Concept Paper

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Conceptual Analysis

Medical Mistrust: A Concept Analysis

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Abstract: Background The term "medical mistrust" has increased in literary usage within the last ten years, but the term has not yet been given a full conceptualization. This article analyzes usage of the term "medical mistrust" in extant literature in order to articulate its antecedents, attributes, and consequences. The aim of this article is to provide a preliminary conceptual definition and conceptual figure for medical mistrust. **Methods** Walker & Avant's (2019) conceptual analysis method was used. PUBMED, CINAHL, SCOPUS, PSYCinfo, and Google search engines were used. **Results** Medical mistrust is a social determinant of health fueled by a fear of harm and exploitation, and is experienced at both the interpersonal and institutional level, reinforced by structural racism and systemic inequalities. Medical mistrust is predicated by historical trauma, socioeconomic disparities, medical gaslighting, medical traumatic experiences, maladaptive health beliefs and behaviors, individual minority identity, and is transmitted intergenerationally and culturally. Consequences of medical mistrust include underutilization of health services, delays in diagnosis and care, poor treatment adherence, poor health outcomes, negative psychological effects, and an increase in the uptake of medical misinformation and maladaptive health behaviors. **Conclusion** The findings of this concept analysis have important implications for healthcare providers, healthcare systems, researchers, as well as healthcare policy makers.

Keywords: medical mistrust; healthcare; concept analysis; nursing; provider

1. Introduction

1.1. Definition of Medical Mistrust

Merriam-Webster defines *medical* as "of, relating to, or concerned with physicians or the practice of medicine" ("Medical," 2023). However, several articles and forums that discuss medical gaslighting appear to use "medical" as an umbrella term referring to all healthcare professionals including nurses, advanced practice nurses (APNs), doctors, and other practitioners. Medical mistrust, then, is a nuanced idea that can be challenging to define. It generally refers to the lack of confidence or trust in healthcare providers, institutions, and systems [1–3]. It encompasses components such as suspicion towards advice or treatments, doubts about the motives of healthcare professionals, and fear about being mistreated or deceived by the medical industry [4]. This concept has garnered attention for years due to its impact on patient outcomes and the overall delivery of healthcare services. In many instances, individuals who have faced discrimination based on their race/ethnicity or socioeconomic status are more likely to harbor feelings of mistrust towards the system [5,6].

Medical mistrust is an issue that significantly impacts both individuals and the healthcare system [2]. When patients lack confidence in their healthcare providers or hesitate to comply with suggested treatments, it can impede effective disease management and result in poor health outcomes [4]. Moreover, people who hold negative perceptions about the healthcare industry may be more likely to avoid seeking treatment even when they experience symptoms that require immediate attention [7]. In some cases, this hesitancy could stem from fear of being treated differently

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due to their race/ethnicity or socioeconomic status and ultimately this hesitancy s negatively affects overall public health goals, such as reducing healthcare disparities.

Medical mistrust also has economic implications for both patients and healthcare systems. For patients, avoidance or delay in receiving necessary care may result in higher costs later if conditions worsen over time [8]. For healthcare systems, providing services without patient trust can mean lower patient satisfaction rates, leading indirectly to financial losses resulting from decreased patient volume.

In short, understanding the significance of medical mistrust is crucial as it impacts patients and healthcare systems. Additionally, it has the potential to have lasting consequences on the well-being of society. Understanding medical mistrust will help shed light on the factors contribute to its development and lead to potential interventions that can decrease disparities in healthcare access within various communities and locations.

1.2. Difficulties Defining Medical Mistrust

Medical mistrust has been defined and characterized in various ways in the literature. Some authors describe it as a general lack of trust towards healthcare providers or institutions, while others emphasize its roots in historical events such as unethical research practices on marginalized communities, or in systemic racism. One reason it is challenging to pinpoint a precise definition for medical mistrust is that it varies widely among individuals and communities based on a multitude of factors, including individual experiences with the traditional healthcare system [9]. For some people, past negative encounters with healthcare providers may contribute significantly to medical mistrust; others may vicariously develop medical skepticism from hearing stories about others' negative experiences in the healthcare system. Moreover, what constitutes trust also differs across cultures and historically disadvantaged populations, making a universally agreed-upon definition of medical mistrust even harder to establish. Incorporating different perspectives into defining this term is essential to understanding how complex this phenomenon is.

According to Shaughnessy and colleagues (2023), medical mistrust is "a patient's low level of confidence that their healthcare provider will act with benevolence during clinical interactions." This definition highlights the importance of trust between patients and providers within specific encounters, but does not capture other dimensions of medical mistrust [8].

Another commonly description of medical mistrust is "the suspicion held by individuals toward the motives underlying social situations involving health care delivery" [4,10]. This broader definition encompasses factors beyond individual interactions with healthcare providers and acknowledges societal influences on attitudes towards healthcare. Some common characteristics associated with medical mistrust include skepticism, fear, and uncertainty about treatments suggested by healthcare providers [11].

The consequences of medical mistrust can be detrimental both to individuals and healthcare systems. Individuals who mistrust the healthcare system may be less likely to seek necessary treatment, which may both cause their conditions to deteriorate and result in higher costs [7]. Moreover, it can also lead to poorer health outcomes that reflect negatively on the healthcare services. It can also contribute to the uptake of medical misinformation and maladaptive health behaviors. This conceptual analysis will provide a foundation to understanding the comprehensive nature of medical mistrust and its implications on both individuals' health outcomes and healthcare systems.

