Differences in reproductive health discussions in an urban Hispanic population with SLE: lessons from the field

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ABSTRACT

Objective Management of reproductive health-related issues is crucial for patients with SLE, given this is a disease that primarily affects women of childbearing age. Little is known as to how the 2020 American College of Rheumatology (ACR) Reproductive Health in Rheumatic Disease Guideline is experienced by an underserved, primarily Hispanic population and their physicians as it relates to pregnancy planning and contraception conversations. Given this population experiences high rates of unplanned pregnancies and worse SLE outcomes compared with the non-Hispanic white population, it is crucial to understand how reproductive health is discussed in this setting.

Methods A survey based on the 2020 ACR Reproductive Health Guideline was created and distributed in English and Spanish in the outpatient setting to 151 patients with SLE to determine patients' beliefs, experiences and limitations with reproductive health discussions. Associations between categorical variables were evaluated using Pearson's χ^2 or Fisher's exact test, as appropriate, and differences in continuous variables were assessed using Wilcoxon rank-sum test.

Results English language survey respondents were significantly more likely to report having conversations regarding contraception, pregnancy planning and peripartum medication use than the Spanish survey respondents. Two-thirds of all respondents relied on the rheumatologist as a top source of reproductive health information.

Conclusion Disparities exist regarding reproductive health conversations on multiple topics between English-speaking and Spanish-speaking populations with SLE. Further understanding is needed to clarify why reproductive health conversations occur at lower frequencies in Spanish-speaking SLE populations.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ SLE is a chronic autoimmune disease that primarily affects women of childbearing age; hence, timely conversations regarding reproductive health are paramount for this population.

⇒ Unfortunately, the literature demonstrates that both patient-reported and physician-reported barriers exist in regard to routine reproductive health conversations, leading to unacceptably low rates of appropriate contraception use and pregnancy planning discussions.

WHAT THIS STUDY ADDS

⇒ Our study demonstrates that Spanish-speaking patients with SLE receive contraception counselling at lower frequencies than their English-speaking counterparts, as well as less frequent conversations regarding pregnancy planning and peripartum medication use.

⇒ Some, but not all, of these differences may be due to Spanish-speaking patients with SLE on average being older.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Clinicians who care for patients with SLE must consistently address reproductive health concerns with this population and should especially make a concerted effort to do so with patients lacking English fluency.

INTRODUCTION

SLE is a chronic autoimmune disease that predominantly affects women of childbearing age, requiring them to navigate issues regarding contraception and planning for a family throughout the course of the disease. Further, SLE classically has a greater burden in both frequency and severity in non-Caucasian ethnic groups, including the Hispanic white population compared with the non-Hispanic white population.[1 2] Compared with their non-Hispanic white counterparts, US Hispanic patients with SLE are known to have worse outcomes, including but not limited to higher rates of renal disease and mortality from all causes. The US Hispanic SLE population also has higher rates of adverse pregnancy outcomes, recently reported in the Predictors of Pregnancy Outcome: Biomarkers in

1

Antiphospholipid Antibody Syndrome and Systemic Lupus Erythematosus (PROMISSE) cohort and other studies.[3–5]

In an attempt to improve on the way reproductive healthcare is delivered to patients with SLE and other rheumatic diseases, the American College of Rheumatology (ACR) compiled and published their first set of guidelines in 2020, addressing the management of reproductive health in rheumatic and musculoskeletal conditions.[6] While these guidelines are a welcome 'first step,' it would be important to understand the degree that they are implemented within clinical practice following their publication and dissemination from the organisation that created them. Further, these guidelines were compiled and created from published data that did not emphasise a population that represents a classically underserved, socioeconomically disadvantaged, primarily Hispanic patient population such as found in our institution, the Los Angeles General Medical Center (LAGMC), the largest safety net hospital in Los Angeles, affiliated with the University of Southern California.[7]

In the study reported here, we distributed a survey based on the 2020 ACR Guideline for the Management of Reproductive Health in Rheumatic and Musculoskeletal Diseases (2020 ACR Guidelines) to determine patients' beliefs, experiences and barriers with reproductive health discussions in our outpatient SLE patient population after publication of the guidelines. The goal is to obtain patient-reported data on how the 2020 ACR Guidelines are managed by and experienced by our primarily Hispanic SLE patient population and the physicians who work with them, and to provide preliminary data for future intervention planning.

