

REVIEW



## Ubiquitous Yet Unclear: A Systematic Review of Medical Mistrust

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### ABSTRACT

Peer-reviewed articles ( $n = 124$ ) examining associations between medical mistrust (MM) and health outcomes from four databases, between January 1998 and May 2018, were reviewed; 36 qualitative and 88 quantitative studies met the inclusion criteria. The Williams and Mohammed framework guided our narrative synthesis of the studies; it argues that basic causes (e.g., biased institutions) affect the social status of marginalized groups which in turn effects multiple proximal pathways leading to responses and poor health. Most studies were cross-sectional with US-based samples. The MM in qualitative studies were categorized as interpersonal ( $n = 30$ ), systemic ( $n = 22$ ), and/or vicarious ( $n = 18$ ); 25% did not explicitly note the basic causes of MM and race/ethnicity was often confounded with socioeconomic status (SES). All but three studies discussed an association between MM and a behavior response; no study focused on an actual health outcome. Most quantitative studies used multivariate regression analyses; only 15 of the 88 utilized advanced modeling techniques (e.g., mediation). Most (75%) studies did not describe basic causes for MM and 43% utilized low income samples. MM was conceptualized as a predictor/proximal pathway (in 73 studies) associated with a variety of responses, most commonly behavioral (e.g., diminished adherence); 14 studies found an association between MM and a specific health measure. This review underscores the need for future qualitative studies to place MM central to their research questions as in-depth descriptions of MM were limited. Future quantitative studies should replicate findings using more advanced analytical strategies that examine the relationship between MM and health outcomes.

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## Introduction

The landmark publication, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*<sup>1</sup> recognized medical mistrust as a social determinant of health and health care disparities among racial and ethnic minority groups and other marginalized groups. To date, medical mistrust has been associated with a variety of health-related and service outcomes. For instance, greater medical mistrust has been associated with lower adherence to cancer screening guidelines, lower adherence to antiretroviral medication among men with HIV, poor patient-provider relationships, and engaging in risky behaviors.<sup>2–6</sup>

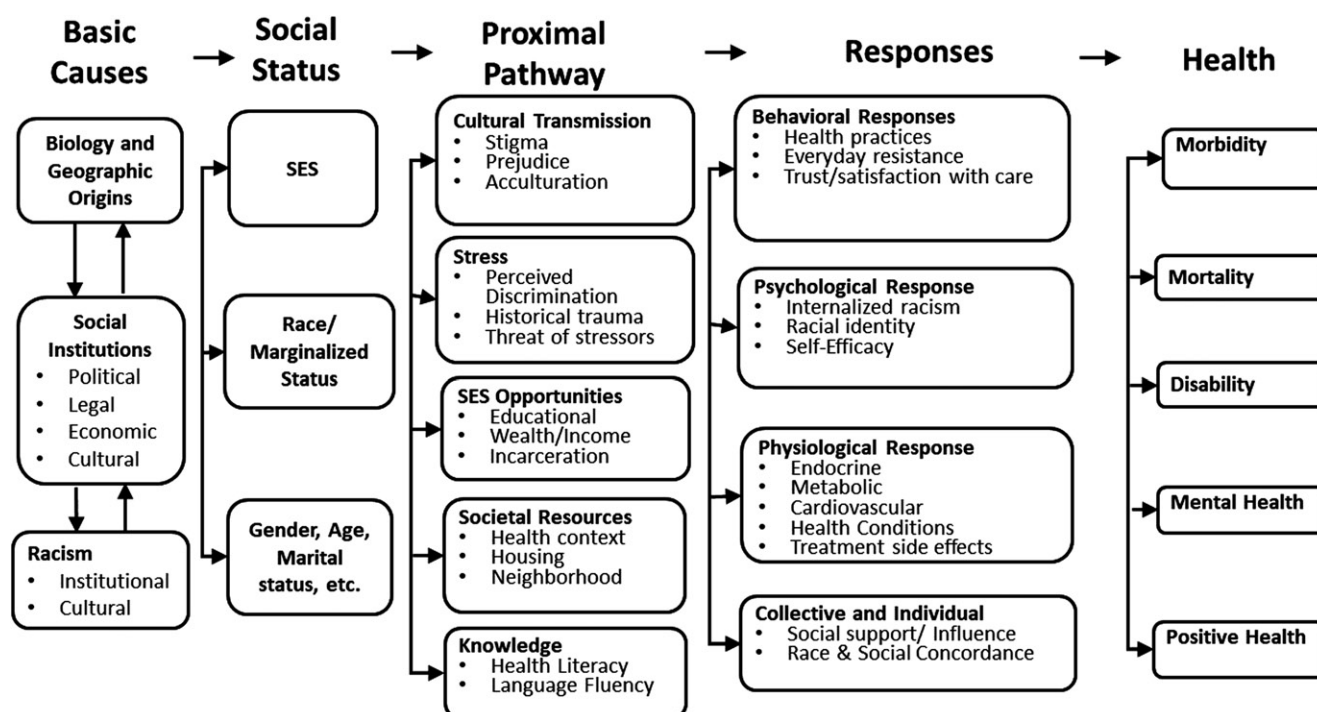
Despite the variations in conceptual definitions and operationalization of medical mistrust (MM), we define MM as a tendency to distrust medical systems and personnel believed to represent the dominant

culture in a given society. As such, MM is not country-specific. It is an active response to direct or vicarious (e.g., intergenerational or social network stories) experiences of marginalization. Like Thompson and colleagues,<sup>2</sup> we argue that MM is most commonly “group-based”, in that it is a tendency to distrust those who do not belong to one’s group and/or distrust systems in which one’s group are poorly represented. The “group” may be variably defined to include multiple marginalized populations, such as persons of color, people living with HIV, sexual minorities, and the socioeconomically disadvantaged. We also argue that MM is a distinctly different concept from interpersonal trust; MM is not part of a continuum ranging from low trust to high trust. In fact, as distinct concepts, trust and MM may influence<sup>7</sup> or contradict one another.<sup>6</sup> MM is not the same as “no trust”; rather MM implies that a trustor’s negative beliefs are that the trustee will go against the

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**Figure 1.** Framework for the study of medical mistrust and health. Adapted from Williams and Mohammed, 2013.

person's best interest.<sup>8</sup> For instance, a person may trust a specific clinician, but may hold suspicious attitudes towards the broader healthcare system and its providers. Finally, we argue that a social-ecological perspective is critical in conceptualizing MM. Mistrust is rooted in histories and hierarchies that influence the nature of one's relationship to institutions, communities, and other individuals, and shape enduring beliefs about one's position and vulnerability within those relationships.

