



Does patient-provider race/ethnicity concordance impact outcomes for adults with lupus?

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Abstract

Background: Health disparities exist among the 1.5 million Americans with lupus, with women of color bearing higher disease rates and burden. Complex reasons include genetics, comorbidities, and socioeconomic factors. These factors may lead to differences in health-related outcomes in lupus.

Aim: To determine if patient-provider racial/ethnic concordance plays a role in outcomes for adults with lupus.

Method: For this scoping review, the authors searched PubMed Medline and CINAHL using keywords and subject headings for lupus, race or ethnicity, and patient-health professional concordance.

Results: Despite an intentionally broadened search of literature, the authors identified a lack of studies examining the topic.

Conclusions: Certain factors may explain the results: a lack of scientists studying the phenomenon, a focus of funding on bench science, and a non-diverse U.S. healthcare provider workforce. Other factors may exist. Implications for practice, policy, and research are presented.

Keywords

lupus; concordance; race; ethnicity; patient-provider relations

Cover Page Footnote

None

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ABSTRACT

Background: Health disparities exist among the 1.5 million Americans with lupus, with women of color bearing higher disease rates and burden. Complex reasons include genetics, comorbidities, and socioeconomic factors. These factors may lead to differences in health-related outcomes in lupus.

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Conclusions: Certain factors may explain the results: a lack of scientists studying the phenomenon, a focus of funding on bench science, and a non-diverse U.S. healthcare provider workforce. Other factors may exist. Implications for practice, policy, and research are presented.

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INTRODUCTION

Lupus affects approximately 1.5 million Americans, of whom around 90% are female. Individuals of African-American, Native American/Alaska Native, Asian/Pacific Islander, and Hispanic backgrounds bear disproportionate rates of lupus and greater disease severity (Lupus

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Foundation of America (LFA), 2016). Racial health disparities in lupus exist with women of color developing lupus at a younger age, experiencing more serious complications, and having a higher rate of mortality from lupus than white women. African-American women experience more seizures and cerebrovascular accidents than other groups, while Hispanic women suffer more cardiac problems (Office on Women's Health, 2019). Although they experience similar manifestations of lupus as women, kidney and skin involvement may be more common in men (LFA, 2013). Health disparities experienced by individuals with lupus are complex and may be due to a combination of comorbidities, genetics, and socioeconomic determinants (National Association of Chronic Disease Directors (NACDD) & LFA, 2015).

Lupus affects multiple body systems, causes chronic pain, fatigue, mood disturbances, and sleep disruption, and leads to life-threatening organ damage, multifactorial uncertainty, and impaired quality of life (Delis, 2019; Jolly et al., 2016; LFA, 2016). Due to disease and treatment complexity, individuals with lupus often require the skills of both primary care providers and specialists, thus leading to multiple provider-patient relationships, the quality of which could impact patient outcomes.

A therapeutic relationship that includes good rapport and effective communication with ones' healthcare providers is imperative to ongoing and successful lupus management and can improve the patient's ability to cope (Faith et al., 2018; Sutanto et al., 2013). Through thematic analysis, Faith et al. (2018) identified *patient-physician relationships* as one of three thematic areas arising in their study of a peer mentoring program for African-American women with lupus to improve self-management of their disease. Subcategories that emerged under *patient-physician relationships* included the importance of *familial relationships with physician care*, and *empathy among physicians* (p. 5). They also highlighted the need for other healthcare personnel to display more empathy and understanding of the challenges, both clinical and life-related, experienced by those with lupus.

Low levels of patient-provider communication and lack of care coordination were associated with an increase in organ damage (Yelin, Yazdany, & Trupin, 2017). A higher level of depression, disease activity, and educational attainment in African-American patients with lupus was associated with poorer patient-provider communication, and those with high levels of depression reported less personable interaction with their provider (Drenkard, Gaobin, Lewis, Pobiner, Priest, & Lim, 2019). Singh et al. (2015) identified effective patient-physician communication as a facilitator to medication decision-making. Active involvement of both physician and patients with lupus in treatment decision-making is associated with higher technical quality of care (Yelin et al., 2015).