1.3. Purpose of the Analysis

1.3.1. Clarify the Meaning of Medical Mistrust

The primary purpose of this concept analysis is to clarify what medical mistrust means in healthcare settings, as it is a multifaceted term that can be interpreted differently by individuals and communities. By exploring its various characteristics, factors influencing its development, and its consequences, we aim to provide a better understanding of the conceptual underpinnings of medical

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mistrust. Defining medical mistrust accurately will also help distinguish it from related concepts such as patient/provider communication and patient trust.

1.3.2. Identify Key Attributes, Antecedents, and Consequences of Medical Mistrust

Medical mistrust is a multidimensional term. It is influenced by various factors that play a pivotal role in shaping people's attitudes and behaviors toward seeking healthcare services. These factors can include historical events, socioeconomic status, cultural beliefs, and past personal experiences with the medical system. This concept analysis, therefore, will aim to explore these key factors as well as how they interrelate with each other. To achieve this objective, a literature review of studies ranging from 1990 to the present day examining medical mistrust across different populations within the United States was conducted. This review revealed important themes that directed our insights into a better understanding of medical mistrust.

Furthermore, understanding these factors could help healthcare providers and organizations develop interventions to address medical mistrust. For instance, acknowledging the influence of historical events, such as unethical research practices on marginalized communities, could aid in building trust with those who have been historically mistreated by the medical system. Moreover, addressing socioeconomic disparities that contribute to unequal access to healthcare services can also play a role in reducing medical mistrust within disadvantaged populations.

In summary, the purpose of this concept analysis is not only to define this term but also to promote recognition of its significance within our current societal framework. Addressing medical mistrust as a multifaceted concept should assist future development of strategies that improve health outcomes and equity across different population groups.

2. Methods

Walker and Avant's (2019) method of conceptual analysis was used to explore both terms. Walker & Avant's procedures for concept analysis include eight steps [14]:

1. Select a concept.
2. Determine the aims or purposes of analysis.
3. Identify all uses of the concept that you can discover.
4. Determine the defining attributes
5. Identify a model case.
6. Identify borderline, related, contrary, invented, and illegitimate cases.
7. Identify antecedents and consequences
8. Define empirical referents.

As described, this analysis aims to clarify the meaning of *medical mistrust* through the provision of a preliminary conceptual definition of the term. Due to the usage of gray definitions of this phrase, gray literature such as expert editorials, news articles, and blogs were also searched for discussions of the phenomenon in order to not omit potentially relevant work [12] and unnecessarily subject the analysis to the effects of publication bias [13]. In the case of this analysis, exclusion of grey literature would create an inaccurate description of the phenomenon.

This search was completed in two phases: First, the term "medical mistrust" was individually searched across databases. Following this search, 'medical mistrust" was searched as a compound phrase across databases. Multiple databases were searched including CINAHL, SCOPUS, PubMed, PSYCinfo, and Google's search engine, and no date limiters were applied. Publications were included if they were in English and described the components of medical mistrust or antecedents and consequences of medical mistrust. Blog posts were included if they focused on the primary lived experience of medical mistrust (rather than a general discussion of the topic). References obtained were evaluated and sorted into attributes, antecedents, and consequences of both concepts for the purpose of comparison. Walker & Avant (2019) explain that the eight steps of conceptual analysis

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may occur either in order or simultaneously [14]. As such, attributes, antecedents, and consequences will precede the other steps in this analysis to mitigate the flow of findings.

2.1. Literature Review

Firstly, a thorough literature review was conducted to gather relevant studies and materials on medical mistrust from reputable sources such as academic journals, books, and dissertations/theses. Various databases, including PubMed, CINAHL, and PsycINFO, were searched using the keywords "medical mistrust," "mistrust, "distrust," and "healthcare disparities" and their combinations. In addition to searching these academic databases, grey literature such as dissertations/theses and conference abstracts on similar topics were searched as well. This step aimed to capture unpublished but relevant studies that may not be found in traditional academic sources.

The inclusion criteria for this concept analysis include articles published within the last 34 years (1990-2024) in the English language. This time frame was chosen to capture recent studies on medical mistrust as societal attitudes and behaviors towards healthcare may have changed over time. Data extraction was then carried out on the identified studies by identifying key domains and themes related to medical mistrust. These included historical events that contributed to mistrust in healthcare systems, socioeconomic disparities that influence access to care among different populations, cultural beliefs about health and illness, and previous experiences with the healthcare system that may have shaped attitudes towards seeking care.

On the other hand, exclusion criteria consisted of non-English publications, studies conducted outside of the United States, opinion or editorial pieces, articles focusing solely on provider-patient communication issues or patient trust towards specific healthcare institutions rather than medical mistrust. While these topics are related to medical mistrust, our aim is to provide a thorough understanding of its meaning and implications at a larger scale that goes beyond individual interactions or trust in providers.

Quality assessment was also conducted on each article by evaluating factors such as clear research objectives/questions addressed in the study design, methodology used, analysis of data, results obtained, and discussion of findings/conclusions drawn. This step aimed to ensure that only high-quality studies were included in this concept analysis. Finally, literature reviews, along with grey literature searches, revealed components that influenced people's perceptions regarding medical mistrust. All sources were critically examined using rigorous evaluation techniques such as content analysis and generalization strategies to interpret the data comprehensively. The use of both qualitative and quantitative methods adds strength to the analysis by providing diverse perspectives on medical mistrust.