Based on the Racism and Health framework developed by Williams and Mohammed<sup>9</sup> (see Figure 1), health disparities are shaped by historical and contemporary experiences of injustice and discrimination. These experiences operate in multiple contexts and pathways but are rooted in "basic causes," such as geographic origins, social institution and systemic disparities, and both institutional and cultural racism. For example, decades of oppression and discrimination from institutions and the sociopolitical environments (e.g., slavery, forced relocation of Native people) has led marginalized group members to live in residentially segregated neighborhoods, exposing them to environmental toxins, social stressors, and poor access to health care.<sup>10</sup> Thus, basic causes directly impact marginalized groups' health and social mobility. The restricted access to resources such as education and employment can exacerbate poor health outcomes through a range of mechanisms, including

the added stressors (e.g., financial stress, employment stress) that they produce.<sup>11</sup> As shown in Figure 1, multiple proximal pathways (e.g., SES opportunities, cultural transmission) may mitigate or strengthen the relationship between basic causes and social status and responses at the individual level (healthcare usage and engagement with treatment).<sup>12–14</sup> While MM is not included in the framework, we contend that MM acts as an appropriate response to exposure to racism, maltreatment or a hostile social milieu experienced in the health care system<sup>15,16</sup> and ultimately affects health outcomes. Indeed, MM (and its subcomponent, conspiracy beliefs) may be a protective or defensive response or as Mackenzie<sup>17</sup> argues a counternarrative to the dominant group in power. To date, the literature is inconsistent in the conceptualization of MM from a sociological framework; it remains unclear if MM functions as a cultural transmission or protective response. For instance, MM may be a learned attitudinal response that is shared by members of the same group (cultural transmission).<sup>15,18</sup> MM may also be a protective response, operating in the form of caution, skepticism, or self-preservation (i.e., a healthy cultural "paranoia") due to the exposure to basic causes (e.g., discrimination, stigma) within and outside the health care system.<sup>16</sup>

A recent review<sup>19</sup> of quantitative studies found that most studies of MM focused on a mixed race/ethnic

or predominantly African American/Black sample within the context of cancer care/screening, general or HIV care in the United States. While not noted in the review, most studies focused on health care–related outcomes, such as antiretroviral treatment adherence or colon cancer screening. Researchers have assessed the interrelationship between perceived discrimination (i.e., exposure to discrimination/racism in institutions or interpersonal interactions), MM, and health behaviors and outcomes, finding that MM both moderates and mediates the relationship between perceived discrimination and health-related outcomes.<sup>20</sup> Yet, there remains a need to clarify other antecedents and consequences of MM to untangle the pathways that lead to the persistent health disparities among marginalized populations.<sup>21,22</sup> Using Williams and Mohammed framework provides a great opportunity to identify factors that affect MM and elucidate the pathway by which MM affects health. The prior review only focused on quantitative studies, which limits our understanding of the larger social-ecological influences of MM on health. By assessing qualitative studies, we can gain a better understanding of the contextual factors that influence MM and allow us to disentangle potential complexities of a person's health care experiences. To our knowledge, there has been no systematic review that attempts to enhance our understanding of the complexities of the MM concept, the pathways by which MM is associated with health outcomes, and the factors that may facilitate or buffer the effects of MM on health.

The aims of this article are to systematically review the empirical literature—both quantitative and qualitative research—to better understand the antecedents and consequences of MM using the Williams and Mohammed framework as a guiding theory. Through this analysis, we review and highlight limitations in the extant literature evidence and provide recommendations for future research.

## Methods

### *Study design and search strategy*

A systematic search of peer-reviewed research, published between 1998 and 2018, was completed following the PRISMA-P (preferred reporting items for systematic reviews and meta-analyses protocols) guidelines.<sup>23</sup> Since the ground-breaking work on MM was published in 2000,<sup>24</sup> we chose to examine the research on MM from the last 20 years assuming we would capture the breadth of MM empirical literature. Four databases (PubMed, CINAHL, PsycINFO, and

EMBASE) were searched using combinations of Medical Subject Headings (MeSH) and text words for: “medical mistrust,” “mistrust,” “cultural mistrust,” “distrust,” and “patients.” These databases were chosen as they provide the sources for health outcomes and MM articles from medicine/public health (PubMed), nursing/allied health (CINAHL), psychology (PsycINFO), and for international articles (EMBASE). We initially reviewed ERIC for medical education and Communication and Mass Media Complete for health communications but no new sources were found. The Prospero systematic review number is CRD42018110098.

### *Screening and inclusion/exclusion criteria*

Abstracts and titles of the articles were screened by three authors (RB, EDM, DK) using the inclusion criteria: (1) published in English; (2) quantitative or qualitative research; and (3) related to medical mistrust in health care. Two authors rated all titles and abstracts using a topic rating system with a scale of 1–5, with higher scores indicating good fit based on our three inclusion criteria. All low rated citations (scores 1–3) were secondarily reviewed by the other two authors (HT, AC). The team excluded reviews, letters to the editor, opinion pieces, instrument analyses, non-peer reviewed empirical findings, and articles focused on MM of organ donation, genetic testing and medical research. While MM is associated with organ donation and genetic testing decisions and medical research participation, in most cases, donation of organs to others, genetic testing, or medical research participation are not proximal to health outcomes. Given the complexity of multiple operational definitions of MM,<sup>2,12,25</sup> the authors excluded articles with MM measures with less than 4 items unless the measure was a subscale of an existing tool, such as, the suspicion subscale of the Group Based Medical Mistrust Scale [GBMMS]).<sup>2</sup> Full texts of the eligible articles were divided and summarized in table format; uncertainties were resolved through discussion and consensus with the other coauthors.