Vina, Masi, Green, and Utset (2012) examined the role of racial/ethnic differences in treatment preferences regarding lupus, and found that an increased level of trust in the physician and education about proposed nephritis treatment could impact the decision to accept or reject treatment recommendations. They also reported that overall African-American patients reported higher level of trust in physicians ($p= 0.001$). While the researchers asked whether or not patients preferred seeing race, sex, and/or age concordant providers, actual patient-provider racial/ethnic concordance is not reported. A study by Ford, Konrad, Godette, and Corbie-Smith (2008) suggested that it makes a difference in outcomes for women with sexually transmitted diseases (STDs). The authors examined if racial congruence in the patient/provider dyad played a role in acceptance of Enzyme-linked Immunosorbent assay (ELISA) testing by black women with STDs.

In this secondary data analysis, racial and gender concordance was associated with higher odds of acceptance of routine ELISA testing, with 80% of those with concordant dyads accepting ELISA testing versus 55% of those without such combined concordance.

Alternatively, Schoenthaler et al. (2014) found no change in blood pressure control among African-American patients in racial/ethnically discordant patient-physician dyads. White patients receiving care from race concordant physicians were more likely to report better medication adherence, while little difference existed among African-Americans in concordant vs. discordant patient-physician dyads. High levels of trust were associated with improved outcomes in blood pressure control and medication adherence, however, racial/ethnic concordance for either African-American or white patients did not impact actual blood pressure control. Scheid and Smith (2016) examined the relationship between race and gender concordance and trust in low income women. While controlling for factors related to environment, population characteristics and health behaviors, they identified that race and gender concordance were not significantly associated with trust in one's physician.

The current inquiry examined published literature for studies that would provide data to address the question: Does patient-provider race/ethnicity concordance impact outcomes for adults with lupus?

METHODS

The interdisciplinary research team, consisting of nursing, rehabilitation, and library science professionals, came together in fall of 2018 with the intent to explore the impact of patient-provider dyad racial/ethnic concordance. In 2019, we searched PubMed Medline and CINAHL using keywords and subject headings for lupus, race or ethnicity, and patient-health professional concordance. Search terms are explicated in Figure 1. Additionally, the following limits were used: U.S. study setting, peer-reviewed, English language, within the past 10 years, adults aged 18 or older. Grey literature was not explored as we only sought peer-reviewed research data consistent with the aims of this inquiry.

Figure 1. *Search terms*

PubMed: (((("Lupus Erythematosus, Systemic"[Mesh] OR lupus))) AND (("Ethnic Groups"[Mesh] OR "Continental Population Groups"[Mesh] OR "Race Relations"[Mesh] OR race OR racial OR racially OR ethnic OR ethnicity OR ethnically OR culture OR culturally))) AND (((("Professional-Patient Relations"[Mesh] OR "Professional-Family Relations"[Mesh] OR "concordance"[All Fields] OR "Professional-Patient Relations"[Mesh] OR "Physician-Patient Relations"[Mesh] OR "health communication"[All Fields] OR "provider communication"[All Fields] OR "patient communication"[All Fields] OR "physician communication"[All Fields] OR "doctor communication"[All Fields] OR "patient-centered communication"[All Fields] OR "provider-patient communication"[All Fields] OR "patient-provider communication"[All Fields] OR "physician-patient communication"[All Fields] OR "patient-physician communication"[All Fields] OR "clinician-patient communication"[All Fields] OR "patient-clinician communication"[All Fields] OR "physician-patient relationships"[All Fields] OR "patient-physician relationships"[All Fields] OR "patient-provider relationships"[All Fields] OR "provider-patient relationships"[All Fields] OR "clinician-patient relationships"[All Fields] OR "patient-clinician relationships"[All Fields] OR "doctor-patient communication"[All Fields] OR "patient-doctor communication"[All Fields]))) OR (((patient AND (provider* OR physician OR professional OR doctor) AND (relationship or trust or dynamic or rapport or concordance or partnership or support))) OR ("patient-

