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Using Mistrust, Distrust, and Low Trust Precisely in Medical Care and Medical Research Advances Health Equity

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INTRODUCTION

Trust, mistrust, and distrust influence people's ability to utilize critical resources and make decisions that are best for their health and well-being. Trust is necessary for optimizing health research, eliminating healthcare disparities, and achieving health equity, but efforts to build trust to increase healthcare utilization and research participation may have little effect on attitudes or behaviors that are rooted in distrust or mistrust. Thus, it is critical to be clear if policies and initiatives are designed to improve trust or decrease mistrust and distrust. This paper refines the way that patient trust, mistrust, and distrust are conceptualized. In particular, it focuses on clarifying the distinctions among low levels of trust, mistrust, and distrust, which will strengthen the pillars on which more accurate and effective measures, programs, and policies can be created to promote equity in healthcare utilization and medical research.

HOW IS DISTRUST OR MISTRUST DIFFERENT FROM TRUST?

Trust, mistrust, and distrust are not synonymous nor are they static constructs. If trust is belief in a person's competence to complete a certain task, distrust is a belief that we should question one's motives and view their actions with suspicion because they are likely to act in a way that the quality of care or the accuracy of information provided may be compromised.[1] Trust is largely thought of as an attitude or cognitive assessment of an individual, whereas distrust is a person's logical response based on skepticism, suspicions, and concerns.[1]

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Patient distrust is not the absence of trust; it is an attitude onto itself.[2,3] Beyond just a feeling of disappointment, violations of patient trust can lead to a sense of betrayal and skepticism.[4] Distrust is based on the assumption that providers or healthcare entities may not be trustworthy, that they may not have equal access to state-of-the-art care, that quality is variable at best, and that the patient is likely receiving lower quality than the typical standard of care.

African Americans, Latinxs, and other marginalized groups have a long history of receiving inferior quality of care even when they have a comparable level and type of insurance and access to care as more privileged groups.[5] Members of the lesbian, gay, bisexual, transgender, and queer community also have experienced racism, discrimination, and inferior treatment in health care.[6–8] Scholars also have documented numerous incidents of unethical medical research on African Americans, Native Americans, Hispanic-Latinos and Asian Americans,[3,9–12] many of which occurred well after the historic Belmont Report set standards for human research protections in 1979. Given this history,[3,9] it would be illogical and irrational not to approach providers and healthcare entities with some level of skepticism. The governmental response to coronavirus disease 2019[13,14] and other events in the public health system, such as the lead poisoning from the water in Flint, Michigan, may further reinforce skepticism and distrust of healthcare providers and entities,[15] and undermine their trustworthiness.[16] Grier and Cobbs[17] deemed this phenomenon "healthy cultural paranoia," and described it as an adaptive, reasonable, wise, and valid approach to being African American and interacting with healthcare and other sectors of society that have a long history of racism and discrimination.

IS THERE A DIFFERENCE BETWEEN DISTRUST AND MISTRUST?

Although both distrust and mistrust are similar in that they both refer to a lack of trust, these are not synonyms. Neither distrust nor mistrust is synonymous with lack of trust, though trust is a part of both distrust and mistrust. A prerequisite of trust is that the patient is in a vulnerable position and needs the provider or institution to provide information, a service, or access to resources that they otherwise cannot acquire. Whereas trust may primarily be about facts and beliefs, distrust places facts and beliefs in historical, social, or political context. Distrust, though often preceded by a personal or collective experience or reliable information, is based on a sense that one's trust has been diminished or violated. Distrust includes a heightened sense of fear and skepticism that is not unique to certain racial or ethnic groups; however, there can be unique historical experiences of racism, discrimination, and unethical treatment that certain groups may have experienced that are important to note and consider in promoting trust among those groups.[6,9]

One of the cornerstones of distrust is suspicion. Concretely in this context, distrust is the idea that the patient actively questions and doubts the motives, sincerity, genuineness, and trustworthiness of the specific provider, researcher, organization, or institution.[18] Distrust may reflect a patient's willingness to be vulnerable to or depend on the provider or healthcare entity[1] that may vary by context or situation. Patients who have high levels of distrust are often attempting to draw reasonable inferences about attitudes, decisions, and opportunities that are opaque or hypersensitive to the perceived motives of the provider or healthcare entity. To address distrust, it is critical to recognize that the suspicions, fears, and roots of distrust are logical responses to a history of inequity. It is essential to consider, understand, and address why the suspicion that underlies distrust exists with an individual, practice, organization, or system and match the measurement or intervention strategy to that level.

