



**BRIEF REPORT**

# Use of an Integrated Care Management Program to Uncover and Address Social Determinants of Health for Individuals With Lupus

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**Objective.** We studied patients with systemic lupus erythematosus (SLE) enrolled in a nurse-led, multihospital, primary care–based integrated care management program (iCMP) for complex patients with chronic conditions to understand whether social determinants of health (SDoH), including food insecurity, housing instability, and financial constraints, were prevalent in this population.

**Methods.** The academic hospital-based iCMP enrolls the top 2% of medically and psychosocially complex patients identified on the basis of clinical complexity health care use, and primary care provider referral. A nurse conducts needs assessments and coordinates care. We reviewed the electronic medical records of enrolled patients with SLE to identify SDoH needs and corresponding actions taken 1 year prior to iCMP enrollment using physicians' and social workers' notes, and during enrollment using iCMP team members' notes.

**Results.** Among 69 patients with SLE in the iCMP, in the year prior to enrollment, 57% had documentation of one or more SDoH challenges, compared with 94% during enrollment. iCMP nurses discussed and addressed one or more SDoH issues for 81% of the patients; transportation challenges, medication access, mental health care access, and financial insecurity were the most prevalent. Nurses connected 75% of these patients with related resources and support.

**Conclusion.** Although SDoH-related issues were not used to identify patients for the iCMP, the vast majority of enrolled medically and psychosocially complex patients with SLE had these needs. The iCMP team uncovered and addressed SDoH-related concerns not documented prior to iCMP participation. Expansion of care management programs like the iCMP would help identify, document, and address these barriers that contribute to disparities in chronic disease care and outcomes.

## INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic, multisystem autoimmune disease that disproportionately affects racial and ethnic minorities and individuals of lower socioeconomic status. Black individuals and those with public insurance are more likely to

experience fragmented, inconsistent SLE care, which contributes to a disproportionate burden of adverse outcomes (1). Additionally, treatment for SLE is costly to patients and often increases over time, partially because of high health care use (2). Previous research has shown that almost one in eight Medicaid enrollees with SLE used the emergency department (ED) as their primary

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### SIGNIFICANCE & INNOVATIONS

- Medically and psychosocially complex, high acute care–using patients with systemic lupus erythematosus (SLE) enrolled in an integrated care management program (iCMP) have significant needs related to social determinants of health (SDoH).
- Transportation challenges, medication access difficulties, mental health care access, and financial insecurity were the most prevalent SDoH issues, and despite recurrent interactions with the health care system, most were not uncovered or addressed prior to participation in iCMP.
- Attention to these SDoH-related barriers may begin to reduce the disparities in acute care use and adverse outcomes among individuals with SLE and, more broadly, among individuals with complex chronic diseases.

source of care, suggesting that patients had difficulty accessing sustained ambulatory care (3). This potentially avoidable ED use, as well as hospital admissions, presents financial burdens for both patients and hospitals through direct and indirect costs (4). Measures that improve the coordination of ambulatory care and the quality of preventive SLE care can decrease avoidable acute care use and reduce both morbidity and health care costs (3,4).

Vulnerable patients may struggle to access preventive care or adhere to their care plans because of barriers outside of the direct health care setting known as social determinants of health (SDoH) (5). The World Health Organization defines SDoH as the “conditions in which people are born, grow, live, work, and age” and labels SDoH as the primary contributor to health inequities and rising health care costs (Figure 1) (5). Most hospitals and physician practices in the United States do not screen for SDoH because of a lack of incentive and time (6). Medicaid accountable care organizations and academic medical centers are more likely to screen their patients, possibly because of increased resources that have been allocated over the last several years to understand and address these factors (6). Researchers have called for more thorough investigation to determine the link between adverse outcomes in SLE and SDoH variables. In a medication adherence-related study conducted among rheumatology patients at our academic medical center, a high prevalence of SDoH barriers to medication use were identified, highlighting the importance of screening patients for these factors (7).