### *Data extraction and analysis*

Since the majority ( $n=116$ ) of the eligible studies used cross-sectional designs, the Strengthening the Reporting of Observational Studies in Epidemiology Statement (STROBE) tool elements were used in the table summaries to limit potential biases.<sup>26</sup> Each author was assigned a group of full text articles to

review and place on one of two tables (quantitative or qualitative). Information from each article (data), using the STROBE criteria were extracted and placed on the tables. The Data were analyzed using narrative synthesis, a textual approach that appraises the research of a large and diverse literature base by “telling the story” to explain the findings.<sup>25–27</sup> This approach begins with the development of a guiding theory (i.e., Williams and Mohammed<sup>9</sup>) and then an interpretive synthesis of findings is developed rather than a meta-analysis of data. We did not exclude studies if they did not match our framework or definition. Rather we chose to compare our framework to the current literature. The primary author (RB) independently reviewed the tables (one for qualitative and one for quantitative) of eligible articles creating individual themes of the findings. Themes were then examined by all authors; disagreements were resolved by discussion and consensus.

## Results

Searches across the four databases identified 895 unduplicated articles for title and abstract review (see Figure 2). After the initial title and abstract review process, as described above, 589 articles were excluded. Full text of 313 articles were reviewed using the inclusion and exclusion criteria (as mentioned). The reference lists of the articles were also reviewed for potentially missed but relevant articles. Of these, 124 articles were included in the detailed review; 88 were quantitative studies and 36 were qualitative studies. The narrative synthesis provides a summary of the qualitative and quantitative studies, and an overall assessment of the major themes based on the Williams and Mohammed framework and study types. To further delineate the concept of MM prior to the review of the studies, the authors created a variety of subtypes of MM during the analysis process. Appendix A provides the subtype and working definition of the various subtypes of MM found in the empirical literature. The qualitative studies focused on different aspects of MM and, therefore, can be categorized as interpersonal mistrust ( $n = 30$ ), systemic mistrust ( $n = 22$ ), and vicarious mistrust ( $n = 18$ ). A table providing the working definition of the various subtypes of MM found in the empirical literature, as well as, example quotes, and citations is provided in Appendix A. While interpersonal or systemic mistrust may be clear to readers, we use the term “vicarious” mistrust for the often historically transmitted and sympathetic participation in the development of

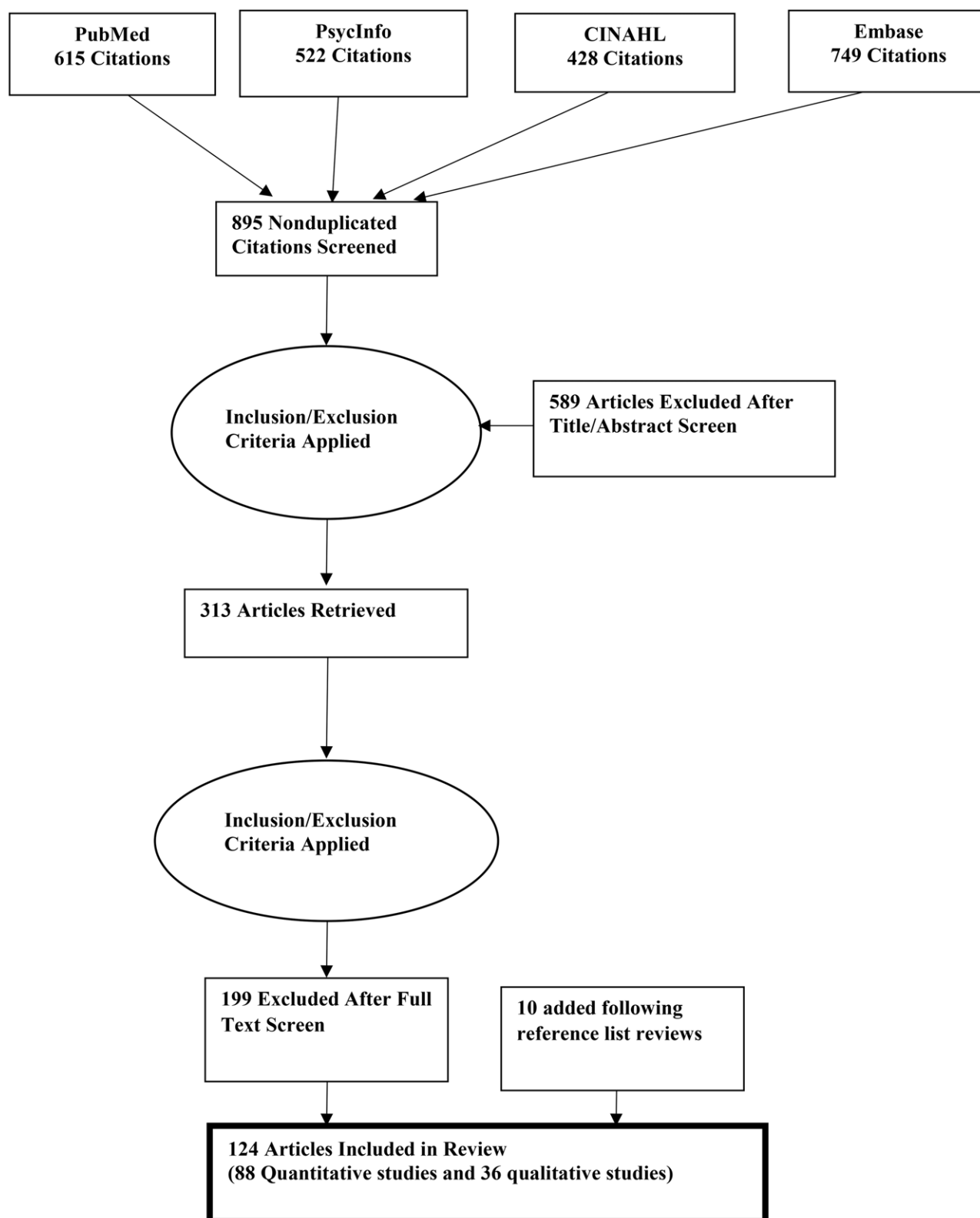
mistrust based on the experience of another. The qualitative literature is replete with these types of mistrust. Given the breadth of literature reviewed, an exhaustive description of every study was not feasible. A supplemental file is available to readers online (see Appendix A; See Supplemental file at <http://www.tandfonline.com/vbmd>).