PATIENTS AND METHODS

Local institutional review board (IRB) approval was obtained. An anonymous 28-question survey was devised based on the 2020 ACR Guidelines and the authors' clinical experiences (online supplemental appendix 1). Briefly, this survey collected pertinent clinical demographics, a patient-reported SLE medication list, reproductive health history and current sexual history/practices, patient-reported characteristics regarding outpatient discussions with 'lupus doctors' (rheumatologists) regarding contraception and family planning, patient-reported knowledge on the need for SLE disease control prior to conception, patient-reported knowledge on the safety of medications during pregnancy and breast-feeding, patient-reported knowledge of hydroxychloroquine use during conception and pregnancy, and limitations to discussing reproductive health issues in the outpatient setting. This survey was written in both English and Spanish and pilot-tested with six English-speaking and six Spanish-speaking patients with SLE for comprehension, logic and flow, acceptability and length/adherence. Feedback from patients was used to edit words and phrases for improved comprehension. The final English and Spanish

versions were then uploaded as electronic versions into REDCap, an electronic cloud-based database software.

The LAGMC rheumatology clinic is staffed by five to six attending physicians per half day, five to six rheumatology fellows, and four to seven internal medicine residents. On average, 85% of our clinic self-identifies as Hispanic and is of Mexican or other Central American heritage, and 85% are insured by Medi-Cal (California's Medicaid programme). One attending rheumatologist is natively bilingual (English/Spanish), two are learnt bilingual and three rely on medical translation services for full care. The majority of rheumatology and internal medicine trainees rely on medical translation services to provide care for the Spanish-speaking patients at the LAGMC clinic.

Inclusion criteria included female with a confirmed diagnosis of SLE by a rheumatologist, between the ages of 18–50 per the electronic medical record (EMR) at the time of clinic assessment, and able to read English or Spanish on an electronic tablet. Two patients self-identified as >50 years old despite them meeting the inclusion criteria based on the information on the EMR. Ultimately, the age limit was expanded to include these two patients to be more representative of the SLE clinic population. The LAGMC outpatient clinic sees approximately 12 eligible patients with the above criteria per week. Patients in each clinic session were reviewed for eligibility by LMW via electronic medical record and marked as potential candidates. Eligible patients were approached in the clinic by one of the study team members or the Division of Rheumatology research coordinator, Sara Madrigal. Each study member who was not bilingual in both English and Spanish used a certified medical language interpreter when approaching each patient. Patients were offered either the English or Spanish language survey based on patient preference. The survey was distributed from 14 March 2023 to 19 September 2023. Eligible patients who agreed to take the survey answered the questions on the electronic tablet via the REDCap application and received $30 as compensation. Patients did not have to complete the survey to receive full compensation. Our response rate from patients during the above period was 94%.

Due to the nature of some questions, branching logic was used, and not all questions were available to all patients. For example, if a patient reported *not* attempting or experiencing a pregnancy *after* SLE diagnosis, then questions that collected data on pregnancy in light of SLE diagnosis (ie, use of hydroxychloroquine during pregnancy; the importance of SLE disease control in the peripartum period) did not populate in the electronic software for patients to answer.

Survey questions were summarised using frequency (percent of total) for categorical variables and median (IQR) for continuous variables. Associations between categorical variables were evaluated using Pearson's χ^2 or Fisher's exact test, as appropriate, and differences in continuous variables were assessed using Wilcoxon rank-sum test. Multivariable analysis was conducted using logistic regression. All tests were two sided and a p value

<0.05 was considered statistically significant. All analyses were done in R V.4.2.3.

