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NOTES FROM THE FIELD

Disinformation, Misinformation and Inequality-Driven Mistrust in the Time of COVID-19: Lessons Unlearned from AIDS Denialism

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During a pandemic about which too little is known, public health is facing a crisis on multiple levels, including regarding COVID-19 related- health messaging. With the federal government's inadequate, inconsistent and largely non-evidence-based response [1–3], and the far reach of social media "armchair experts" [4, 5], tremendous uncertainty, fear, and anger has emerged with respect to the origins, treatments and prevention methods regarding COVID-19. Much of the evidence needed to fully inform clinical and public health responses is not yet available, making COVID-19 uniquely vulnerable to a proliferation of disinformation, misinformation, and medical mistrust, including what are often called "conspiracy beliefs" [6, 7]. Disinformation (strategically and deliberately spread false information), misinformation (false information, not necessarily with intent to mislead), and mistrust (more than the lack of trust; suspicion of ill intent) are multi-faceted phenomena, with heterogeneous underlying motivating factors. The purpose of this commentary is to suggest that understanding the etiologies of disinformation, misinformation, and medical mistrust must be an important component of the public health response to COVID-19. This is especially critical when considering how the pandemic has affected communities of color, including Asian communities who have been blamed for the introduction of SARS-CoV-2 to the U.S. [8, 9] and Black communities who have been blamed for higher fatality rates among Black populations [10]. We propose that two main forms of pushback against dominant scientific evidence have become prominent during COVID-19: (1) disinformation propagated at the institutional/federal government level to preserve power and undermine already marginalized groups, and (2) inequality-driven mistrust among communities that have been made vulnerable by historical and ongoing structural inequities. While these two forms do not constitute a strict dichotomy, this distinction can help inform strategies to address erroneous information and mistrust and inform public health messaging.

"Conspiracy beliefs," characterized as "attempts to explain the ultimate cause of an event…as a secret plot by a covert alliance of powerful individuals or organizations, rather than as an overt activity or natural occurrence" [11], feature prominently in disinformation, misinformation, and inequality-driven mistrust. It can be difficult to persuasively present evidence to refute these types of ideas, especially because experts are often seen as part of the conspiracy [12], and new pieces of contrary evidence can be rationalized into an existing narrative [13]. For example, a Pew Research Center survey conducted in March 2020 found that 29% of Americans believed that SARS-CoV-2 was developed intentionally in a lab [14], with many pointing to Wuhan, China as the source [15]; President Trump has given this theory institutional legitimacy [16], despite scientific consensus [17–20] and the consensus of the U.S Intelligence services that SARS-CoV-2 is not human-made [21]. This strategic disinformation has served several agendas: casting doubt on evidence presented by Dr. Anthony Fauci, the Director of the National Institute of Allergy and Infectious Diseases and member of the White House Coronavirus Task Force, validating and reinforcing pre-existing xenophobia and racism [22], and redirecting attention away from the White House's inadequate and delayed response to COVID-19.

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State-sanctioned disinformation has proven disastrous in the past. In South Africa during Thabo Mbeki's presidency (1999–2008), AIDS denialism was institutionalized at the highest levels of government. This disinformation delayed official recognition of HIV as the etiology of AIDS and the accessibility of life-saving anti-retroviral therapy, which directly contributed to more than 330,000 preventable deaths [23–26]. These examples of disinformation share some commonalities: assertions and preservations of power, authoritarianism, fear mongering, scapegoating to deflect blame, and the creation or reinforcement of states of collective shock, which can be used to facilitate the implementation of political and economic agendas that are more difficult to achieve during periods of stability [27].

COVID-19 disinformation appears to reflect agendas of white supremacy [28, 29], anxiety over social and economic instability [30], opportunistic unrestrained capitalism, and the cult of personality regarding the president [31, 32]. This is a contrast to the inequality-driven mistrust held by people who continue to experience disenfranchisement [33]. In the COVID-19 pandemic, beliefs about deliberately withheld vaccines [34, 35] and the intentional human-made origins of SARS-CoV2 appear to be emerging in some Black communities [36]. While disinformation and inequality-driven mistrust may result in similar or even shared fallacious beliefs, understanding their different origins is vital to delivering effective public health messaging. Government officials promulgating disinformation about the origins of COVID-19 or possible therapies—whether rooted in racism and xenophobia, or whether motivated by goals of deflecting responsibility and accountability—is fundamentally different from marginalized individuals or groups endorsing the same beliefs, for whom mistrust is rooted in ongoing trauma and direct memories of real betrayals [37].