## Qualitative studies of MM

Of the 36 studies, the sample sizes were diverse, from 10 to 196 participants. Most ( $n = 13$ ) studies focused solely on African American subpopulations (e.g., young adults,<sup>28</sup> veterans living with HIV<sup>29</sup>). Other studies included socioeconomically disadvantaged Whites<sup>30,31</sup> and Native Americans or First Nation peoples.<sup>32–37</sup> Seven additional studies had samples of foreign-born or recent migrant populations (e.g., Bangladeshi patients,<sup>38</sup> Hmong immigrants in Oregon,<sup>39</sup> Kenyan community health workers<sup>40</sup>). The remaining studies ( $n = 9$ ) used mixed race samples.

Synthesis of the studies guided by the Williams and Mohammed framework (see Figure 3) provided general support for the framework and notable gaps in the literature. A summary of the studies by the major constructs of the framework is provided below. Individual in-depth interviewing ( $n = 23$ ) or focus group ( $n = 14$ ) were the predominant methodologies. A few ( $n = 3$ ) utilized ethnographies with participant observations.<sup>31,35,41</sup> The predominant analytical processes included line by line coding and inter-rater agreements ( $n = 22$ ) followed by constant comparative and grounded theory approaches ( $n = 13$ ). The remaining analytic strategies were study-specific (e.g., content analysis of texts from discussion boards<sup>42</sup>). Few studies reported on external validity processes (e.g., member checking processes).<sup>37</sup> While the majority of the studies were theory-building research, three studies were guided by an existing theory, such as the Health Belief Model.<sup>43</sup>

**Basic Causes.** While we argued that exposure to discrimination and/or racism and/or bias in institutions or interpersonal interactions is a noted precursor to medical mistrust, nine studies<sup>28,40,42–48</sup> did not explicitly note these associations in the background to the study despite the results indicating that MM was a result of these causes. Our categorization of systemic MM provided exemplars of the basic causes and was the second most common type of MM described in the qualitative studies ( $n = 22$ ). Systemic mistrust was often described as a broad concept. Participants did not delineate between the three main basic causes,

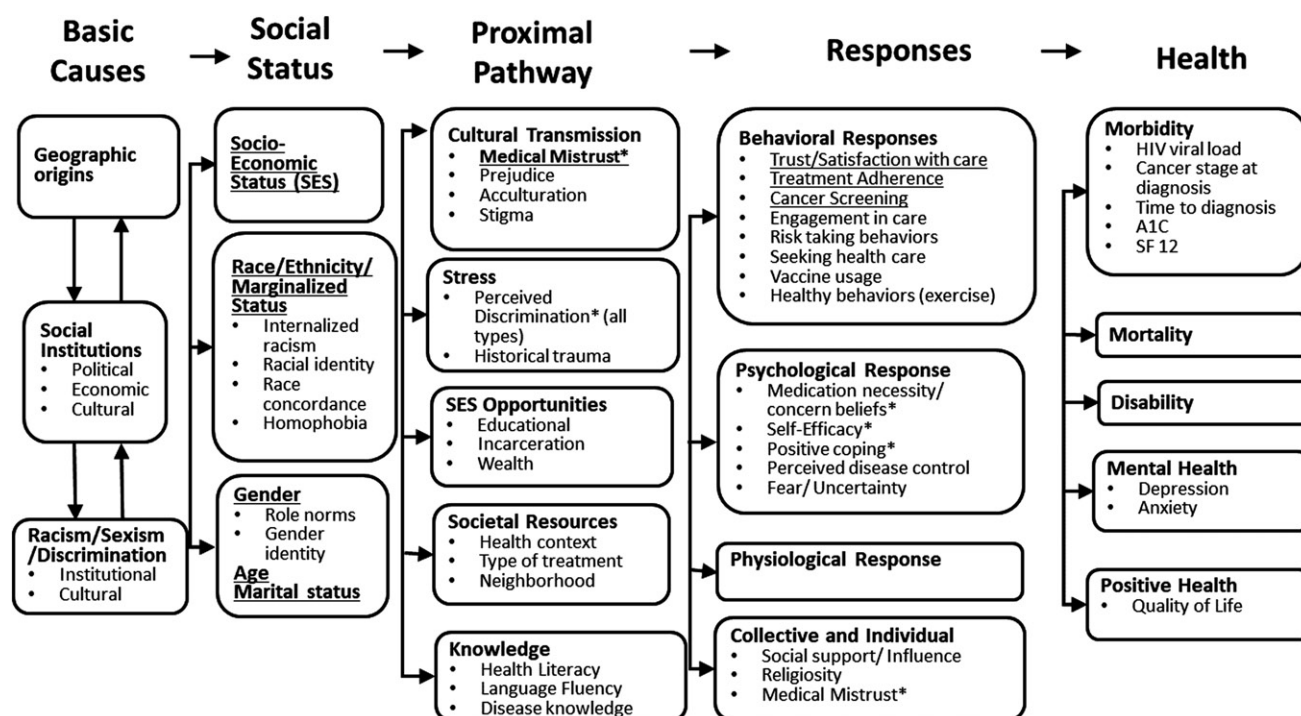


**Figure 2.** Steps in article selection process.

biology and geographic origins, social institutions, or racism. Systemic mistrust is consistent with basic causes as described in the Williams and Mohammed framework such that the “systemic” was often used to

signify the “healthcare system,” “pharmaceutical industry,” or “Ministry of Health” and the discrimination and/or racism experienced in these systems. While the descriptions of “systemic” MM implied past





**Figure 3.** Summary of variables found in the literature using an adapted version of the Williams and Mohammed framework, 2013.

social institutions, policies, or events that had devastating effects in these groups, few of the “system” qualitative studies explored in-depth the meaning of these terms (e.g., “healthcare”) leaving an ill-defined concept for readers. In studies that focused on participants with HIV or who were at risk for HIV, systemic MM often overlapped with conspiratorial theories about the healthcare and the pharmaceutical industries. Nevertheless, systemic MM was often described by participants as a distrust toward the health system that is often driven by the “bottom line”<sup>49</sup> which entailed seeking financial profit for personal or systemic gain with little regard for the health and well-being of “the patient.”<sup>50</sup>