Of note, the nine patients who endorsed sterilisation as their method of contraception were included in our analysis as sterilisation could include monogamous male partner sterilisation (and hence, patients could be sexually active with another male partner in the future and should be appropriately counselled on teratogenic medication). Additionally, we felt that female patients who had experienced sterilisation should still be screened for appropriate contraception use, as a history of female sterilisation is not always readily apparent on chart review and these patients should still be screened for pregnancy potential if on teratogenic medications. Finally, given the high rates of serious SLE in our clinic requiring long-acting teratogenic mediations, as mentioned above, we opted to analyse all answers to the questions regarding conversations on pregnancy and contraception rather than stratifying by teratogenic medication use for this manuscript or by disease activity (the latter which we did not collect in this study).

RESULTS
Demographics
Results from 151 respondents are shown in table 1. There were important differences between the English and Spanish speakers. Women who chose to participate in the Spanish language survey were significantly older than those who chose to participate in the English language survey. Respondents of the Spanish language survey were more likely to identify as married or in a domestic partnership. A significantly greater proportion (34.9%) of respondents to the Spanish-language survey reported less than a high school education, compared with English language survey respondents (5.8%). Notably, the majority (98.4%) of participants in the Spanish language survey were foreign-born, compared with only 40.7% of the English language survey respondents.

Regarding sexual activity and pregnancy intentions, table 1 highlights that 45.9% of women in the Spanish survey reported being sexually active while actively avoiding pregnancy. This contrasts with 28.9% of women in the English study who expressed similar intentions. Contraceptive practices also exhibited variation, with 20.9% of participants in the English survey reporting no use of contraception, compared with 32.3% of those in the Spanish study.

Key clinical questions
When surveying participants about whether their lupus physician had posed the 'One Key Question' (originally developed as a simple way for all clinicians to routinely screen women for pregnancy plans in the next 1 year) regarding their pregnancy plans for the upcoming year, a higher proportion of respondents (73.8%) from the English survey responded in the affirmative, in contrast to 45.3% of participants who took the Spanish survey

(p<0.001) (table 2).[8] However, in multivariable analysis after adjusting for age and other covariates, this relationship was no longer significant (online supplemental table 1). When asking participants if their lupus doctor has had at least one discussion regarding contraception in the past 1 year, 72.6% of respondents from the English survey affirmed such discussions. In contrast, only 29.5% of participants from the Spanish language survey had such a discussion with their lupus physician (p<0.001), and this remained significant after adjusting for age and other covariates in multivariable analysis (table 2; online supplemental table 2).

For those participants who had a pregnancy or attempted pregnancy after SLE diagnosis, a very large (and similar) proportion of respondents in both the English (84.0%) and the Spanish language (85.0%) groups indicated that their lupus doctor discussed the importance of obtaining disease remission in anticipation of pregnancy (table 2). Likewise, many women from both the English and the Spanish language groups reported discussing which medications they should continue when trying to conceive or are expecting (70.8% vs 60.0%, respectively; p=0.45). However, when discussing which medications should be discontinued when pregnant or trying to conceive, only 55.5% of Spanish-survey respondents endorsed such conversations compared with 82.6% of English-survey respondents (p=0.049).

Limitations in initiating conversation
Figure 1 illustrates the leading obstacles limiting patients from discussing contraception and pregnancy with their lupus doctor. Over a fifth (21.9%) of women disclosed that concerns about whether or not it was even safe for them to become pregnant hampered their discussions with clinicians. A minority (17.9%) of women noted that their lupus doctor recommend that they speak with an OB-GYN instead. On the contrary, a considerable proportion (37.7%) remarked that there were *no barriers* in regard to having reproductive health conversations with their lupus doctors. Moreover, language was *not* marked as a reproductive health conversation limitation by any Spanish language survey respondents (online supplemental table 3). Nor was appointment time, comfort level or perception of provider knowledge.

In regard to sources of reproductive health information as it relates to lupus, the most frequently selected (patients could select more than one) three sources noted by patients were rheumatologists (64.9%), information found on the internet (31.1%) and OB-GYNs (25.8%) (figure 2). More English language survey respondents noted the internet as a top source (43.0% vs 15.4%; p=0.002; online supplemental table 4); otherwise, there were no significant differences between survey language group respondents.