Our health care organization initiated an integrated care management program (iCMP) in 2006 to identify patients at high risk for acute care use and adverse outcomes. The program began at Massachusetts General Hospital and then was expanded to Brigham and Women’s Hospital in 2009, with patient enrollment starting in 2010. The program connects these patients with a nurse care coordinator and a care team of social workers, community resource specialists, and pharmacists who help coordinate patients’ medical care. This

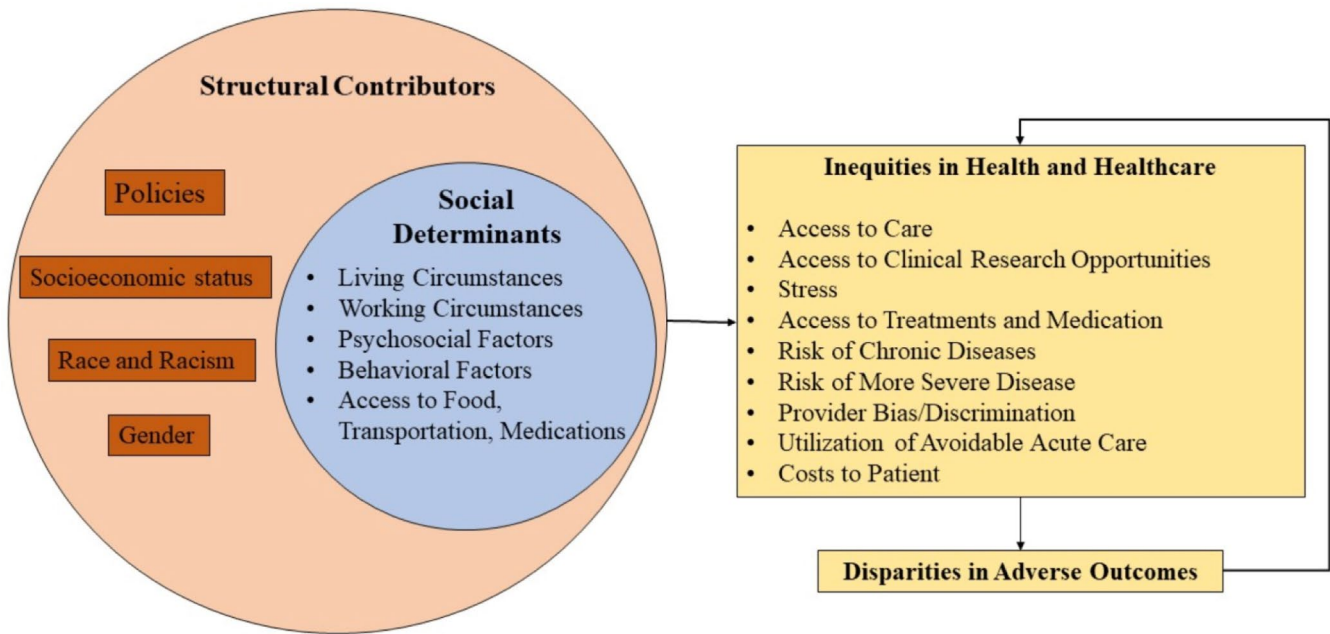
iCMP team is multilingual and multicultural, and Spanish-speaking patients in the program may be connected with Spanish-speaking nurses, social workers, and community resource specialists. This program has been shown to reduce acute care use and mortality for Medicare beneficiaries as well as decrease medical spending (8). Cost savings were primarily driven by reductions in inpatient health care use while patients were enrolled in the iCMP (8). Patients enrolled in the iCMP are routinely asked about their SDoH needs along with their physical and mental health concerns (8). Patients remain in the program for as long as they are part of their primary care practice, they continue to be considered high risk with needs that require these services and that are not being met elsewhere, and they are able to engage with the program.

We focused our study on SLE given prior research demonstrating significant racial/ethnic and socioeconomic disparities among individuals with this complex condition. In addition, there are high rates of costly acute care use and of medication nonadherence. We studied individuals with SLE enrolled in the iCMP to understand whether SDoH needs, such as food insecurity, housing instability, and financial constraints, were prevalent in this high-risk population. We hypothesized that the majority of the high-risk patients with SLE in the iCMP would have SDoH needs even though they were not explicitly selected for participation in this program on the basis of these factors. We also hypothesized that the iCMP teams would uncover and address SDoH issues that were likely present but not documented by patients’ care teams prior to enrollment.