Distrusting beliefs of a patient may include ≥1 of the following 5 components: (1) competence—the provider or institution does not have the capacity to do what needs to be done; (2) benevolence—the provider or institution does not care about the outcome or is not motivated to act in one's best interest; (3) integrity—the provider or institution do not make good faith agreements, tell the truth, or fulfill promises; (4) predictability—the provider or institutional actions are not consistent enough that they can be accurately forecasted, or the situation is not one that the institution has addressed regularly enough to have confidence in the success; and (5) assurance— it is unclear if the protective quality assurance structures are in place.[1] These 5 cognitive dimensions may be strong foundations on which to build a measure of distrust. Whereas distrust is a transitive verb that requires a direct object to clarify what or whom is the object of the sentiment, mistrust is an intransitive verb that is not used with a direct object.

Different from distrust, mistrust does not necessarily or explicitly name what or whom is not trusted. Mistrust also is often a general sense of unease or suspicion toward someone or something that is predicated either on the notion that the provider or healthcare entity may not act in the patient's best interest and they may actively work against the patient.[19] Mistrust may originate from distinct historical experiences linked to group identity, personal experience, vicarious experiences, and oral histories.[19–22] The Tuskegee Study of Untreated Syphilis in the Negro Male is arguably the most infamous example of unethical medical research.[23–25] Despite this U.S. Public Health Service study illustrating that concerns about medicine and public health's lack of trustworthiness are not unfounded,[5,9,23,26] knowledge of the Syphilis Study and other unethical research studies is not solely responsible for African American patients' mistrust.[27] In the case of the Syphilis Study and many other instances of unethical medical research,[12,28,29] part of the deception was that the research was disguised and presented to patients as medical care, which may make it difficult for patients to view medical care outside of the context of medical research.[24] It also is noteworthy that the principal investigators of the Syphilis Study had strong reputations as physicians and researchers who had demonstrated commitment and concern regarding the health of "Negroes," and that the racial disparities in the prevalence of syphilis were due to poor social and economic status, not inherent racial susceptibility.[11,23]

In sum, patients may distrust a provider, researcher, organization, or institution because they know or have heard specific things about what they have done. Patients also may mistrust medical care, providers, researchers, health-related organizations, or institutions in general because of the legacy of the Tuskegee Study of Untreated Syphilis in the Negro Male and other examples of unethical research or poor treatment of marginalized groups. Moreover, it is critical to acknowledge and approach patient distrust from the perspective that it is a legitimate method of coping with racism and discrimination in health care, which are root causes of the skepticism and distrust. Kramer[18] argues that, "distrust and suspicion may constitute appropriate and even highly adaptive stances toward institutions" (p. 590), and vigilance and wariness about patients and healthcare entities may—in fact—be healthy responses to the history of racism and discrimination in medicine and health care. Though not only shaped by cognitive or factual information, there may be important dimensions of beliefs about the trustworthiness or distrust of providers or healthcare entities to anchor self-report measures of distrust.

DISCUSSION

Lack of trust is often framed as something that needs to be changed in individuals who do not trust rather than something that needs to change in providers and organizations that have not demonstrated that they are trustworthy.[16,30] Second, it often is assumed that the object of trust is trustworthy, which may not necessarily be the case given the history of unethical research and public health practice.[9,10,15,25] Third, despite extensive research to the contrary, studies of patient trust often assume that patients have equal access to care, are likely to receive the same quality of care, and that their fears that they may not receive equal quality of care as other patients (e.g., White Americans) are unfounded or irrelevant.[5,31] Fourth, placing trust in people and systems that are not trustworthy can be profoundly harmful.[32] Fifth, although it tends to be stable, patient trust can change if they have new experiences or receive new information that affects their perceptions of trust. Patient trust can build and be formed or reformed, stabilize or be reinforced, and decline or dissolve; patient trust is fragile, and it is subject to change based on experiences.[3]