Table 1 Demographic associations between survey language groups

Variable	Survey language group		P value
	English survey (n=86)	Spanish survey (n=65)	
Age (years)	33.0 (17.8)	43.0 (8.5)	<0.001*
	(min=20, max=56)	(min=18, max=53)	
Education level			<0.001*
Less than high school	5 (5.8%)	22 (34.9%)	
High school diploma or equivalent	44 (51.2%)	31 (49.2%)	
Technical/vocational training	17 (19.8%)	8 (12.7%)	
Bachelor's degree	19 (22.1%)	2 (3.2%)	
Master's degree or above	1 (1.2%)	0	
Marital status			<0.001*
Never married	53 (64.6%)	13 (22.0%)	
Married/in a domestic partnership	22 (26.8%)	32 (54.2%)	
Widowed	1 (1.2%)	1 (1.7%)	
Divorced or separated	6 (7.3%)	13 (22.0%)	
Nativity (place of birth)			<0.001*
In the USA	51 (59.3%)	1 (1.6%)	
Outside of the USA	35 (40.7%)	63 (98.4%)	
Sexual activity			0.124
Never sexually active with a male partner	12 (14.5%)	3 (4.9%)	
Have been sexually active with a male partner but not currently active	30 (36.1%)	16 (26.2%)	
Currently sexually active with a male and trying to get pregnant	3 (3.6%)	2 (3.3%)	
Currently sexually active with a male and trying to AVOID a pregnancy	24 (28.9%)	28 (45.9%)	
Currently sexually active with male and neither trying to get pregnant or avoid it	14 (16.9%)	12 (19.7%)	
Methods of contraception			
Abstinence or not sexually active with male partner	18 (20.9%)	10 (15.4%)	0.385
Natural methods	7 (8.1%)	1 (1.5%)	0.139
Barriers or spermicidal methods	18 (20.9%)	8 (12.3%)	0.165
Short-acting birth control	8 (9.3%)	8 (12.3%)	0.552
Long-acting reversible birth control	17 (19.8%)	10 (15.4%)	0.487
Sterilisation	5 (5.8%)	4 (6.2%)	0.999
None—I do not use any contraception	18 (20.9%)	21 (32.3%)	0.114
How many times have you been pregnant?	1.0 (3.0)	2.0 (1.0)	<0.001*
	(min=0, max=7)	(min=0, max=20)	
How many miscarriages have you had?	0.0 (1.0)	0.0 (1.0)	0.611
	(min=0, max=7)	(min=0, max=2)	
How many elective (also called medical or surgical abortions) have you had?	0.0 (1.0)	0.0 (0.0)	0.044*
	(min=0, max=7)	(min=0, max=2)	
Have had at least one miscarriage			0.504
No	56 (69.1%)	35 (63.6%)	
Yes	25 (30.9%)	20 (36.4%)	
Have had at least one elective abortion			0.046*
No	59 (73.8%)	45 (88.2%)	
Yes	21 (26.3%)	6 (11.8%)	

Numbers represent frequency (column percent) for categorical variables and median (IQR) for continuous.
*Significant at p<0.05.

Table 2 Medications and survey questions by survey language group

Variable	Survey language group		P value
	English survey (n=86)	**Spanish survey (n=65)**	
In the past 1 year, my lupus doctor has had at least one discussion regarding contraception with me			<0.001*
No	23 (27.4%)	43 (70.5%)	
Yes	61 (72.6%)	18 (29.5%)	
In the past 1 year, my lupus doctor has asked what my plans are, if any, for pregnancy			<0.001*
No	22 (26.2%)	35 (54.7%)	
Yes	62 (73.8%)	29 (45.3%)	
My lupus doctor has told me that it's important that my lupus is in remission before becoming pregnant†			0.999
No	4 (16.0%)	3 (15.0%)	
Yes	21 (84.0%)	17 (85.0%)	
My lupus doctor has explained which medications I should continue when I'm trying to become pregnant or when I'm pregnant†			0.450
No	7 (29.2%)	8 (40.0%)	
Yes	17 (70.8%)	12 (60.0%)	
My lupus doctor has explained which medications I should NOT continue during a pregnancy or if I'm trying to get pregnant†			0.049*
No	4 (17.4%)	9 (45.5%)	
Yes	19 (82.6%)	11 (55.5%)	

Numbers represent frequency (column percent).
*Significant at p<0.05.
†These questions were answered only by individuals who had answered 'yes' to trying to become pregnant or ever being pregnant after receiving a diagnosis of SLE.

