Patient Education and Counseling xxx (2018) xxx–xxx

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Review article

A systematic review of medical mistrust measures

Lillie D. Williamson*, Cabral A. Bigman

Department of Communication, University of Illinois at Urbana-Champaign, Urbana, IL, USA

ARTICLE INFO

Article history:
Received 2 November 2017
Received in revised form 4 May 2018
Accepted 5 May 2018

Keywords:
Medical mistrust
Health disparities
Systematic review
Health promotion

ABSTRACT

Objective: Medical mistrust is seen as a barrier to health promotion and addressing health disparities among marginalized populations. This study seeks to examine how medical mistrust has been measured as a step towards informing related health promotion efforts.
Methods: A systematic review of medical mistrust scales was conducted using four major databases: PubMed, PsycINFO, ERIC, and Communication & Mass Media Complete. Databases were searched using the terms "medical mistrust scale" "medical mistrust" and "medical distrust."
Results: The search returned 1595 non-duplicate citations; after inclusion and exclusion criteria were applied, 185 articles were retained and coded. Almost a quarter of studies used a single-item or a few items. Among validated scales, the Group-Based Medical Mistrust Scale, Medical Mistrust Index, and Health Care System Distrust Scale were most frequently used. There were important differences among these scales such as the object of mistrust (e.g., system, individual physician) and referent specificity (e.g., group). The measurement of medical mistrust varied by health topic and sample population.
Conclusion: These differences in scales and measurement should be considered in the context of intervention goals.
Practice Implications: Researchers should be aware of differences in measures and choose appropriate measures for a given research question or intervention.

Contents

* Corresponding author at: 3001 Lincoln Hall, University of Illinois at Urbana-Champaign, 702 South Wright Street, Urbana, IL, 61801, USA.
E-mail addresses: lwllmsn2@illinois.edu (L.D. Williamson), cbigman@illinois.edu (C.A. Bigman).

https://doi.org/10.1016/j.pec.2018.05.007
0738-3991/

1. Introduction

Medical mistrust—distrust of medical personnel and organizations [1]—has been found to be negatively associated with a variety of health-related behaviors including clinical trial participation, cancer screenings, organ donation, and utilization of healthcare services [2–5]. The recognition of medical mistrust as a health barrier has resulted in calls for strategies to reduce mistrust [6]. However, to achieve this, scholars must first have a clear understanding of medical mistrust and how best to assess it.

Despite an abundance of scholarship on medical mistrust and its recognition as an important factor in advancing health equity, few studies examine measurement of medical mistrust. However, definitional ambiguity surrounding medical mistrust in the literature suggests a systematic review of the conceptualization and measurement of medical mistrust is a critical and missing component of the literature. For instance, some scholars conceptualize medical mistrust as rooted in interethnic group relations and whether respondents perceive medical personnel and health organizations as extensions of the dominant culture [4]. Other scholars conceptualize medical mistrust as separate from perceptions of race-based discrimination [7]. Because scholars might be using the same term (i.e., medical mistrust) to describe different beliefs and because this has implications for health promotion efforts, we sought to examine how scholars are quantitatively measuring medical mistrust.

To our knowledge, no systematic reviews of medical mistrust have been conducted. A systematic review conducted by Ozawa and Sripad in 2013 examined measures of *trust* in the health system [8]. In contrast, our focus is on scales and indices specifically intended to measure medical *mistrust*. Conceptually, trust and mistrust are related, but distinct concepts. Trust refers to the belief that the trustee (the person or organization in whom faith is placed) will act in the best interests of another (i.e., the truster) [9]. This is different from distrust/mistrust, which is not only predicated on the belief that the trustee will not act in the truster's best interests, but also that they may actively work against them. Recent empirical evidence supports the assertion that trust and mistrust are related, but also have distinct relationships to health beliefs and behavior [10]. Pellowski and colleagues found that although medical mistrust predicted lower medication adherence, neither trust in one's own physician nor trust in one's healthcare provider did. Such findings bolster the argument that trust and mistrust are not simply two sides of the same coin.

1.1. Role of medical mistrust in health outcomes

Medical mistrust has been cited as a potential social determinant of health, particularly when examining racial or ethnic disparities [11,12]. There is evidence that medical mistrust is a health barrier and is associated with worse outcomes across many parts of the health care continuum. For instance, higher reported medical mistrust is associated with unwillingness to participate in clinical research and trials [13–16]. Medical mistrust is also associated with reduced use of preventive services such as routine check-ups and cancer screenings [2,4,17–19]. Once individuals are receiving medical care, medical mistrust is related to lower levels of patient satisfaction and treatment adherence [7,20,21]. Finally, medical mistrust has been found to be associated with worse general physical and mental health [22].

Although medical mistrust is a barrier to improvement of health generally and cuts across demographic groups, it is especially problematic for marginalized populations that already face health disparities. Groups marginalized in society—due to race, behavior, or some other stigmatized status—are often more likely to be mistrustful about medical institutions and personnel based on personal experience, or vicarious experiences, including oral histories. These firsthand and secondhand experiences can result in heightened medical mistrust among these groups [23,24], and in turn contribute to the perpetuation of health disparities. In the U.S., historical legacies include not only the Tuskegee Syphilis Study, but also the medical evaluation of immigrants, medical experimentation on prisoners, and the sterilization of female prisoners [25–28]. As a result, concerns about medical mistrust may originate from distinct historical experiences linked to group identity. For instance, for African Americans, medical mistrust may be tied to concerns about the treatment of their social group and racism.

Given the role of medical mistrust as a barrier to health care and equity and calls by scholars to reduce medical mistrust [6], we investigated how scholars have operationalized and utilized medical mistrust measures in health-related studies. Because addressing medical mistrust as a health barrier depends on a clearly conceptualized understanding of medical mistrust and its operationalization, the current project sought to document the major scales, indices, and items used to quantitatively measure medical mistrust in the literature. In doing so, we provide a nuanced look at which medical mistrust scales are being utilized. We also examine the health topics and racial and ethnic populations in studies examining medical mistrust.

1.2. Evaluating medical mistrust measures

We approached this systematic review with a priori research questions. The questions emerged from research conducted in the context of medical mistrust and organ donation [29], but were suited to a broader systematic review of the medical mistrust literature. The first question was how medical mistrust is assessed in the literature. Medical mistrust may be measured in different ways (e.g., a single item, a few items, subscales, scales with multiple dimensions). Examining how medical mistrust is measured provides insight as to how scholars are conceptualizing medical mistrust. Thus, we posed the following research questions:

RQ1a: How is medical mistrust quantitatively measured?

RQ1b: What are the primary items or scales that scholars use to measure medical mistrust?

Additionally, medical mistrust is sometimes linked to group membership and that group's position in society. For some scholars, this structural positioning is inherent in some definitions of medical mistrust [4]. This conceptualizes medical mistrust as linked to a group's treatment in society. Groups that have historically or currently experience structural disadvantage are also more likely to face health disparities across a wide range of conditions, including cardiovascular disease and diabetes. Given the historical medical injustices experienced by certain groups (e.g., African Americans, prisoners), it is also important to take inventory of the health contexts and populations examined in conjunction with medical mistrust measures. Thus, we put forth the following research questions:

Please cite this article in press as: L.D. Williamson, C.A. Bigman, A systematic review of medical mistrust measures, Patient Educ Couns (2018), https://doi.org/10.1016/j.pec.2018.05.007