The analysis also focused on studies conducted with diverse populations within the United States, including marginalized communities such as racial/ethnic minorities, individuals of low socioeconomic status, and those facing discrimination based on their gender or sexual orientation. This focus aimed to highlight the impact of systemic inequalities in shaping experiences of medical mistrust among these groups.

A significant body of biomedical literature has explored various dimensions of medical mistrust among different populations within the United States. A review of the literature finds that racial and ethnic minorities who experience healthcare disparities and inequalities that impact a person or group's interaction with medical institutions or individuals, medical mistrust has been described as "group-based" to reflect mistrust towards individuals or systems that have historically or currently treated that group poorly. This "group" can refer to any population of individuals but extant literature reflects that it has been studied in minority groups, including patients with HIV, African Americans (AA), Latin/Hispanic Americans, and individuals who identify as LGBTQ [4,15–24]. Some studies suggest that medical mistrust serves as a protective measure and a form of "self-preservation" for certain minority groups [2,25].

Among the extant literature, it is found that people of color report higher levels of medical mistrust and conspiracy beliefs towards the healthcare system than non-Hispanic whites [26–29]. Medical mistrust is prevalent within the African American community due to the historical

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mistreatment that African Americans have experienced, dating back to slavery, and the Tuskegee Study of Untreated Syphilis in the Negro Male (TSUS) [30–34]. Because of the exposure to experimentation and medical abuse experienced by this group in the past, it is not surprising that research has found higher levels of medical mistrust within the AA community [15–24].

While mistrust and trust can be considered by the lay person to be simply the opposite of each other, this is untrue, as they are both distinct concepts. Trust in the medical profession refers to the patient's expectation that the healthcare providers or organizations will act in the patient's best interest [35]. Medical mistrust, as it revolves around a patient's suspicion that medical providers and healthcare organizations will actively engage in behaviors that will harm them [4], is not a lack of trust. Trust is fundamental to the relationship between medical establishments, public health officials, healthcare providers and their patients. Trust affects a patients' willingness to seek services [36], provide health information [37], to consent to receive treatment and to adhere to the treatment recommendations [37], to be pleased with services [36], and to continue services with the same physician [38]. Medical trust has proven to be a significant area of study in patient-provider relationships and treatment adherence. Halbert and colleagues (2009) indicate that trust is a factor that is impacted by race and exposure to healthcare providers [39]. African Americans, in particular, report significantly lower medical trust in healthcare providers and the healthcare system compared to European Americans [40–45].

Medical mistrust can be differentiated from the concepts of trust and distrust in that medical mistrust involves and evokes negative emotions [4]. The two terms should not be used interchangeably, as medical mistrust does not involve a lack of trust or exist on the trust measurement scale ranging from low trust to high trust [46]. Trust, as defined and measured, does not include suspicion of the provider or healthcare system. Higher levels of trust have been shown to be associated with fewer emergency room visits, increased treatment plan adherence particularly in the management of hypertension and HIV [47–55], and increased willingness to seek and stay in care [56–59].

3. Results

3.1. Attributes of Medical Mistrust

Medical mistrust has been defined and described in various ways in extant literature. In this section, we will identify defining attributes or characteristics of medical mistrust by reviewing different definitions from authors and relevant studies on this topic.

A. Interpersonal mistrust: Suspicion and skepticism towards healthcare providers' intentions

One common attribute found in definitions of medical mistrust is suspicion towards healthcare providers [4,34]. This involves doubting the intentions, actions, or advice given by healthcare providers. For example, an individual may question their doctor's recommendation for a specific screening test due to concerns about potential harm or its necessity. This attribute can stem from past negative experiences with healthcare providers that have left individuals feeling betrayed or disappointed [34,37]. It can also be influenced vicariously by cultural beliefs related to disease causation and treatment preferences [46]. This attribute also includes doubts about the supportive nature of healthcare providers, as well as the belief that healthcare providers do not support individuals like them [4].

B. Institutional mistrust: Lack of confidence in healthcare institutions/systems

In addition to suspicion towards individual healthcare providers, another key aspect of medical mistrust is a lack of confidence in larger institutions such as hospitals, insurance companies, and pharmaceutical companies [61,62]. According to LaVeist et al. (2009), this includes questioning the fairness and integrity of these institutions and their ability to provide unbiased care [63]. Such mistrust can be rooted in historical events, such as the Tuskegee Syphilis Study, which have eroded trust within minority communities [34]. It can also stem from personal experiences with discrimination or mistreatment within healthcare settings [64,65].

C. Fear of exploitation & harm

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Fear of exploitation & harm is another defining attribute associated with medical mistrust [34,64,66]. This involves a concern that individuals may be taken advantage of by the healthcare system for profit or research purposes without being fully informed about potential risks [67]. This fear may come from past incidents of unethical practices by health professionals toward marginalized groups or by incidents where vulnerable populations were exploited in clinical trials [68] or through vicarious experiences of family and friends experiencing medical maltreatment [69]. It can also arise from concerns about unequal access to high quality healthcare based on socioeconomic status or race/ethnicity [70,71]. Fear is a cornerstone attribute of medical mistrust, and medical mistrust can be seen as a protective survival technique to prevent future mistreatment or as a coping mechanism to deal with ongoing discrimination [64].