DISCUSSION

While the USA is a historical 'melting pot' of many cultures and languages, it is well documented that many sociocultural healthcare disparities do exist, a critical one being non-English fluency as a barrier to care for Latino populations.[9–11] This is particularly concerning, as it is already clearly seen that the Hispanic population, compared with the non-Hispanic white population, has worse outcomes from SLE, including higher rates of adverse pregnancy outcomes. Our study revealed that women who participated in the Spanish survey were significantly less likely to be asked by their rheumatologist the 'One Key Question' regarding their pregnancy plans for the upcoming year compared with their English-speaking counterparts (45.3% vs 73.8%); however, the statistical significance was blunted when adjusting for age. Moreover, 70.5% of participants from the Spanish survey *denied* discussing contraception with their lupus doctor in the year leading
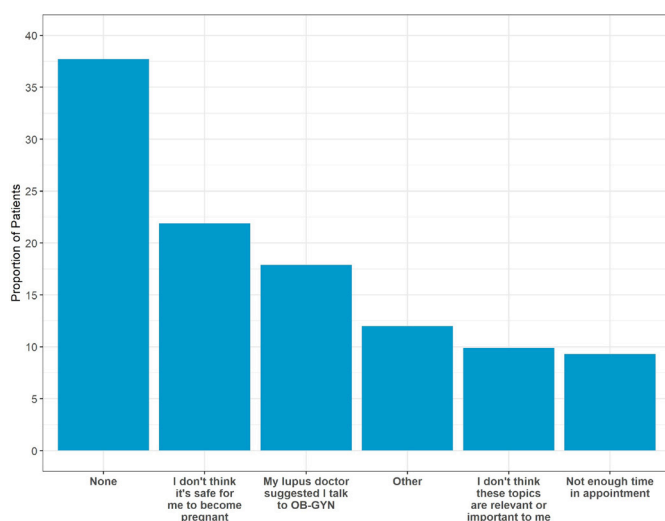

Figure 1 Barriers to discussing contraception and pregnancy with lupus doctor.
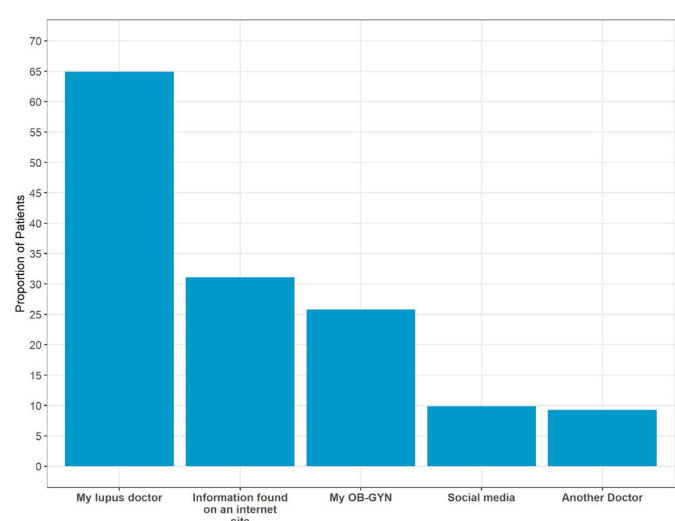

Figure 2 Top sources of information regarding lupus and reproductive health.

up to the survey, compared with only 27.4% from the English survey, and this striking difference persisted even when adjusting for age. Spanish survey respondents also had lower rates of contraception use compared with the English survey respondents, with only 67.7% using contraception, compared with 79.1%, respectively.