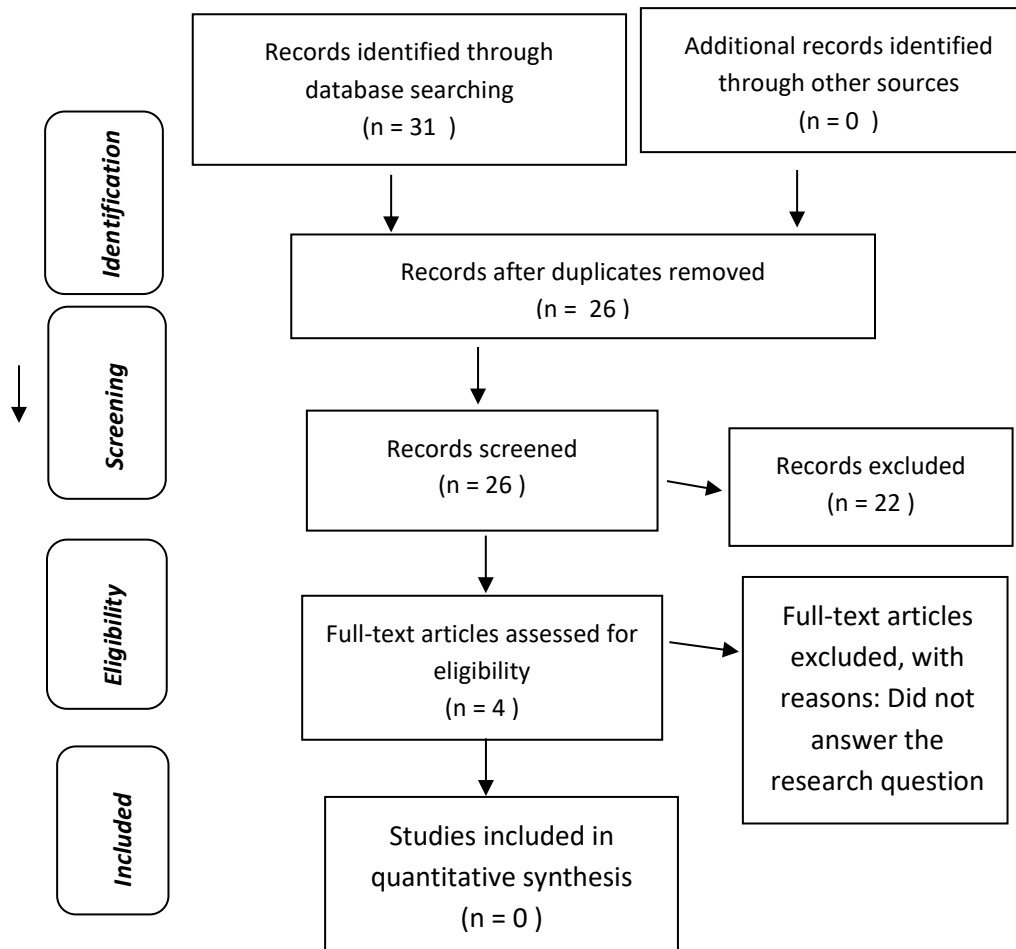
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provider" OR "physician-patient" OR "doctor-patient" OR "patient-physician" OR "patient-health care professional")) AND (concordance OR discordance OR concordant OR discordant OR similar or identical or alike or different or dissimilar or unlike or match or matching)))

CINAHL: (((((lupus))) AND (("Ethnic Groups" OR "Continental Population Groups" OR "Race Relations" OR race OR racial OR racially OR ethnic OR ethnicity OR ethnically OR culture OR culturally))) AND (((("Professional-Patient Relations" OR "Professional-Family Relations" OR "concordance" OR "Professional-Patient Relations" OR "Physician-Patient Relations" OR "health communication" OR "provider communication" OR "patient communication" OR "physician communication" OR "doctor communication" OR "patient-centered communication" OR "provider-patient communication" OR "patient-provider communication" OR "physician-patient communication" OR "patient-physician communication" OR "clinician-patient communication" OR "patient-clinician communication" OR "physician-patient relationships" OR "patient-physician relationships" OR "patient-provider relationships" OR "provider-patient relationships" OR "clinician-patient relationships" OR "patient-clinician relationships" OR "doctor-patient communication" OR "patient-doctor communication")))) OR (((patient AND (provider* OR physician OR professional OR doctor) AND (relationship or trust or dynamic or rapport or concordance or partnership or support))) OR ("patient-provider" OR "physician-patient" OR "doctor-patient" OR "patient-physician" OR "patient-health care professional")) AND (concordance OR discordance OR concordant OR discordant OR similar or identical or alike or different or dissimilar or unlike or match or matching)))