Mistrust and distrust may be rooted in a unique combination of historical and contemporary factors that vary by individual, population, or other characteristics; yet, it is critical not to use a person's perceived or self-identified race, ethnicity, or other socially defined characteristic as a proxy for their level of trust, mistrust, or distrust. Political affiliation, religious affiliation, income, race, and ethnicity also can contribute to not only levels of trust but also levels of distrust or mistrust in ways that may not be obvious or intuitive.[33–35] Dismissing any aspect of low levels of trust as being based in misinformation, fallacy, or ignorance misses the history of inequality and contemporary inequities in access to care, quality of care, opportunities to participate in research, and ability to benefit from medical research. Because these are distinct concepts, it is critical to be precise and intentional about the goals of efforts to promote trust or reduce mistrust or distrust. Individuals and populations may have concerns about ≥1 aspects of the health sector but not others. In addition, questions about the competence, motives, and values that underlie the opportunities, experiences, and outcomes of some patients and research participants are well founded and need to be addressed. Addressing mistrust and distrust must be at the center of efforts to promote trust and mitigate the decline in trust in physicians, medical care, and medical research. It is essential to recognize that lack of faith and skepticism in the motives and competence of medical care and medical research providers and institutions are based on patients' and research participants' recognition that it is not wise or in their best interest to blindly trust medical care or medical research to put their health, safety, and well-being first.

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REFERENCES

1. McKnight DH, Chervany N. While trust is cool and collected, distrust is fiery and frenzied: a model of distrust concepts. AMCIS 2001 Proceedings. 2001:171 https://aisel.aisnet.org/amcis2001/171. Accessed September 1, 2020.
2. Lewicki RJ, McAllister DJ, Bies RJ. Trust and distrust: new relationships and realities. Acad Manage Rev. 1998;23(3):438–458. 10.5465/amr.1998.926620.
3. Gamble VN. Trust, medical care, and racial and ethnic minorities. In: Satcher D, Pamies R, eds. Multicultural Medicine and Health Disparities. New York, NY: McGraw-Hill; 2006:437.
4. Hall MA, Dugan E, Zheng B, Mishra AK. Trust in physicians and medical institutions: what is it, can it be measured, and does it matter? Milbank Q. 2001;79(4):613–639. 10.1111/1468-0009.00223. [PubMed: 11789119]
5. Smedley BD, Stith AY, Nelson AR. Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Washington, DC: National Academies Press; 2003 10.17226/12875.
6. Jaiswal J, Halkitis PN. Towards a more inclusive and dynamic understanding of medical mistrust informed by science. Behav Med. 2019;45(2):79–85. 10.1080/08964289.2019.1619511. [PubMed: 31343962]
7. Malebranche DJ, Peterson JL, Fullilove RE, Stackhouse RW. Race and sexual identity: perceptions about medical culture and healthcare among Black men who have sex with men. J Natl Med Assoc. 2004;96(1):97–107. [PubMed: 14746359]
8. Bogart LM, Wagner GJ, Green HD Jr, et al. Medical mistrust among social network members may contribute to antiretroviral treatment nonadherence in African Americans living with HIV. Soc Sci Med. 2016;164:133–140. 10.1016/j.socscimed.2016.03.028. [PubMed: 27046475]
9. Washington HA. Medical Apartheid: The Dark Histoiy of Medical Experimentation on Black Americans from Colonial Times to the Present. New York, NY: Doubleday; 2007.
10. Reverby SM. Ethical failures and history lessons: the US Public Health Service research studies in Tuskegee and Guatemala. Public Health Rev. 2012;34:13 10.1007/bf03391665.
11. Reverby SM. “Normal exposure” and inoculation syphilis: a PHS “Tuskegee” doctor in Guatemala, 1946–1948. J Policy Hist. 2011;23(1):6–28. 10.1017/s0898030610000291.
12. Spector- Bagdady K, Lombardo PA. US Public Health Service STD experiments in Guatemala (1946–1948) and their aftermath. Ethics Hum Res. 2019;41(2):29–34. 10.1002/eahr.500010.
13. Plohl N, Musil B. Modeling compliance with COVTD-19 prevention guidelines: the critical role of trust in science. Psychol Health Med. In press. Online 6 1, 2020 10.1080/13548506.2020.1772988.
14. Spalluto LB, Planz VB, Stokes LS, et al. Transparency and trust during the coronavirus disease 2019 (COVID-19) pandemic. J Am Coll Radiol. 2020; 17(7): 909–912. 10.1016/j.jacr.2020.04.026. [PubMed: 32387089]
15. Gibbons J. The effect of segregated cities on ethnoracial minority healthcare system distrust. City Community. 2019;18(1):321–343. 10.1111/cico.12370.
16. Griffith DM, Jaeger EC, Bergner EM, Stallings S, Wilkins CH. Determinants of trustworthiness to conduct medical research: findings from focus groups conducted with racially and ethnically diverse adults. J Gen Intern Med. In press. Online 6 3, 2020 10.1007/s11606-020-05868-1.
17. Grier WH, Cobbs PM. Black Rage. New York, NY: Basic Books; 1968.
18. Kramer RM. Trust and distrust in organizations: emerging perspectives, enduring questions. Ann Rev Psychol. 1999;50:569–598. 10.1146/annurev.psych.50.1.569. [PubMed: 15012464]
19. Williamson LD, Bigman CA. A systematic review of medical mistrust measures. Patient Educ Conns. 2018;101(10):1786–1794. 10.1016/j.pec.2018.05.007.

