). "A Gay Man and a Doctor are Just like, a Recipe for Destruction": How Racism and Homonegativity in Healthcare Settings Influence PrEP Uptake Among Young Black MSM. *AIDS and Behavior*, 23(7), 1951-1963. <https://link.springer.com/article/10.1007/s10461-018-2375-z>

Tekeste M, Hull S, Dovidio JF, Safon CB, Blackstock O, Taggart T, et al. Differences in medical mistrust between Black and White women: implications for patient-provider communication about PrEP. *AIDS Behav.* 2018:1-12. <https://www.ncbi.nlm.nih.gov/pubmed/30264207> <https://link.springer.com/article/10.1007%2Fs10461-018-2283-2>

B. Books

AIDS Crises Among African Americans - Dr. Eloise Lee <https://outskirtspress.com/aidscrisesamongafricanamericans>

Ojikutu, B.O., & Stone, V. (Eds.) HIV/AIDS in U.S. Communities of Color. Forthcoming (Expected December 2019). New York: Springer. [Note: 2019 edition has a chapter on medical mistrust and HIV] <https://www.springer.com/gp/book/9780387981512>

HIV-related Medical Mistrust (aka HIV conspiracy beliefs): General Papers, Associations with HIV Prevention and Treatment Behaviors

A. Peer-Reviewed Journal Articles

Bogart LM, Wagner GJ, Green Jr HD, Mutchler MG, Klein DJ, McDavitt B, et al. Medical mistrust among social network members may contribute to antiretroviral treatment nonadherence in African Americans living with HIV. *Soc Sci Med*, 2016;164:133-40. <https://www.sciencedirect.com/science/article/pii/S0277953616301289>

Bogart LM, Thorburn S. Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans? *J Acquir Immune Defic Syndr*, 2005;38(2):213-8. <https://www.ncbi.nlm.nih.gov/pubmed/15671808>

Bogart, L.M., Wagner, G., Galvan, F.H. and Banks, D., 2010. Conspiracy beliefs about HIV are related to antiretroviral treatment nonadherence among African American men with HIV. *Journal of acquired immune deficiency syndromes* (1999), 53(5), p.648. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2845717/>

Brooks, R.A., Allen Jr, V.C., Regan, R., Mutchler, M.G., Cervantes-Tadeo, R. and Lee, S.J., 2018. HIV/AIDS conspiracy beliefs and intention to adopt preexposure prophylaxis among black men who have sex with men in Los Angeles. *International journal of STD & AIDS*, 29(4), pp.375-381. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6221185/>

Eaton LA, Kalichman SC, Price D, Finneran S, Allen A, Maksut J. Stigma and conspiracy beliefs related to pre-exposure prophylaxis (PrEP) and interest in using PrEP among Black and White men and transgender women who have sex with men. *AIDS Behav*, 2017;21(5):1236-46. <https://link.springer.com/article/10.1007/s10461-017-1690-0>

Ford CL, Wallace SP, Newman PA, Lee SJ, Cunningham WE. Belief in AIDS-related conspiracy theories and mistrust in the government: relationship with HIV testing among at-risk older adults. *Gerontologist*. Dec. 2013;53(6):973-984. <https://academic.oup.com/gerontologist/article/53/6/973/634618>

Potential Interventions/Recommendations to Address Medical Mistrust

A. Peer-reviewed Journal Articles

Adams LM, Simoni JM. The need for multi-level mitigation of medical mistrust among social network members contributing to antiretroviral treatment nonadherence in African Americans living with HIV: comment on Bogart et al.(2016). *Soc Sci Med*, 2016;159:58-60. <https://europepmc.org/articles/pmc5078811>

Rolfe A, Cash-Gibson L, Car J, Sheikh A, McKinstry B. Interventions for improving patients' trust in doctors and groups of doctors. *Cochrane Database Syst Rev*, 2014(3). <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD004134.pub3/abstract>

Tulsky JA, Arnold RM, Alexander SC, Olsen MK, Jeffreys AS, Rodriguez KL, et al. Enhancing communication between oncologists and patients with a computer-based training program: a randomized trial. *Ann Intern Med*, 2011;155(9):593-601. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3368370/>

B. Popular Press

Restoring Trust In Medical Research Among African Americans - R.Morgan Jr., 2018 - *Stat Online Science & Business Magazine* October 17th, 2018. <https://www.statnews.com/2018/10/17/medical-research-african-americans-trust/>

Stigmatizing language

<https://twitter.com/kkidia/status/1275460547883008000?s=10>

The exploitation of professionalism (how we shouldn't have to rely on providers overcompensating for a broken system)

<https://www.nytimes.com/2019/06/08/opinion/sunday/hospitals-doctors-nurses-burnout.html>

A powerful series of tweets by Dr. Manning at Grady/Emory about an encounter with a transgender patient.

<https://threadreaderapp.com/thread/1282541776696475648.html>

She has many other such threads: <https://threadreaderapp.com/user/gradydoctor>

Cult Med Psychiatry (2011) 35:163-182

DOI 10.1007/s11013-011-9213-3

En-case-ing the Patient: Disciplining Uncertainty in Medical Student Patient Presentations

Seth M. Holmes • Maya Ponte

Cultural humility versus cultural competence: A critical distinction in defi...

Melanie Tervalon; Jann Murray-Garcia

Journal of Health Care for the Poor and Underserved; May 1998; 9, 2; Research Library

pg. 117

I don't know if you have seen this study, which relates to medical mistrust.

<https://www.pewresearch.org/fact-tank/2020/06/04/black-americans-face-higher-covid-19-risks-are-more-hesitant-to-trust-medical-scientists-get-vaccinated/>

Influencing health care providers to adopt strategies supported by research seems like a goal for policy core. Additionally, finding ways to make research findings more accepted by patients by combating medical mistrust is another dissemination goal.

Simon, M., C. Baur, S. Guastello, K. Ramiah, J. Tufte, K. Wisdom, M. Johnston-Fleece, A. Cupito, and A. Anise. 2020. Patient and family engaged care: An essential element of health equity. *NAM Perspectives*.

Discussion Paper, National Academy of Medicine, Washington, DC. <https://doi.org/10.31478/202007a>

<https://nam.edu/patient-and-family-engaged-care-an-essential-element-of-health-equity/>

<https://www.pewresearch.org/fact-tank/2020/06/04/black-americans-face-higher-covid-19-risks-are-more-hesitant-to-trust-medical-scientists-get-vaccinated/>