Despite an intentionally broad approach, the search retrieved only 31 results, five of which were duplicates. We then used Covidence, a web-based application designed to manage systematic and scoping reviews, to screen the articles. Of the 26 articles screened, the first two authors (Delis and Corless) independently reviewed titles and abstracts for inclusion, discussed and resolved any disputed manuscript decisions to come to consensus. They deemed 22 articles irrelevant to the needs of this project for the following reasons: 1. not U.S. based nor patient-provider concordance (n = 6), 2. not adult nor patient-provider concordance (n = 3), or 3. not patient-provider concordance (n = 13). They screened the full text of the four remaining articles considered eligible for data extraction, yet none addressed patient-provider racial/ethnic concordance and the impact on outcomes in adults with lupus (see Figure 2).

Figure 2. PRISMA flow diagram



RESULTS

Using both CINAHL and PUBMED searches for the timeframe of 2009-2019, no published research papers were identified that examined the impact of patient-physician racial/ethnic concordance on outcomes in adults with lupus.

DISCUSSION

Despite many attempts made over the course of months to improve upon the search results through the broadening of search terms, a dearth of appropriate studies existed. This led the team to ask why.

Why were no studies identified?

Is anyone exploring this issue? In 2015, with funding from the Centers for Disease Control and Prevention (CDC), the National Association of Chronic Disease Directors (NACDD) and the LFA developed the National Public Health Agenda for Lupus 2015 (CDC, 2015).

This agenda placed a high priority on public health research studying health disparities, and identified the need to investigate variables contributing to health inequities and disparities in outcomes. It appears, however, that bench science makes up the majority of clinical trials in lupus.

Of 40 active (not recruiting) studies of lupus (adults) listed in ClinicalTrials.gov (August 20, 2019), 36 are interventional: 28 drug/biological, two diagnostic test, one device, two activity and/or nutrition, and one each comparing medical management and employment. The non-interventional studies include pregnancy in lupus, use of PET scans in neuropsychiatric lupus, scale development and assessment, and monitoring (National Institutes of Health (NIH), 2019a). At this point in time, it appears that no studies examine patient-provider racial/ethnic concordance.

Are patient-provider racial/ethnic concordance studies funded? Current research funding opportunities available through the US-based Lupus Research Alliance (LRA) focus on biomedical research that ultimately leads to a cure through discovery of improved diagnostics and medical treatment, and advancement of clinical and translational research (2019). Funding opportunities through the Lupus Foundation of America (LFA), likewise, emphasize on basic science, and clinical and translational research (LFA, 2019). A search for funding through the NIH Grants and Contracts site using the search term “lupus” for active funding opportunities released within the past 5 years (July 2014-July 2019) reveals funding for microbiome, medicines, and genomic research (NIH, 2019b).

Are there sufficient lupus providers of diverse racial/ethnic backgrounds to create the dyads needed for this research? Historically, the medical community in the US has had an overwhelming majority of white, male providers. According to the American Association of Medical Colleges (AAMC) (2019), the percentages of non-White medical school matriculants remain underrepresented (see Table 1). As of 2016-2017, the percent applicants to an osteopathic medical school from underrepresented minorities (URM) (defined as Hispanic/Latino ethnicity, Black/African American, Native American/Alaska Native, and Asian/Pacific Islander) is 15%, up from 11.1% in 2009-10 (American Association of Colleges of Osteopathic Medicine, 2019), while overall percentage of URM matriculating into osteopathic medical schools increased from 7.7% to 8.5% during the same period.