20. Jamison AM, Quinn SC, Freimuth VS. "You don't trust a government vaccine": narratives of institutional trust and influenza vaccination among African American and white adults. Soc Sci Med. 2019;221:87–94. 10.1016/j.socscimed.2018.12.020. [PubMed: 30576982]
21. Thompson HS, Valdimarsdottir HB, Winkel G, Jandorf L, Redd W. The Group-Based Medical Mistrust Scale: psychometric properties and association with breast cancer screening. Prev Med. 2004;38(2):209–218. 10.1016/j.ypmed.2003.09.041. [PubMed: 14715214]
22. Valera P, Boyas JF, Bernal C, Chiongbian VB, Chang Y, Shelton RC. A validation of the group-based medical mistrust scale in formerly incarcerated Black and Latino men. Am J Mens Health. 2018;12(4):844–850. 10.1177/1557988316645152. [PubMed: 27192716]
23. Brawley OW. The study of untreated syphilis in the Negro male. Int J Radiat Oncol Biol Phys. 1998:40(1):5–8. https://doi.og/10.1016/s0360-3016(97)00835-3. [PubMed: 9422551]
24. Gamble VN. Under the shadow of Tuskegee: African Americans and health care. Am J Public Health. 1997;87(11): 1773–1778. 10.2105/ajph.87.11.1773. [PubMed: 9366634]
25. Gray FD. The Tuskegee Syphilis Study: The Real Story and Beyond. NewSouth Books; 1998.
26. 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(suppl 1):146–161. 10.1177/1077558700057001s07. [PubMed: 11092161]
27. Brandon DT, Isaac LA, LaVeist TA. The legacy of Tuskegee and trust in medical care: is Tuskegee responsible for race differences in mistrust of medical care? J Natl Med Assoc. 2005;97(7): 951–956. [PubMed: 16080664]
28. Rodriguez MA, García R. First, do no harm: the US sexually transmitted disease experiments in Guatemala. Am J Public Health. 2013;103(12):2122–2126. 10.2105/ajph.2013.301520. [PubMed: 24134370]
29. Lee SS, Grutman AJ. Seeking justice for victims of the Guatemalan Sexually Transmitted Disease Experiments 1946–1948. Columbia J Gend Law. 2020;39(2):54–90. 10.7916/cjgl.v39i2.5700.
30. Crawley LM. African-American participation in clinical trials: situating trust and trustworthiness. J Natl Med Assoc. 2001;93(12 suppl):14S–17S. [PubMed: 11798059]
31. Jaiswal J Whose responsibility is it to dismantle medical mistrust? Future directions for researchers and health care providers. Behav Med. 2019;45(2): 188–196. 10.1080/08964289.2019.1630357. [PubMed: 31343959]
32. Fritz Z, Holton R. Too much medicine: not enough trust? J Med Ethics. 2019;45(1):31–35. 10.1136/medethics-2018-104866. [PubMed: 30367013]
33. Metzl JM. Dying of Whiteness: How the Politics of Racial Resentment is Killing America's Heartland. Hachette UK; 2019.
34. Blendon RJ, Benson JM, Hero JO. Public trust in physicians—US medicine in international perspective. N Engl J Med. 2014;371(17):1570–1572. 10.1056/nejmp1407373. [PubMed: 25337746]
35. Gallup. Confidence in institutions. 2019; https://news.gallup.com/poll/1597/confidence-institutions.aspx. Accessed July 26, 2019.