### PATIENTS AND METHODS

The iCMP uses nurses, social workers, community health workers, and pharmacists to coordinate care for high-risk, high-cost primary care patients. It enrolls the top 2% of medically and psychosocially complex patients within our multihospital primary care practices and identifies these patients as high risk with a machine learning algorithm that incorporates age, sex, 20 or more high-risk complex chronic conditions (not including SLE), and health care use (9). SDoH needs are not currently factored into this system. Identified patients are deemed eligible for iCMP after consultation with their primary care providers. Primary care providers may also recommend appropriate patients for enrollment in the iCMP in a separate process from this algorithm. Separate machine learning models are run for commercial insurance, Medicare, and Medicaid patients and EMR data are linked with administrative claims data. Individuals with SLE enrolled in the iCMP were identified with a separate validated machine learning algorithm to detect SLE (positive predictive value = 90%) and verified by chart review using 1997 American College of Rheumatology (ACR) or 2012 Systemic Lupus International Collaborating Clinics (SLICC) classification criteria (10).

We reviewed patients’ electronic medical record (EMR) encounters to identify discussions about SDoH needs prior to iCMP enrollment primarily using notes from physicians and social



Adapted from the WHO Framework

**Figure 1.** Relationship between structural factors, social determinants, inequities in health and health care, and disparities. Adapted from the World Health Organization (WHO) Framework (5).

workers, and throughout iCMP enrollment using notes from iCMP nurses and team members. In these encounters, we searched for mention of difficulties accessing food, medical care, medications, mental health services, childcare, education, transportation, and housing as well as mention of job instability, difficulties with insurance, and concerns about personal or neighborhood safety. Specifically, we searched for mention of difficulty affording, accessing, or preparing food and challenges getting medical care due to accessibility constraints, cost, insurance, or difficulties related to appointment scheduling. Difficulty accessing medications was defined as challenges affording, obtaining, or refilling medications, and difficulty accessing childcare was defined as challenges finding affordable, available, and adequate childcare for the patients’ children or grandchildren. Difficulty accessing education was defined as challenges connecting with or attending educational opportunities. Difficulty accessing transportation was defined as challenges finding affordable, reliable, or handicap-accessible transportation to obtain resources such as medical care, food, or medications. We defined difficulty accessing housing as trouble finding affordable or accessible housing or challenges remaining in stable housing. Job instability was defined as challenges finding sustained employment, and financial issues were defined as mention of financial strain that impacted patients’ access to resources such as food, housing, and health care. Difficulty with insurance was defined as troubles accessing or affording medications or medical care due to undercoverage or lack of insurance coverage. Concerns about personal or neighborhood safety was defined as instances in

which the patient reported fearing for their personal safety or feeling unsafe in their neighborhood environment. We also looked for mention of emotional distress related to these SDoH needs.

We recorded any mention of these SDoH factors during the 12 months prior to the date of the patient’s enrollment in the iCMP and throughout their enrollment. The 12-month period prior to the date of the patient’s enrollment in the iCMP was considered the pre-iCMP period. The patient’s iCMP enrollment period was considered to begin at the date of enrollment in the program and continued until the date of our data collection or the patient’s discharge from the program. Each mention of SDoH variables was documented in a REDCap form created by research staff. Each entry contained the date the note was entered, the writer’s role in the care team, and a brief description of the SDoH issue mentioned. During iCMP enrollment, we recorded the SDoH factors that were discussed with the iCMP nurse and the actions taken to address them. We also documented whether patients were connected with other care team members or with resources by their iCMP care teams. The frequency for the occurrence of each SDoH factor was calculated for the patients enrolled, and examples of how these factors were identified and addressed were recorded as qualitative descriptions. This study was reviewed and approved by the Mass General Brigham Human Research Committee.

**RESULTS**

There were 69 patients with confirmed SLE enrolled in the iCMP with EMR and insurance claims data for 12 months prior

to and during iCMP enrollment. These patients were 93% female, 56.5% White, 24.6% Black, 2.9% Asian or Pacific Islander, and 15.9% of other or unknown race, and 20.6% identified as having Hispanic ethnicity (Table 1). Race and ethnicity were not considered to be mutually exclusive in this analysis. The patient cohort had a mean (SD) age of 60.1 (16.3) years and met a mean (SD) total of 5.3 (1.6) 1997 ACR criteria for SLE. These patients were enrolled in the iCMP between January 2012 and February 2019. The mean (SD) duration of iCMP enrollment for patients with SLE was 3.8