**Social Status.** MM described among solely racial and ethnic minority groups or mixed-race samples in the qualitative studies was often confounded with socioeconomic status (SES). Many studies ( $n = 18$ ) utilized low income samples of racial and ethnic minority groups or provided no data on the SES ( $N = 12$ ) making it difficult to disentangle the racial and ethnic minority groups and socioeconomic components of MM. For instance, Canales and colleagues<sup>29,30,34</sup> found among socioeconomically disadvantaged Native American adults in the Northeastern United States that discussions of MM arose when participants shared past experiences of poor care due, in part, to their lack of SES opportunities (e.g., income, education, adequate health care access). Only four

studies<sup>39,50–52</sup> examined the heterogeneity of SES within racial and ethnic minority groups.

**Proximal Pathways.** MM experiences were tied to direct or vicarious past experiences of discrimination or poor treatment (e.g., cultural transmissions).<sup>9</sup> The negative direct experiences or vicarious experiences that resulted in MM often included descriptions of discrimination, bias, stigmatization, and inadequate communications. Of the 36 qualitative studies in this review, 18 provided explicit descriptions of vicarious MM; most of the vicarious experiences ( $n = 11$ ) were intergenerational. As noted previously, this type of mistrust is often historically transmitted through stories shared from one generation to another with the person actually experiencing the bias or discrimination himself or herself; it is based on the experiences of another. All studies that featured vicarious mistrust were from research that focused on Native American/First Nation, older African American or non-US based samples. MM was often associated with historical injustices committed by the dominant culture or government toward the participants’ respective group (Basic Causes). In contrast, the exemplars of intergenerational or vicarious MM ( $n = 18$ ) were similar across studies and included depictions of atrocities that were directed toward the sample participants’ relatives, families and friends (e.g., Native Americans being forced to attend “residential schools,”<sup>32</sup> “mistreatment by the dominant culture”<sup>33</sup>). Most of the discussions

of intergenerational and vicarious MM, among African American samples, commonly described the “systemic” problems facing African Americans as both current experiences of mistrust<sup>51</sup> as well as awareness of historical mistreatment as the Tuskegee experiment and slavery.

**Responses.** Perceived interpersonal MM pervaded reports when patients, particularly marginalized group members, discussed their healthcare experiences. Perceived interpersonal MM was often described as a response to poor treatment (e.g., a cultural transmission of prejudice or stigma) during health care provider–patient interactions and it was the most common type of medical mistrust ( $n = 30$ ) described by participants. Except for one study,<sup>42</sup> all participants described interpersonal medical mistrust the derived from prior direct negative experiences with health-care personnel.

In most studies, the participants described the negative impact of MM on behavioral responses as health practices or nonresponses, primarily cancer screening (e.g., adhering to a provider’s advice or altering self-reports to the provider about treatment and follow up ( $n = 8$ ), and seeking health or mental health care ( $n = 5$ ). HIV prevention and current treatment were also affected by MM ( $n = 7$ ). In three studies<sup>31,51,53</sup> MM was not discussed as influencing behavioral responses; in these studies, the participants saw the value of self-care over the impact of MM on behaviors.

**Health Outcomes.** Participants’ reports of MM focused on the effect of MM on several behavioral responses (e.g., screening, care seeking); however, no qualitative studies specifically addressed health outcomes as described in the Williams and Mohammed framework. All 36 studies focused on the responses to basic causes, social status and proximal pathways without focusing on a specific health outcome of targeted participants (e.g., with diabetes mellitus patients;<sup>32</sup> with hypertension<sup>52</sup>).

### Quantitative studies of MM

Of the 88 quantitative studies, all but one<sup>54</sup> utilized 100% US-based samples. Most of the literature focused solely on African American, non-Hispanic ( $n = 34$ ) or mixed race ( $n = 25$ ). Sexual minorities who were also often racial and ethnic minority groups minorities ( $n = 12$ ) were the participants in studies focusing on a dimension of MM, HIV conspiracy beliefs. Few studies solely included Latinx/Hispanic ( $n = 11$ ) or Native American ( $n = 2$ ) samples.

Cross-sectional designs with multivariate (linear [ $n = 38$ ] and/or logistic [ $n = 42$ ]) regression analyses were the predominant analytic methodologies. Few studies utilized path analysis,<sup>22,55,56</sup> mediation modeling,<sup>14,56–63</sup> or moderation modeling<sup>64–66</sup> and advanced modeling techniques, such as structural equation modeling<sup>62,67,68</sup> or repeated measures with longitudinal designs; e.g.,<sup>3,69–72</sup> Eighteen studies (see [Appendix A](#)) tested existing theoretical models. Those that did most frequently ( $n = 8$ ) tested Anderson’s behavioral model of service use.<sup>20,58,61,73–75</sup>

Using [Figure 3](#) as a pictorial representation of the variables found to be associated with MM, only a few paths have been tested sufficiently to provide strong assertions of the effect of MM on responses or health outcomes. The underlined variables in the framework figure have been tested in at least 10 studies; and those with an asterisk were used as mediators. The path between race-ethnicity or socioeconomic status and MM is well established. Similarly, most studies find that perceived racial and ethnic minority groups discrimination and MM are negatively associated with multiple behavioral patterns or responses (e.g., treatment adherence, intention to use a health service, such as cancer screening, and health service delivery outcomes, such as satisfaction with care). Still, the mediating or moderating effect of MM, as opposed to perceived discrimination (as proximal pathways), and subsequent responses remain largely theoretical with limited testing of the similarities or differences in these pathways. A summary of the studies by the major constructs of the framework is discussed next.