D. Mistrust about the medical care

Another defining attribute associated with medical mistrust is patient's doubts and suspicions about the quality of medical care itself [72]. This includes doubts or fear about the validity or safety of prescribed treatment plans, as well as medical procedures and techniques, with particular fear about side effects [73–75]. Individuals who harbor medical mistrust demonstrate the psychological safety need of wanting to control what goes into their bodies, including medications, in order to prevent anything unnecessary or potentially harmful being inside of them [76].

3.2. Antecedents and Consequences of Medical Mistrust

A. Antecedents of Medical Mistrust

The antecedents of medical mistrust are multifactorial but often rooted in historical instances of unethical research or medical practices, or discrimination experienced by individuals within the healthcare system. Other factors such as socioeconomic status, cultural beliefs, and personal experiences with healthcare providers can contribute significantly towards developing medical mistrust.

1. Historical trauma

The historical context plays a significant role in shaping an individual's experience and understanding of medical mistrust [2]. Previous unethical research practices such as the Tuskegee Syphilis Study or forced sterilization have contributed to a legacy of mistrust and suspicion towards the medical system within marginalized communities [7]. This also includes unethical medical research practices that have contributed to mistrust within minority communities. For some populations, such as Indigenous peoples who have experienced intergenerational trauma due to colonization and systemic racism by settler societies, this historical context further reinforces negative views towards Western medicine [77].

2. Socioeconomic disparities

Individuals from low-income backgrounds may face difficulties accessing high quality healthcare services, leading to a lack of trust in their ability to receive adequate care [78]. Regardless of ethnicity, individuals with lower education and lower income demonstrate higher levels of medical mistrust than individuals with higher income and education levels [46,79,80].

3. Personal experiences with discrimination

Discrimination based on race/ethnicity or gender outside of healthcare settings can contribute significantly to an individual's mistrust of healthcare providers [81]. Societal interactions, as well as social experiences of racism, impact an individual's willingness to trust strangers. As this can lead to negative socialization patterns with healthcare [82], then in healthcare settings, this can breed medical mistrust [80,83]. Indeed, medical mistrust has been found to significantly mediate the relationship between perceived discrimination and health behaviors such as medication adherence [21,116].

4. Medical Trauma

Direct medical trauma or vicarious medical trauma leads to the development of medical mistrust. Medical trauma can be psychological trauma, or physical trauma. An individual can be traumatized during a medical encounter by a healthcare provider's poor bedside manner, which could entail poor communication, no transparency in decision making, demonstrating little to no respect for the patient's body, violating the patient's confidentiality or privacy, etc. [84,85].

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5. Medical Gaslighting

Medical gaslighting is considered a form of medical trauma [86]. It is defined as occurring occurs when a physician or other medical professional dismisses or trivializes a person's symptoms [87,88]. It can lead to patients developing psychological shock, shame, depression, and anxiety about medical encounters [88], and reasonably can be considered a contributor to the development and persistence of medical mistrust in individuals who experience medical gaslighting. Medical gaslighting can be demonstrated by healthcare providers in the form of poor provider buy-in during health encounters, dismissive behaviors, belittlement or condescension, and victim blaming of the patient for their condition [86].

6. Health beliefs, health values, health literacy/knowledge

Low health literacy has been found to be a contributor to medical mistrust [89]. Additionally, individuals who endorse health beliefs that are consistent with conspiracy beliefs also endorse some level of medical mistrust [90,91]. As a way to have causal reasoning for the inequities seen in society, an individual may hold conspiracy beliefs. Reportedly, people of color endorse both higher levels of medical mistrust and conspiracy beliefs towards the healthcare system than non-Hispanic whites [24–29]. For example, racial and ethnic disparities in HIV incidence and mortality have been a persistent feature of the epidemic in the United States since its inception 40 years ago. In response, HIV-related conspiracy theories, such as HIV is a man-made virus or AIDS was created by the US government to control the Black population, have developed as common beliefs within the Black/African American community [92].

7. Intergenerational transmission

Family systems theory supports the notion families teach the younger members about racial identity perform racial socialization and teach children about what it means to belong to a minority group and how to respond to racial interactions. Family systems theory supports the notion that intergenerational medical trauma exists and this leads to transmission of medical mistrust and impacts the way future generations interact with healthcare systems. Similarly, families who don't talk about healthcare and diminish the importance of trusting healthcare providers and adhering to treatment plans also contribute to an intergenerational pattern of transmission of medical mistrust. [69,93,94].

8. Cultural transmission

Among those with shared identity and shared cultural experiences, medical mistrust can be a learned response to adversity [46,95,96]. Culturally transmitted medical mistrust can be seen as a tool of empowerment and self-protection, especially if an individual operates on a basis of seeing systems operating against their self-interest [97,98]. This cultural transmission of medical mistrust can occur in the setting of an individual's ethnic community, from their peers, and vicariously through social media usage [99].