**Table 1.** Demographic characteristics of patients with SLE enrolled in iCMP

Variable	Results
Age, mean (SD), years	60.1 (16.3)
Race, n (%)	
White	39 (56.5)
Black	17 (24.6)
Asian or Pacific Islander	2 (2.9)
Other	11 (15.9)
Ethnicity, n (%)	
Non-Hispanic	54 (79.4)
Hispanic	14 (20.6)
Sex, n (%)	
Male	5 (7.3)
Female	64 (92.8)
Marital status, n (%)	
Married	23 (33.3)
Single	23 (33.3)
Widowed	11 (15.9)
Divorced	12 (17.4)
Language, n (%)	
English	61 (88.4)
Spanish	7 (10.1)
Other	1 (1.5)
Primary insurance, n (%)	
Medicare	61 (88.4)
Medicaid	4 (5.8)
Commercial	4 (5.8)
Secondary insurance, n (%)	
Medicare	1 (1.7)
Medicaid	32 (54.2)
Commercial	26 (44.1)
Verification of SLE diagnosis, n (%)	
Met 1997 ACR criteria for SLE	63 (91.3)
Met 2012 SLICC criteria for SLE	4 (5.7)
Diagnosed by rheumatologist	2 (2.9)
SLE manifestation, n (%)	
Malar rash	22 (31.9)
Discoid rash	8 (11.6)
Photosensitivity	26 (37.7)
Oral ulcers	9 (13.0)
Nonerosive arthritis	50 (72.5)
Pleuritis or pericarditis	41 (59.4)
Renal disorder	26 (37.7)
Neurologic disorder	13 (18.8)
Hematologic disorder	49 (71.0)
Immunologic disorder	51 (73.9)
Positive antinuclear antibody test result	68 (98.6)

Abbreviations: ACR, American College of Rheumatology; iCMP, integrated care management program; SLE, systemic lupus erythematosus; SLICC, Systemic Lupus International Collaborating Clinics.

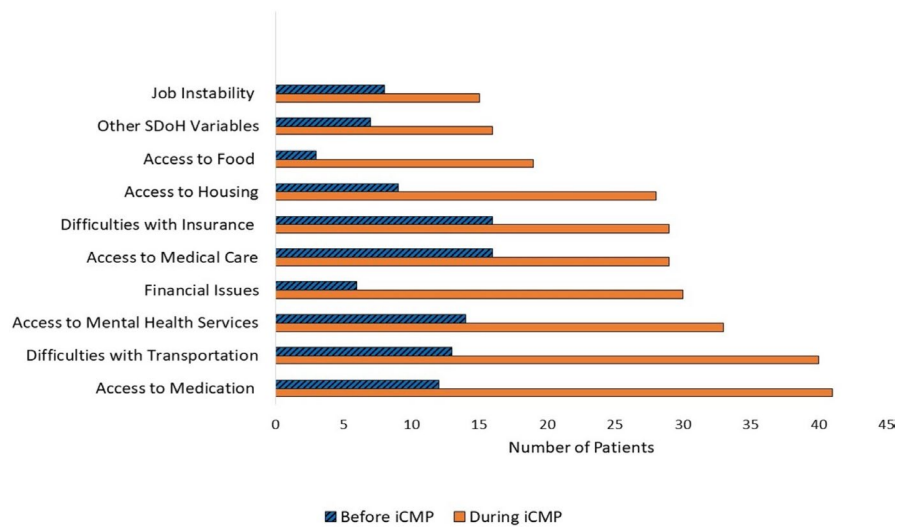
(2.4) years. Prior to iCMP enrollment, 57% of the patients had documentation of one or more SDoH factor by their care teams in EMR notes, compared with 94% during enrollment (Figure 2). The iCMP nurses addressed one or more SDoH factor for 81% of the patients with SLE enrolled and completed high-risk assessments for each patient, and 72% of patients discussed these needs within the first year of enrollment. During enrollment in the iCMP, the mean (SD) number of SDoH needs documented for each patient with SLE was 4.06 (2.61), compared with 1.51 (1.74) SDoH needs documented before enrollment. These high-risk assessments included questions about the patient's living arrangements, health status, specialized medical equipment needs, medications, health risk factors, and use of long-term services and supports.