Medical mistrust is well documented among Black people and other populations placed at risk for disproportionate harm [38–45]. For example, endorsement of HIV-related "conspiracy beliefs" is associated with worse HIV-related outcomes among some Black populations [46–48]. This manifestation of HIV-related mistrust can include the beliefs that the U.S. federal government was involved in creating or disseminating HIV as a form of genocide against people of color, that anti-retroviral therapies are harmful, and that a cure is available but is being secretly withheld by the government and pharmaceutical companies [46, 49]. Referring to these ideas as "conspiracy beliefs" frames these beliefs as being irrational or even paranoid, yet for populations made socially and economically vulnerable by interlocking structures of inequality [50], these ideas are often intergenerational in nature and can resonate strongly with ongoing stigmatizing and exclusionary experiences with healthcare, government, law enforcement, and criminal justice systems [37, 51–53]. Similarly, inequality-driven mistrust around COVID-19 may deter or prevent individuals from seeking COVID-19-related medical care or adhering to evidence-based COVID-19 prevention guidelines, such as physical distancing and self-quarantining. This is a critical consideration, as Black, Native, and Latinx populations have been disproportionately affected by COVID-19 infection, morbidity, and mortality [54–59, 69], are disproportionately arrested for physical distancing violations [3, 60], and appear to be less likely to receive COVID-19 testing [61]. More effective public health messaging is urgently needed to address these inequities. We suggest the following recommendations:

Bridging the Mistrust Gap

The onus is on researchers and clinicians to better understand these beliefs and to more effectively bridge the mistrust gaps [62]. A Social Determinants of Health framework [63] can help public health and medical professionals address the impact of population-level inequalities on health outcomes in addition to facilitate enhanced understandings of how social and economic conditions engender inequality-driven mistrust. It is vital to consider how people, as individuals and as members of groups, experience and interpret social and economic inequality, and how those experiences affect their trust in or mistrust of evidence-based public health messaging, as well as their readiness to accept any promulgated misinformation or disinformation [64].

Addressing Racism

Public health and medicine must address structural racism directly [65]. Effective public health responses to the pandemic, and to its disproportionate impact on communities of color and other vulnerable populations, must recognize the complex dimensions of mistrust. This requires attention to the issues of structural racism and systematic discrimination which create, perpetuate, and sustain mistrust and influence people's acceptance or rejection of misinformation or disinformation. The failure to fully address differential risk at the community and structural level, and differential risk among various populations placed at greatest risk for harm, further drives mistrust, which then reinforces mistrust arising from people's daily lived experiences of racism, classism, and stigma [66]. Anti-racism education as well as training on research with and care for marginalized populations, must be more fully integrated into public health and medical education [67].

Framing the Message

Avoiding terms like "conspiracy beliefs" may position us to better understand, and thus more effectively address disinformation, misinformation and inequality-driven mistrust that has emerged during this pandemic. Referring to ideas as "conspiracy beliefs" risks obscuring and denying meaningful aspects of people's lived experiences, particularly regarding inequality-driven mistrust, and is an ethical and strategic mistake for public health [49, 68]. Thus, we propose that public health abandon this term and instead endeavor to identify and distinguish the underpinnings of such beliefs, highlighting how false information may be driven either by agendas of power and racism, or instead driven by mistrust deriving from ongoing social and economic exclusion. This distinction will avoid placing blame on communities that are structurally placed at risk for disproportionate harm by elucidating the role of historical and ongoing social and economic inequalities, while recognizing the forces underlying propagated disinformation and holding accountable those with structural power.

Conclusion

Distinguishing between disinformation and inequality-driven mistrust and shifting language away from "conspiracy beliefs" can help avoid pushing people further toward endorsing misinformation and disinformation. Moreover, language without the negative connotations of "conspiracy beliefs" may leave rhetorical space for marginalized populations to express concerns shaped by historical and current trauma, and for public health to better understand why some people endorse such beliefs. Public health and medical professionals have a responsibility to communicate science in an effective, accurate and accessible manner, without bias—and with the understanding that structural racism and other forms of oppression are root causes of inequality-driven mistrust. While erroneous beliefs may appear to similar in nature, the critical distinction is in the source of and paths to those beliefs.

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