Generally speaking, individuals with lupus get the majority of their care from rheumatology and/or primary care providers. A lack of diversity exists in adult rheumatology specialists with 73.6% identifying as white, and 83.5% as non-Hispanic. Further racial/ethnic breakdown is as follows: Hispanic 8.5%, Native American 0.3%, Asian 15%, African American 0.8%, Native Hawaiian/Pacific Islander 0.1%, 2 or more races 2.2% (American College of Rheumatology, 2017). Similarly, among the 189 thousand nurse practitioners/midwives in the US in 2017, approximately 83.5% identify as white, 8.4% identify as Black, and 5.9% identify as Asian (Data USA, 2017). According to the American Association of Nurse Practitioners (AANP), approximately 73% of all nurse practitioners engage in the delivery of primary care (2019).

The CDC lupus funded initiatives (2018) include developing continuing medical education to support family medicine physicians’ expertise in lupus identification, diagnosis, and treatment in collaboration with the American Academy of Family Physicians (AAFP). This avenue may have significance in reducing health disparities in lupus as diversity in family medical practitioners has improved dramatically in some areas. At least 90% of family physicians board-certified in 1987 were white, whereas only 61% of those first certified in 2017 identified as non-Hispanic white. Additionally, those first certified in 2017 were more than three times as likely to be Asian and

twice as likely to be Hawaiian/Pacific Islander than the general US population. The same group were only half as likely, however, to identify as black, African American, Hispanic, or

Table 1: Percent of medical school matriculants by race/ethnicity

Race/ethnicity	2014-2015	2018-2019
Native American or Alaska Native	1%	1%
Asian	21.2%	25.4%
Black or African American	6.9%	8.6%
Hispanic or Latino	9.1%	10.7%
Native Hawaiian or Pacific Islander	0.3%	0.3%
White	57.9%	57.7%
Other	3.7	3.4

Note: Percentages reflect those identifying with the race/ethnicity alone or in combination with other races/ethnicities

Latino as the general US population (Peabody, Eden, Douglas, & Philips, 2018). The focus on improving diversity in this physician group continues through AAFP's Center for Diversity and Health Equity initiative (AAFP, 2019).

CONCLUSION

The diversity in our physician and nurse practitioner populations do not adequately represent the diversity of the U.S. population, and especially that of individuals bearing the highest burden of lupus. It remains a challenge to study racial/ethnic patient-provider concordance and the impact such concordance may have on the care of persons with lupus. As efforts are made to diversify a historically white-male professional workforce, the question remains as to whether an increase in the number of physicians of color will increase the number of those providing lupus care. It also remains unclear as to whether or not racial/ethnic concordance will make a difference in lupus outcomes.

This article identified a significant gap in research related to patient-provider concordance and its potential effect on lupus-related outcomes in adults. The reasons for this gap may be due to such issues as: 1. a focus on bench science working towards treatment and cure in areas such as lupus-specific pharmacotherapeutics, 2. preponderance of funding going towards diagnostics, genomics, basic and clinical sciences, and medical treatment, and 3. a current lack of diversity in lupus-focused healthcare providers resulting in a small population of racial/ethnic concordant dyads in the minorities most affected by lupus. Other factors not identified in this paper likely exist that create the paucity of minority provider/patient dyads.

It is to be hoped that whatever the disease, whatever the skin color of the health care provider, that persons with lupus or any other disease will not receive inferior care based on patient and/or provider race/ethnicity. Unfortunately, the literature currently has no data to provide information on this question.

Implications for practice

Despite racial/ethnic congruence or lack thereof, a therapeutic patient-provider relationship remains imperative to lupus care. Shared decision-making, empathy, high quality patient-provider communication, therapeutic provider-family relationships, effective care coordination, understanding, and trust can all positively impact patient outcomes.

Implications for policy

Policy aimed towards improving minority representation in healthcare providers must continue. While the U.S. has made progress towards increasing diversity in physicians and other providers, the current racial/ethnic provider profile remains mostly white and clearly does not reflect the profile of the U.S. population.

Implications for research

Due to the low levels of diversity in lupus providers, small scale qualitative studies examining what are the most important considerations in patient-provider dyads may inform the role racial/ethnic concordance plays in adults with lupus

Conflicts of Interest

The authors report no commercial associations that might pose a conflict of interest.

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