**Basic Causes.** Utilizing the background and introduction to assess the study’s use of Williams and Mohammed basic causes as a framework, the quantitative studies were equally split between those that described basic causes for the mistrust and those that did not. Those that described basic causes included a background or introduction that argued for historical atrocities or discrimination of varying types (race, sexual orientation, socioeconomic status) as a source of the mistrust ( $n = 33$ ). The articles that did not describe basic causes often relied on the empirical literature to develop a conceptual model (e.g., use of concepts from the Anderson behavior model) with mistrust as one of the variables in the model ( $n = 33$ ). Mistrust was just one of many predictors of a selected outcome. Even when the population of interest (e.g., Native Americans;<sup>76</sup> African Americans<sup>77</sup>) have well-documented health care related injustices, the studies remained silent on the underlying source of mistrust. The remaining 22 studies provided a mixed

perspective in the introduction as to the source of the mistrust often relying heavily on bias or discrimination by health care providers without discussing the larger societal structure that may have influenced the providers. For example, Greer and colleagues<sup>78</sup> discussed the link between discrimination and MM in an African American sample, but the literature review emphasizes the importance of the patient-provider relationship and interactions as the source of discrimination.

*Social Status.* While most ( $n=86$ ) studies controlled for socioeconomic status, the samples were nearly split between those with socioeconomically disadvantaged ( $n=38$ ) or mixed income samples ( $n=42$ ). Given the well-known association between race/ethnicity and MM, all studies attempted to control for race/ethnicity in the statistical analyses; however, in 17 studies, race remained as a key predictor of a health care response or the samples ( $n=53$ ) were limited to a single racial or ethnic group.

*Proximal Pathways.* MM was often conceptualized as an independent predictor of a behavioral pattern or response ( $n=73$ ). Using cross-sectional designs, numerous studies (see [Appendix A](#)) found that higher MM was a statistically significant predictor or pathway between race and multiple behavioral responses. While we placed MM in a proximal pathway based on a study's analytical method (i.e., regression analysis), the multiplicative effects of stigma, discrimination (as cultural transmissions in the Williams and Mohammed framework) and MM on behavioral responses were often indistinguishable. As such, with limited use of path analysis or structural equation modeling and multiple proximal pathways studied simultaneously, it is difficult to isolate the individual impact of these various predictors on the outcome. The only path that was analyzed in more than one study was the one between discrimination and MM ( $n=25$ , see [Appendix A](#)); yet only one study explored this path in any depth. Galvan and colleagues<sup>14</sup> provide one exemplar of an attempt to tease out the paths; in a study of Latinx men living with HIV, they reported that treatment adherence was associated with MM, sexual orientation (heterosexual), perceived gay sexual orientation discrimination, and HIV serostatus discrimination. After controlling for sexual orientation, MM was found to be a significant mediator between Latinx ethnicity discrimination and HIV serostatus discrimination on treatment adherence.

Seven studies<sup>14,55,58,60,62,63,79</sup> tested MM as a mediator between a social status variable (i.e., race) and a response of interest. Despite the mediation modeling,

Lin<sup>62</sup> and Abraido-Lanza<sup>79</sup> provided the only studies that examined MM as a potential mediator of the relationship with other mediators and a behavioral response. Similarly, only three studies<sup>64–66</sup> examined MM as a moderator of the strength of the relationship between MM as proximal pathway predictor and a response. For instance, in their sample of Black women who have sex with women, Brenick and colleagues<sup>66</sup> reported moderator effects of MM as demonstrated by significant two-way interactions between MM and race-based stigma, such that when both predictors were high, self-report of a recent physical exam was lower. These authors<sup>66</sup> also found an interaction between MM and sexual orientation stigma such that high MM was associated with less recent engagement, regardless of the level of stigma. There was also a significant three-way interaction: high MM with high race-based stigma was related to less recent engagement in health care, regardless of whether sexual orientation stigma was high or low, and participants who were low on all three variables reported more recent engagement with care.

Eight studies<sup>6,59,66,67,73,74,80,81</sup> utilized more than one measure of MM to differentiate how various types of MM (e.g., race-based versus general) may be differentially associated with a response or health outcome. For example, Pellowski and colleagues<sup>67</sup> measured race-based MM with the GBMMS and the MMI as general mistrust and found different associations to the response of medication adherence. Higher levels of MM (as measured by the race-based GBMMS) predicted lower medication adherence, whereas, MM (as measured by the general, MMI) did not predict medication adherence. The finding may suggest that race-based MM acts differently on medication adherence than general MM. Lastly, four of the eight studies<sup>59,73,74,81</sup> conflated the concept of mistrust by utilizing a physician trust measure (sometimes reverse coded) as an additional measure of “interpersonal” MM.

Recent research is uncovering the complexities and possible buffers between MM and a behavioral response (e.g., adherence). These buffers may provide viable targets for interventions to improve responses (see the Williams and Mohammed framework) in the context of mistrust. Using structural equation modeling or multiple mediation modeling, three studies<sup>22,67,68</sup> explored paths between MM and the study response or outcome. Pellowski<sup>67</sup> and Kalichman<sup>22</sup> tested the hypothesis that mediation concern beliefs and medication necessity beliefs mediated the relationship between MM and antiretroviral treatment (ART)



adherence. Each study used one<sup>22</sup> or two<sup>67</sup> subscales of the GBMMS<sup>2</sup> to assess the effect of race-based MM, and each found similar and distinct results with distinct samples of African Americans. Race-based MM significantly affected medication concern beliefs<sup>67</sup> but the path between concern beliefs and ART adherence was insignificant; in contrast, Kalichman,<sup>22</sup> using the suspicion subscale of the GBMMS found significant paths between MM, medication necessity beliefs and ART adherence. Maly<sup>68</sup> found significant paths between MM, positive coping style and quality of life.

*Reponses.* The clear majority ( $n = 66$ ) of studies utilized a behavioral pattern/response as the outcome (dependent variable) of interest. Satisfaction with care ( $n = 19$ ), treatment adherence ( $n = 18$ ) and cancer screening ( $n = 16$ ) were the most common behavioral health practices. MM was often associated with low healthcare participation, such as treatment nonadherence or diminished adherence<sup>72</sup> and delays/avoidance of cancer screening or care seeking.<sup>56</sup> Other studies found that higher MM is associated with lower utilization of services<sup>43</sup> and lower engagement in care or no care in past year.<sup>66</sup> The remaining behavior patterns/responses were limited to a few studies (e.g., usual source of care;<sup>82,83</sup> high risk sexual behavior<sup>72,84</sup>).