9. Medical racism

The American healthcare system built its foundation during the antebellum slavery era the tenets of on white supremacy, discriminatory medical practices, and systemic societal racism [100,101]. In 2021, the Director of the Centers for Disease Control declared medical racism as a "serious public health threat" [102]. Discrimination based on race/ethnicity or gender within healthcare settings can contribute significantly to an individual's mistrust of healthcare providers [104]. Implicit biases are the unconscious attributes that people associate with different social identities such as race, sexual orientation, weight, and gender [103]. Implicit biases are often the unconscious thought processes that predicate medical racism, and stories of medical racism discuss healthcare professionals stereotyping patients based on demographic information leading to biased patient-provider communication. It also includes the assumption by healthcare professionals that symptoms are less valid due to the patient's race, gender identity, ethnicity, or weight [22].Perceived racism has been shown to be the strongest correlate of medical mistrust [105]. Medical racism is also perpetuated and exacerbated by racial discordance between patients and providers [106–108].

10. Structural racism/structural inequities

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Medical mistrust has been linked to structural inequities within society that result in unequal access to resources and opportunities among different population groups [2,101]. These structural inequities can lead to disparities in health outcomes and contribute to mistrust of the healthcare system [7,97]. For example, individuals from lower socioeconomic backgrounds may have limited access to high quality healthcare due to financial barriers or lack of insurance coverage. This can result in a perception that the medical system is not designed with their best interests in mind, leading to feelings of mistrust. [109].

11. Identity status

Minority stress is a contributor to the development of medical mistrust [110,111], whether it is minority status due to gender identity, sexual orientation, religious identity, or identity as a racial ethnic minority. Minority stress theory posits that stress that is disproportionately related to minoritized status is linked to psychological distress [112]. Sexual and gender minority youth report worse healthcare experiences and higher medical mistrust than non-LGBT youth [113,114]. Gender identity, as described with binary options of male and female in relevant studies, was found to be significantly associated with medical mistrust. Male gender was consistently noted across studies to be associated with higher levels of medical mistrust than those of female gender [115–120]. For example, HIV related mistrust and conspiracy beliefs were higher among males [115]. Additionally, being a racial/ethnic minority continues to impact the forms of institutional discrimination that minorities experience daily [2,65,121,122]. and is a consistent predictor of medical mistrust [30,123]. Race-related stress as well as perceived provider racial bias have been shown to be a contributor to medical mistrust among African Americans in particular [117]. Specific to healthcare, the perception of discrimination among AA patients has persisted [124–128] and is a persistent contributor for racial health disparities [44,129]. Additionally, medical mistrust is present when religious differences are present between the patient and physician [130], with some suggesting that mitigation of these differences will lead to a resolution of medical mistrust [95].

B. Consequences of Medical Mistrust:

Medical mistrust becomes a social determinant of health leading to health inequities.

1. Underutilization of health services:

Medical mistrust can lead individuals to avoid seeking necessary medical care when needed. Medical mistrust of healthcare providers is a barrier to utilization of healthcare services, and as a result impacts and diminishes quality of life. Medical mistrust has been shown to correlate to higher rates of emergency department utilization, lower rates of preventive health services, and fewer health seeking behaviors [1,3,105,131,132]. It thereby contributes to exacerbations in health disparities between racial and ethnic groups [24,65,105,125,128,133,134], specifically within the Black community [4,5,15–20,22,23,27,32,33].

2. Lack of adherence/compliance with treatment plans:

When patients mistrust their doctors or the recommended treatments, they may be less likely to follow through with the prescribed plan, resulting in ineffective disease management. One clinical health outcome that has been examined frequently in existing studies of medical mistrust is that of medical treatment plan adherence. The World Health Organization defines adherence as "the extent to which a person's behavior including medication-taking corresponds with agreed recommendations from a health provider" (WHO, 2003). Nonadherence leads to increases in morbidity and mortality, increased health expenditures, and poor clinical outcomes [135]. Studies have examined medical mistrust and medication adherence in the context of chronic illnesses such as hypertension [117] and HIV [22,115,116,119] with study participants with high mistrust scores reporting decreased adherence to hypertension and HIV treatment regimens.

3. Delayed diagnosis and treatment:

Mistrusting a healthcare provider or a healthcare system can cause delays in receiving necessary diagnostic tests or starting appropriate treatments early enough for better health outcomes. Medical mistrust has been shown to correlate with delays in screening for diseases such as lung cancer, HIV, breast cancer, colon cancer [15,22,64,136,137] as well as seeking mental health evaluations,

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particularly among African American patients [138]. It has also been linked with delays from initial diagnosis to first treatment [139,140].

4. Poor health outcomes

Due to the fear of exploitation or unequal treatment based on past experiences and current societal contexts, individuals may avoid seeking medical attention altogether. This impacts health outcomes directly, resulting in poorer health outcomes [141]. These health outcomes can be assessed objectively through measurement of clinical outcomes, and also self-reported by individuals themselves, with varying congruence between them. Medical mistrust has been associated with both assessments of health outcomes, such as poorly controlled asthma [142], perceived diabetes control [143], and even predicting health related quality of life [144,145].

5. Psychological effects

There is literature evidence of the psychological effect medical mistrust has on patients. Firstly, medical mistrust is associated with poor satisfaction with healthcare providers and with care [5,21,27,108,146,147]. Secondly, medical mistrust has a bidirectional relationship with emotional distress [148], as medical mistrust persists chronically, it leads to the retention of distressing emotions, such as feelings of inferiority, powerlessness, loss of faith in the healthcare system, etc. Medical mistrust has also been associated with patient anger [149,150] and contributing to both depression [151] and anxiety [152].