For these enrolled patients, iCMP nurses discussed and addressed multiple SDoH issues. The most prevalent issue in this population was medication access (66%), which included difficulty obtaining prior authorizations, challenges getting to pharmacies, and inability to afford medications. The second most prevalent issue was transportation barriers (61%), which encompassed challenges obtaining transportation to medical appointments and access to reliable public transportation. Insurance was also a common issue in this population (50%) and presented as insurance plans denying patients' medications, expensive copayments, difficulties obtaining affordable insurance plans, and challenges renewing insurance. Access to mental health resources was a prevalent issue (48%) and presented as difficulties scheduling appointments with therapy or social work resources, challenges connecting patients with resources that were close to their homes or that accepted their insurance, and difficulties connecting patients with at-home mental health resources. Financial issues (48%), housing concerns (46%), and food insecurity (32%) were also prevalent. These presented as challenges finding accessible and affordable housing, difficulties paying electric and water bills, reaching grocery stores, and accessing fresh, healthy food, and challenges affording food.

The iCMP nurses connected patients with additional resources both within and outside of our academic medical center to help find long-term solutions to these issues. These included new insurance plans to make medications more affordable, door-to-door transportation to medical appointments, support from financial specialists to reinstate insurance plans, housing specialists to help patients avoid eviction, and food stamps (Table 2). The iCMP nurses connected 75% of the patients who discussed SDoH issues with additional resources, including social workers and mental health resources (58%), home health (43%) and elder care (14%) services, pharmacists (14%), and substance abuse programs (6%).

## DISCUSSION

Although SDoH-related issues were not used to identify patients for the iCMP, the majority of enrolled high-risk, medically



**Figure 2.** Social determinants of health (SDoH)-related issues documented prior to and during integrated care management program (iCMP) enrollment.

complex patients with SLE had these needs. The iCMP nurses and care team members uncovered and addressed numerous SDoH-related concerns that were not documented prior to iCMP participation, suggesting that physicians and other health care team members are not routinely screening for or documenting

these issues during ambulatory visits. Screening patients with a high-risk assessment on enrollment in the iCMP and frequently asking patients about their SDoH effectively uncovered and addressed barriers to patients’ health care that prevented them from adhering to treatment plans and accessing preventive care.

**Table 2.** SDoH needs uncovered by the iCMP team and examples of strategies used to address these needs

SDoH factors	Patients with SLE with issues addressed (n = 56), %	Example of issue	Examples of strategies used by iCMP teama to address issue
Medication access	66	Patient could not afford copays for medications	Connected patient with new insurance plan to make medications more affordable
Transportation needs	61	Patient needed transportation to medical appointments	Coordinated door-to-door transportation to appointments
Insurance difficulties	50	Patient’s health insurance was revoked	Connected to financial services to reinstate insurance
Mental health service access	48	Patient would like to see mental health services but has significant difficulty leaving her home	Referred to at-home psychiatrist
Financial issues	48	Patient could not pay utility bill	Utility protection letter composed for patient
Housing instability	46	Patient given eviction notice from apartment after unable to pay rent	Connected with emergency housing and helped during appeal of eviction
Food instability	32	Patient could not afford to eat	Referred to elder services and Meals on Wheels
Other SDoH variables	32	–	–
Access to childcare	–	Patient had no resources to support children while she was admitted	Connected with services to help with childcare and home upkeep while admitted
Personal/neighborhood safety	–	Patient experienced domestic violence	Family helped while finding a long-term care facility for patient
Education access	–	Patient not able to start school on time due to illness	Helped patient contact her academic advisor for assistance delaying her enrollment
Job instability	–	Patient reported difficulty finding work after catastrophic medical event	Helped patient search for jobs that could accommodate her functional needs

Abbreviations: iCMP, integrated care management program; SDoH, social determinant of health.

<sup>a</sup> iCMP team included iCMP nurse, social workers, care coordinators, community resource specialists, and pharmacists.