A few studies described psychological responses ( $n = 4$ ; e.g., pregnancy stress<sup>63</sup>) as dependent variables; no other response (e.g., physiological) per the Williams and Mohammed framework were found. Fifteen studies (see [Appendix A](#)) conceptualized MM as a response (or dependent variable of interest) from a proximal pathway (e.g., discrimination, stigma). Based on our definition of MM, it may be functioning as a collective or individual resilience response (see Williams and Mohammed framework); it is an appropriate, protective response to exposure to racism, maltreatment, or a hostile social milieu experienced in the health care system. Yet, only six<sup>59,61,85–88</sup> of the fifteen appear to support our framework as the six studies described a basic causes perspective in their background sections and/or discussions that would justify MM as a protective response to societal discrimination.

*Health Outcome.* Fourteen studies (see [Appendix A](#)) analyzed a direct or indirect association between MM and a specific health measure as defined by the Williams and Mohammed framework (e.g., quality of life, HIV viral load, hemoglobin A1C, etc.). Yet, the paths remain inconsistent. Quinn et al.,<sup>89</sup> found a direct relationship between MM (as a general mistrust versus conspiracy beliefs) and detectable viral loads among participants on antiretroviral regimens, such

that a one-unit increase in the MM subscale was associated with more than a threefold increase in detectable viral loads. In contrast, Jiang and colleagues<sup>90</sup> found that while MM directly predicted quality of life, personal communication with a physician and self-efficacy were more significant predictors of quality of life and symptom distress than MM. The authors suggest that physician communication and self-efficacy may be facilitating or buffering the effect of MM on quality of life.

## Discussion

In the current review, 124 articles (36 qualitative and 88 quantitative studies) were identified that focused on MM and behavioral responses or health-related outcomes. Articles were organized by methodological approach, qualitative and quantitative, and within each domain, we identified themes and specific areas of interest within the literature using the Williams and Mohammed framework as a theoretical guidepost. Qualitative studies have illustrated that interpersonal MM often arises from prior negative experiences in the healthcare system, many of which are perceived to be discriminatory. Many participants who belong to marginalized communities also report mistrust due to historical experiences of discrimination and injustice that their community have faced. Quantitative studies demonstrate that MM is an important influence on behavioral patterns and responses, often negatively affecting satisfaction with care (or trust in the provider), treatment adherence or cancer screening. In a few studies, MM also affects health-related outcomes, particularly health related quality of life and health morbidity.

While our study supports the findings of Williams and Bigman's systematic review<sup>19</sup> (e.g., GBMMS<sup>2</sup> and the MMI<sup>12</sup> are the two most commonly used measures of MM), we move the previous research a step further, by including qualitative studies in our review and focusing on a wider range of outcomes. Using the Williams and Mohammed framework as a guide, we were able to identify potential direct or indirect associations between basic causes and MM and consider MM as part of proximal pathways that influence behavioral responses and health outcomes. Nevertheless, both qualitative and quantitative studies had limitations.

A primary dilemma within much of the qualitative literature that described MM as a theme is the broad nature of the research aims. Because many of these studies sought to better understand several other

aspects of patients' experiences, MM was often not central to the research question itself nor a specific part of an interviewers' queries. The broad aims decreased opportunities for researchers to ask questions that could help to vividly describe factors that influenced MM or identify factors that are influenced by MM. Therefore, apart from two studies,<sup>34,91</sup> most qualitative studies described MM as one of many factors that impact a particular health outcome of interest. While the studies may have additional data that provide more in-depth descriptions of MM, the reported findings are often limited to one or two quotes from a single participant. Future research, possibly using phenomenological approaches, should make MM more central to the study design as this would improve our understanding of the context and "lived experience" of MM and can improve the validity of existing measurements.

While the qualitative samples were more diverse than the quantitative studies, most of these studies have focused on two major populations: African Americans and Native Americans. While emerging research is beginning to include other groups, they are often not the sole interest in the studies. Few studies focused predominantly (at least 50% of the sample) on Latinx<sup>92,93</sup> or Asian (East or South) samples,<sup>38,39,41,48</sup> and even fewer sought to understand MM from using a heterogeneous ethnic sample (e.g., a Latinx sample from Mexico, Puerto Rico, Dominican Republic).<sup>94</sup> Due to their cultural milieu and their own unique historical and contemporary experiences of discrimination, these unique marginalized groups may express MM differently. The qualitative identification of factors that contribute to MM for these groups would be particularly important for measurement development as well as quantitatively examining factors associated with MM. Furthermore, sexual minorities are an underserved group that confronts multiple healthcare barriers due to marginalized status. In particular, sexual minorities who are also racial and ethnic minorities confront intersectionality due to social categorizations such as race, class, and gender that create overlapping and interdependent systems of discrimination or disadvantage. Future MM qualitative research must address these complexities to better understand how they overlap or independently interface with MM.

The quantitative research on MM has grown substantially in the last decade. Yet, since the concept is in the beginning stages of clarification and measurement, few researchers have replicated the use of similar measures with similar or different populations of

interest. A review of [Appendix A](#) clearly suggests that replication studies using identical study variables in new populations would significantly add to the literature, and more importantly, highlight areas for interventions that might reduce health disparities. Early research (1998 to mid-2000s) found that multiple demographic variables (e.g., race/ethnicity, low income, low education level etc.) are significantly associated with race-based MM. The association between MM and constructs related to marginalized groups' experiences, such as racism and mistreatment are less clear. Most studies have found an association between race and MM, with non-Whites, particularly African Americans, reporting greater MM than Whites, but using our framework, authors did not explicitly describe the source of these experiences. Later research (2010 and onward) has attempted to tease out various interrelated concepts (trust, perceived racism, and racial identity) and examine how they independently affect health disparities and health outcomes, but the studies are limited. We know very little about the proximal pathways contributing to MM; only seven studies<sup>7,14,55,58,59,61,95</sup> specifically measured these concepts as precursors to MM and only two<sup>14,55</sup> used advanced modeling to support the associations or mediation effect. Moreover, only Galvan<sup>14</sup> sought to understand different types of discrimination, race-based and sexual orientation. Most of the research evaluated MM, along with the precursors as one of many predictors of a behavioral response.