6. Uptake of medical misinformation

It has also been found that race-based medical mistrust significantly negatively predicts patients' medical necessity beliefs, as well as contributed to higher concerns about their medications [120]. The pervasive and oftentimes negative influence of social media in contributing to the spread of medical misinformation remains high and continues to increase [153]. Patients and individuals interested in obtaining health related information increasingly are utilizing social media and public forum websites to do so [154–156]. However, many of these sites are not peer-reviewed and full of false information [157,158], thus potentially contributing to negative public health outcomes [159].

7. Increase in maladaptive and dysfunctional health behaviors. Individuals who experience and endorse medical mistrust have been shown to have downstream, maladaptive health behaviors. These include avoidance of healthcare encounter entirely, and also aversions to certain healthcare sites or medical procedures/treatments. These also include changes in behaviors that affect health communication during or prior to doctor appointments, such as reducing or omitting disclosure of risky behaviors, mental health issues, inaccurately filling out medical history and intake forms, and symptom concealment [80,160–162]. These factitious behaviors, again, are understood to be a psychological protective behavior in individuals who harbor medical mistrust, with the hope it will protect them from medical harm. However, these behaviors serve to worsen health self-management and increase health disparities [162].

In summary, the attributes, antecedents and consequences of medical mistrust are key factors that significantly influence an individual's attitudes towards the health system as well as their health-related behaviors and health outcomes. It is essential to further explore these attributes, antecedents and consequences in order to gain a more comprehensive understanding of this complex concept. Descriptions of the attributes, antecedents, and consequences of medical mistrust can be found in Table 1. The model, related, and contrary cases are based on the results of the search. Given the aim of this analysis and the focus on medical mistrust, these hypothetical cases will be presented in relation to medical mistrust rather than medical trust. Figure 1 is the proposed conceptual model of medical mistrust based on these findings.

3.2. Figures, Tables and Schemes

Table 1. Attributes, Antecedents, and Consequences of Medical Mistrust.

Attributes	Antecedents	Consequences
Interpersonal mistrust: suspicion and skepticism towards healthcare providers and their intentions	Historical traumas	Underutilization of health services

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Institutional mistrust: toward healthcare systems	Socioeconomic disparities	Poor adherence with treatment plan
Mistrust about treatment plans, medical techniques, and quality of care provided	Personal experiences with discrimination	Delayed diagnosis and treatment
Fear of exploitation	Medical trauma	Poor health outcomes
Fear of harm	Medical gaslighting	Increased uptake of medical misinformation
	Medical racism	Negative psychological effects: anger, powerlessness, loss of faith in healthcare system, depression, anxiety
	Health beliefs, health values, health literacy/knowledge	Increase in maladaptive health behaviors
	Intergenerational transmission	
	Cultural transmission	
	Structural racism/Structural inequities	
	Identity status including ethnic identity, gender identity, sexual orientation, and religious identity	

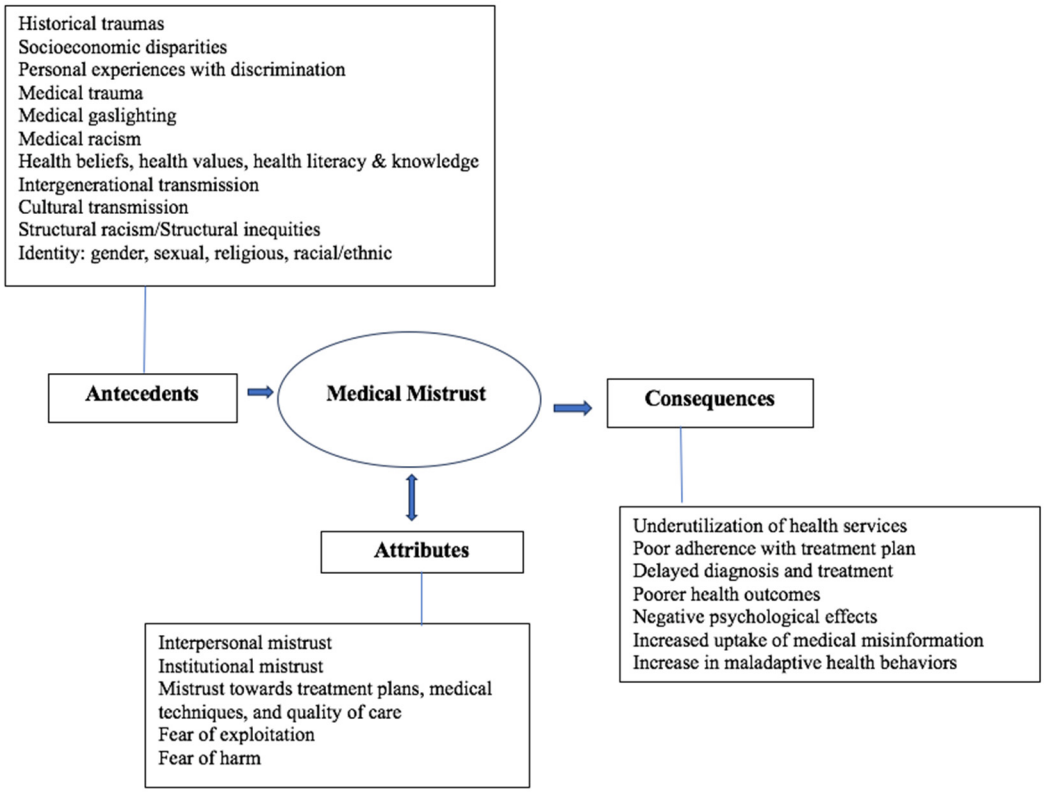

Figure 1. Conceptual model of medical mistrust.