The increase in discussed SDoH issues once patients were enrolled is not surprising given that these issues were shown to be highly prevalent among patients with SLE in research from our own large rheumatology center, which showed that in a sample of 110 patients with systemic rheumatic diseases, 86% described at least one barrier to consistent medication use or rheumatology care and many suffered from depressive symptoms (11). Additionally, physicians report that they lack the incentive, time, and financial resources to routinely screen patients for SDoH issues during visits, particularly if their hospitals or clinics lack the appropriate resources and infrastructure to address these issues (6,12). Rather than just identifying and documenting patients' SDoH issues, through the iCMP, resources were available to assist these patients. The significant increase in documentation and the coordinated approach to address the issues that were uncovered demonstrate the importance of an integrated care management strategy to mitigate SDoH issues. Further studies are needed to affirm the hypothesis that addressing SDoH barriers decreases the costs to the health care system and reduces disparities in both care quality and outcomes. The iCMP offers a sustainable and adaptable framework to screen patients at high risk for avoidable acute care use for SDoH and to begin to tackle these issues.

Identification of SDoH-related barriers and incorporation into existing algorithms used to identify high-risk patients also seems necessary to improve patient outcomes for those with SLE. Traditional models used to identify high-risk patients often do not include SDoH variables, and they therefore identify high-risk patients in a more downstream manner, once they are already suffering from potentially avoidable adverse outcomes. Research using models to predict disease outcomes for cardiology patients demonstrated that incorporating SDoH into predictive models increased their accuracy for cost of care, hospitalizations, and death, and models using solely SDoH predicted health outcomes just as well as one based on comorbidities (13). Furthermore, the SDoH screens that are currently used in ambulatory care sites may not effectively identify high-risk patients. A study performed by Boston Medical Center demonstrated that their EMR-based SDoH screening tool captured only 16% of patients at risk of having their utilities shut off (14). Effective screening is especially important for patients with SLE because socioeconomically disadvantaged patients with SLE have been shown to accrue higher levels of disease damage, ultimately increasing mortality (15). The Centers for Medicare and Medicaid Services updated its Medicaid managed care rule in 2016 to include certain nonclinical services in calculations of capitation rates and medical loss ratios. The goal was to provide a financial incentive for health systems and state governments to address patients' SDoH, improve care coordination, adopt alternative payment models, and connect patients with long-term services and home and community support (16).

Strengths of this study include the evaluation of the ability of a well-established integrated care management model to assess, document and address the SDoH needs of patients with SLE. Because this study was performed retrospectively, all patients had available records and we were able to examine patients' charts before and during their enrollment in the iCMP to assess the effectiveness of the program to understand SDoH needs. A key strength of this intervention is the standardization of SDoH documentation by iCMP nurses on patients' enrollment in the iCMP. It is clear that without standardization in the pre-iCMP period, documentation of SDoH in patients' medical records requires patients to self-report their needs and providers to ask patients about their SDoH, neither of which occur consistently. This study had several limitations, the first of which is the difference in the length between the pre-iCMP data collection period and the data collection period while patients were enrolled. We chose to restrict the pre-iCMP period to one year before enrollment in the iCMP to ensure that all patients would have near-complete medical records available for the same period. This could have introduced errors because although more issues were uncovered while patients were enrolled in the iCMP, the data were collected over a longer time period. However, nearly three-quarters of the enrolled patients discussed an SDoH issue with a care team member within the first year of enrolling in the iCMP, making it unlikely that the increase in addressed SDoH factors was due to the extended data collection period. The increase in the percentage of patients who discussed SDoH needs with their iCMP nurses over the course of their enrollment demonstrates that SDoH needs are dynamic and that the care management process must be longitudinal. Our small sample size could influence the generalizability of this study; however, the size of our academic medical center and diversity of our patient population make us believe that this study is generalizable to other urban academic hospital systems and high-risk patient populations.

Because SDoH needs directly impact the care that patients access and because of the heightened burden of adverse outcomes among vulnerable populations, the health care system must develop and expand sustainable strategies like this iCMP to identify, document, and address these issues. The coronavirus disease 2019 pandemic has rapidly expanded the SDoH-related barriers that are disproportionately faced by racial and ethnic minorities. Deeper investigation is needed to determine the impact of addressing SDoH on improving preventive care as well as on reducing acute care use and disparities in longer-term adverse outcomes among vulnerable populations.

## AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Dr. Feldman had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study conception and design.** Taber, Williams, McLaughlin, Vogeli, Cunningham, Wichmann, Feldman.

**Acquisition of data.** Taber, Huang, Vogeli, Cunningham, Wichmann, Feldman.

**Analysis and interpretation of data.** Taber, Williams, Huang, McLaughlin, Cunningham, Feldman.

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