It is well-established that MM is associated with a variety of health-related and service outcomes yet the quantitative research exploring the complexities of MM deserves further study using complex modeling, longitudinal, and mediator/moderator analyses. While we can surmise that lower adherence to medical recommendations or a specific treatment regimen leads to poorer health, we know very little about whether MM contributes to poor health long term or whether a potential intervention target between MM and the behavioral response or health outcome exists. From the few studies that explored the complexities or buffers between MM and a response/outcome, medication necessity or concerns beliefs<sup>22,67</sup> and coping styles<sup>68</sup> may provide intermediary targets for diminishing health disparities in disadvantaged populations. Because most studies were cross-sectional, it is also difficult to make any causal inference. There may be other external factors outside of the health care system that may buffer the effects of MM on health, such as social support<sup>90</sup> among marginalized groups.

Mistrust remains debated among researchers. The research argues that the concept is either: (1) a

component of interpersonal trust and as such on a continuum from high trust to mistrust or (2) as an independent concept distinct from the interpersonal trust literature. While we attempted to explicitly place MM within the context of a history-based framework (and as a distinct concept) nearly 50% of the studies (more quantitative than qualitative) relied on the Pearson and Raeke's<sup>96</sup> review to support the importance of "low trust" rather than MM on health care, particularly the provider patient relationship. The Williams and Mohammed framework assumes that marginalized populations may enter the treatment relationship or health system with a wariness based on historical injustices; thus, our position is that the Hall and colleague's<sup>8</sup> argument that "distrust" as opposed to trust is the preferred conceptual underpinnings for the study of MM. There is consensus that MM is a multidimensional construct that can be conceptualized in multiple ways; however, many researchers were silent on the effect of the historical injustices. Institutional and interpersonal communication represent perceived inequitable or oppressive treatments that are collectively experienced by socially disempowered groups. The lack of explicitly framing the concept in a larger context impedes the development of the concept and the literature.

Many studies, both quantitative and qualitative, continue to conflate the conceptualization of trust and medical mistrust. One primary confusion found in the literature review was the authors' use of an instrument to measure MM that supports the group-based historical injustices as noted in the Williams and Mohammed framework (e.g., GBMMS) while not describing this viewpoint in the background.<sup>77,78,97,98</sup> Even when the authors use a reliable and valid MM measure (e.g., GBMMS), they continue to interchanged interpersonal trust and MM<sup>99</sup> in the description of the concept, the analysis, and the discussion of the findings. Despite our purposeful exclusion of studies that focused on or measured "trust" in health care, some studies that were included inaccurately defined MM as "low trust in a provider or system" or used a measure of "system mistrust" (the MMI) to evaluate "interpersonal mistrust."<sup>100</sup> The qualitative research, while seeking to describe medical mistrust, frequently referenced the term "trust" in the background and discussion sections of the article.<sup>94</sup> Even when studies describe various subtypes of MM under study, the quantitative measures were limited by their conceptual definitions. Researchers did not describe the type of MM they were intending to measure, in part, due to the emerging nature of the concept. As noted earlier, few qualitative studies sought a deeper description of

MM. More consistent use of measures with a clear linkage between the purpose of the chosen measure or a more complex qualitative analysis of the concept is needed to better understand the relationship between MM and health-related outcomes. Future quantitative work should integrate a qualitative methods component to refine existing measures and enhance the depth of our understanding of MM among various marginalized groups.

The review's findings are restricted by the methodological limitations found in the studies and the stringent inclusion/exclusion criteria imposed by the authors. This review included studies with a health behavior or health service as outcomes and excluded studies focused on organ donation, genetic testing and medical research. It was our view that donation of organs, genetic testing or medical research participation do not have a direct impact on marginalized individuals' health care outcomes. Still, with precision medicine and the use of genetic testing to determine treatment plans, the review may have excluded studies relevant to MM. We also did not include non-peer reviewed publications, such as dissertation research. By excluding these publications, our review may have missed some relevant research that would further the work in this area. Few studies from non-US based samples limits our ability to generalize the findings beyond a US context. While we had not excluded non-US based studies from our review, few studies focusing on MM were found. The historical and sociopolitical impact of MM on marginalized populations in other countries may be sufficiently different that it may require a completely different conceptualization. Thus, the findings in our review are applicable to the populations that were sampled in these selected studies. Lastly, while the Williams and Mohammed framework offered a structure to the narrative synthesis, the framework required adaptation; as published, it does not provide for the nuances necessary to synthesize the MM literature. The review may have benefitted from a hybrid framework that incorporated a more specified model of antecedents and consequences of MM, such as those proposed by Penner,<sup>101</sup> Hammond<sup>61</sup> and Molina.<sup>57</sup>

## Conclusions

Based on the current review, we provide a summary of recommendations for future research. First, MM needs to be studied as distinct from trust as a part of proximal pathways influencing health outcomes and as a response to the systemic bias that impacts

marginalized groups at institutional, community, interpersonal, and individual levels. Understanding of this distinction will improve the way in which MM is operationalized and guide appropriate assessment. Second, more qualitative research is needed to better understand the distinction between MM and trust. Having MM become more central to the aims of in qualitative research, studies would yield more fine-grained data that can increase conceptual depth of the construct. Addressing this concern would provide conceptual clarity to quantitative research as quantitative studies are currently conflating MM with interpersonal distrust. Applying a mixed methods approach (i.e., quantitative and qualitative methods) may help strengthen existing models and measures. Third, there is an urgent need to investigate the antecedents and consequences of MM in more diverse populations. This would enhance validity of existing MM measures and strengthen generalizability of the findings. Related, most studies focused on the effects of MM on adherence to treatment regimens and cancer screening. More research is needed to investigate the effects of MM on a variety of health-related outcomes and physiological responses. Finally, prospective studies are direly needed to understand the health effects of MM over time, including effects on objective health measures. Using the framework shown in [Figure 1](#), it is possible to consider other proximal processes (e.g., acculturation, health literacy, past experiences with incarceration) to robustly measure the independent effects of MM on patient outcomes.

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