3.3. Model Cases

The Model Case(s) section of this conceptual analysis will present a hypothetical scenario that exemplifies the key attributes and consequences of medical mistrust in order to provide a clear understanding of its impact on healthcare decision-making. Through these model cases, we aim to illustrate the complexity and potential consequences of medical mistrust.

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3.3.1. Case One: Model Case

Maria was a 45-year-old Hispanic woman who had been diagnosed with breast cancer. She came from a low-income background and had always had limited access to high quality healthcare services due to financial constraints. Her mistrust towards doctors stems from her past experiences where she felt ignored or mistreated by physicians. Because of what happened in previous encounters with medical professionals, when Maria received her diagnosis she became fearful about undergoing treatment because she believed it may not have been necessary or effective. In spite of available interventions, due to her mistrust of the system, Maria avoids seeking follow-up appointments and instead relies solely on home remedies recommended by friends until eventually succumbing to the progression of her cancer.

In this case, all of the attributes of medical mistrust are depicted. Several key factors contributed to Maria's deep-seated interpersonal mistrust of doctors, which resulted in delayed treatment that led to her death. First is the interpersonal mistrust towards doctors due to bad past experiences, and second her institutional mistrust is a result of her limited access to healthcare services. Third is her fearfulness of undergoing treatment and mistrust of the treatment itself. It could be that such things as language barriers and cultural customs could have led to Maria feeling neglected or uncared for. Finally, stories she may have heard from friends about alternative treatments could also have contributed to the development of her medical mistrust.

3.3.2. Case Two: Relevant Case

Robert is a 60-year-old African American man who has had diabetes for over ten years. He manages his condition by regularly taking medication prescribed by his doctor and following a strict diet plan. However, when Robert learns he needs an open-heart surgery due to complications from uncontrolled diabetes, he becomes hesitant and skeptical about going through with it. Robert's mistrust stems from historical events where people of his racial background were used unethically in medical practices. Moreover, he had grown up hearing stories of discrimination against African American individuals within the healthcare system and these stories further reinforce his mistrust towards doctors. Although early intervention is likely to reduce the chances of more severe disease, it was not until Robert had a near-death encounter that he hesitatingly agreed to the surgery.

In this scenario, we see several key attributes come into play. Firstly, his knowledge of historical events where African Americans have been used as uninformed subjects for research purposes without their consent contributed towards his mistrust. Second, Robert's perceived discrimination against individuals based on race within the healthcare industry also plays a role in Robert's skepticism, thus reflecting his institutional mistrust. Finally, his fear of exploitation and harm lead him to skip treatment until he had a near death encounter.

In both model cases, we see interpersonal and institutional mistrust, as well as fear, significantly influencing decisions patients make regarding their health outcomes. Moreover, past experiences with doctors and stories heard from others about mistreatment or discrimination serve as antecedents to medical mistrust. We also observe how these key factors interrelate with each other, resulting in an even deeper level of mistrust towards the healthcare system, overall, leading to disastrous long-term effects [163]. From the cases, we also conclude that medical mistrust increases patient morbidity and mortality.

3.3.3. Case Three: Contrary

Alex is an uninsured, low-income white man who lives in rural Appalachia. He suffers from chronic back pain but avoids seeking treatment. He mistrusts medical institutions because of past experiences when he was unable to pay for necessary procedures. One day, while doing physical labor at his construction job, Alex's pain became unbearable, leading him to have no other choice but to seek emergency room services, where tests revealed an acute herniated disc requiring surgery. Despite his previous negative experiences, Alex's emergency room visit ended up being positive. He is treated with respect and empathy by the healthcare team, who understand that he has a history of

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mistrust towards medical professionals. They explain every step of the treatment process to him clearly and address any questions or concerns he may have. Through this experience, Alex begins to slowly build trust in healthcare providers again as they demonstrate their commitment to providing high quality care regardless of his financial situation. This case highlights how mistrust can be overcome through proper communication and understanding from healthcare providers, even among those with preexisting suspicion towards the system.

3.4. Empirical Referents

Empirical referents are tangible and measurable indicators that provide evidence of a concept's existence. In the case of medical mistrust, various measures have been developed to assess its presence and impact among different populations. These empirical referents can aid in recognizing the extent of medical mistrust within society as well as inform interventions aimed at addressing it.

LaVeist and colleagues (2000) developed the Medical Mistrust Index to measure general medical mistrust in hospital settings. It is a 7-item scale that was developed around a conceptual model that specifies "patient satisfaction as a function of individual predisposing characteristics (gender, educational attainment, and age) and experiential factors (frequency of medical care encounters and other attitudes related to the healthcare system)", and thus measures perceived racism, medical mistrust, and satisfaction with care within an institutional context [27]. It has acceptable internal reliability, with a Cronbach alpha of 0.76 [30,105,146]. It uses Likert-type responses such as "strongly disagree," "disagree," "agree," and "strongly agree". The MMI has been extensively used in research studies focusing on diverse populations, including African American, Native American, and Latino communities [2].

Another widely used instrument for measuring medical mistrust among racial/ethnic minorities is the Group Based Medical Mistrust Scale [4]. The Group Based Medical Mistrust Scale is a 12-item scale with Likert scale response options that was developed by Thompson and colleagues (2004) to measure race based medical mistrust as a barrier to breast cancer screening [4]. The Likert scale ranges from 1 (strongly disagree) to 5 (strongly agree), with the total score being calculated by summing all items' responses, yielding a range of 12 to 60 [4]. Statements from the tool describe mistrust of healthcare providers (e.g. "*Doctors and health care workers sometimes hide information from my racial/ethnic group*") as well as reverse coded statements such as (e.g. "*Doctors have the best interests of people of my racial/ethnic group in mind*"). The group-based aspect of the scale assesses the "tendency to mistrust those who do not belong to one's ethnic group and/or mistrust systems that do not represent one's ethnic group because of a legacy of racism or unfair treatment" [4]. The GBMMS is the first instrument of its kind to measure medical mistrust as its own construct, and the only medical mistrust scale that does not use any components of Hall and colleagues' Trust In Physicians Scale (TIPS), which measures trust on a continuum under the dimensions of fidelity, competence, honesty, confidentiality, global trust.

In addition to developing these standardized measures, other research has examined the influence of contributing factors such as race/ethnicity, socioeconomic status, or past personal experiences with discrimination on levels of medical mistrust among certain populations. For instance, Jaiswal (2019) explored how perceived racial/ethnic bias within healthcare settings affected African American patients' trust in their physicians. Similarly, Bazargan and colleagues (2021) found that individuals from lower-income backgrounds were more likely to report higher levels of medical mistrust because they experienced financial barriers to access of medical care and felt that if they accessed that care, they were discriminated against because of their financial status [25].

Overall, these empirical referents reflect the multifaceted nature of medical mistrust and help to describe its impact on diverse populations' health outcomes. They also highlight the need for culturally sensitive assessments when studying this concept since different groups may experience distrust differently. As a result, the use of standardized measures and exploration of various factors influencing medical mistrust provides valuable evidence about this phenomenon. Incorporation of these empirical referents into future research has the potential to aid in developing effective

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interventions to decrease mistrust between patients and healthcare providers/systems, leading to better health outcomes. Table 2 is a summary of these empirical referents.

Table 2. Tools used to measure medical mistrust.

Tool	# of items	Rating scale	Aspects	Reliability(Cronbach alpha)
Group Based Medical Mistrust Scale (GBMMS)	12	5-point Likert Scale	Subscales are: Suspicion of healthcare providers, Group disparities in healthcare, lack of support from healthcare providers	0.83
Medical Mistrust Index (MMI)	7	4-point Likert scale	Mistrust of healthcare organizations and the medical care systems	0.76

4. Discussion

4.1. Definition

Based on this comprehensive conceptual analysis, we propose the following preliminary definition of medical mistrust:

"Medical mistrust is a social determinant of health fueled by an individual's fear of harm and exploitation, presenting as suspicion and lack of confidence towards healthcare providers and systems, and is experienced at both the interpersonal and institutional level, reinforced by historical precedents and ongoing structural racism and systemic inequalities." This definition highlights the multifaceted nature of medical mistrust and how it encompasses personal experiences, social determinants of health, and historical contexts.

4.2. Future Implications of Medical Mistrust

4.2.1. For Future Research

Further research is needed to explore how medical mistrust impacts health outcomes and healthcare utilization among diverse populations. Studies that involve qualitative methods, such as in-depth interviews or focus groups with individuals who have medical mistrust, can provide valuable insights into the underlying factors influencing this phenomenon. Moreover, more culturally sensitive measures for assessing trust within specific populations should be developed to better capture their experiences. By understanding the complexity through which social and ecological factors contribute to mistrust, nurse researchers may create targeted strategies to address mistrust and increase patient engagement in their care. Understanding medical mistrust can help to inform future intervention studies that target this complex psychological phenomenon.

4.2.2. For Healthcare Providers/Organizations

Healthcare providers must recognize the impact of past historical precedents, ongoing systemic racism and inequalities on patients' perceptions of trust towards them. They must work towards building genuine relationships with marginalized communities in order to reduce medical mistrust. Patient-centered communication promotes attentiveness and empathy towards patients, especially those from disenfranchised minority groups, to improve patient-physician interaction and trust in healthcare professionals and the healthcare system [65]. Organizations should also strive to address socioeconomic disparities by providing equal access to high quality care for all individuals regardless of their income levels or insurance status. By understanding its role, nurses can provide better care for each patient, and ensure the distribution of social justice by dismantling inequity not only in clinical practice but also in the fields of nursing research and education.

4.2.3. For Health Policy Makers

Addressing inequalities in healthcare access and developing policies that promote diversity and inclusivity within healthcare institutions could help build confidence in seeking healthcare services

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for those who may not have had positive experiences. Policies should be developed that aim to develop the structural racist pillars and practices still in place today. Implementation of programs that are directed at decreasing the antecedents of medical mistrust discussed here will help empower patients to improve relationships with their healthcare and ultimately improve health outcomes.

5. Conclusions

In conclusion, understanding medical mistrust is essential in promoting meaningful changes within our current healthcare framework, where health inequities continue to exist. It is essential for healthcare providers to recognize that patients who endorse medical mistrust have legitimate antecedents that lead to its development. Addressing and disrupting the antecedents of medical mistrust will help bridge gaps between patients and healthcare systems, leading to improvements in health outcomes and a decrease in the other consequences of medical mistrust.

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