Finally, our Spanish language respondents also reported significantly fewer interactions with providers regarding appropriate medications to discontinue during pregnancy, raising a concern about potential teratogenic medication exposure during pregnancy (or by inference, when attempting to conceive). This is particularly important for our population, which has a high rate of severe SLE (ie, lupus nephritis, lupus cerebritis, multi-organ involvement, refractory disease) in addition to a challenging rate of being lost to follow-up. As a result, it appears even more important to us that these conversations take place for patients under our care, regardless of medication regimen, in the event that they require urgent or emergent use of medications (such as cyclophosphamide or mycophenolate mofetil) for flare while under the care of another institution.

Women with SLE may have multiple factors that increase their risk of adverse pregnancy outcomes, including but not limited to poorly controlled SLE disease activity, use of teratogenic medications, or comorbid conditions such as antiphospholipid antibodies and lupus nephritis. The 'One Key Question' is described in the 2020 ACR Guidelines as a relatively straightforward way to start the conversation regarding pregnancy plans in a vulnerable population. The importance of pregnancy planning and contraception counselling has been shown to positively increase women's knowledge surrounding the impact of SLE on pregnancy.[12] Accordingly, the 2020 ACR Guidelines emphasise the importance of tailored contraception counselling based on each SLE patient's clinical assessment (ie, antiphospholipid positivity). Our study demonstrated that women with a Spanish language preference had significant deficits as it related to in-clinic discussions regarding safe contraception use in light of their lupus diagnosis. However, we realise that our Spanish-speaking population may not have been asked the 'One Key Question' regarding pregnancy planning as frequently as the English-speaking population due to their older average age. There may have been an (potentially unwarranted) implicit bias that given their older age, pregnancy planning discussions were unnecessary. Despite this, discrepancies regarding contraception conversations—another key clinical question for women of childbearing age frequently on teratogenic medications—exist between English-speaking and Spanish-speaking populations, even when adjusting for age.

Interestingly, our study revealed that most English and Spanish survey respondents understood the importance of attaining clinical remission for their lupus before becoming pregnant, as was confirmed by 85% of participants in the Spanish survey and 84% from the English survey. This raises the possibility that our population's perception of a lack of disease control could hinder reproductive health discussions. Along similar lines, as a sizeable portion of patients (37.7%) *did not report any limitations* in discussing reproductive health matters with their rheumatologists, this suggests that lack of timely reproductive health discussions could be a result of provider-specific difficulties. These could include appointment time constraints (fear of prolonging clinic visit and falling behind on their schedule), lack of knowledge (ie, a trainee rotating through a rheumatology clinic may not feel comfortable addressing this issue with a patient with complex SLE), lack of supervision (not all attending rheumatologists may address reproductive health issues with trainees and patients in academic teaching clinics), varying degrees of interpreter quality/competency, or gender barriers (ie, male physician with a female patient). More information about these complex issues needs to be obtained.

Our analyses focused on the differences between language preference rather than ethnicity, as it has been demonstrated that language plays a large role in patients' disclosure of information, including in the rheumatology clinic setting.[13–16] Patient-centred communication is likely one of the most important factors in patients' disclosure of health information.[13] With this in mind, there may be several factors contributing to the disparities found among our population, which is served by an extremely busy urban academic centre with a large pool of rotating trainees (nearly 200 of which could be working in the outpatient rheumatology clinic, the majority of whom are not natively bilingual in English/Spanish) at any given time, in addition to rheumatology fellows and rheumatology attendings. A lack of continuity of care with rotating medical providers can lead to a decrease in patients' trust and perception of patient-centred care.[17 18] Time constraints of appointments along with language barriers can lead to Spanish-speaking women in particular pretending to understand during their appointments, physicians not establishing rapport, and patients or providers using the lack of time to avoid bringing up sensitive topics.[19] These barriers may even be present to some degree in the English-speaking population.

Finally, as was seen in our study, there may be an incorrect assumption that 'older' patients with SLE of childbearing age are less likely to need conversations regarding pregnancy planning. This may be far from true, as these patients may have deferred pregnancy while their SLE was active and may now desire or pursue pregnancy before menopause and therefore need adequate counsel on peripartum issues as it relates to SLE.

A unique barrier for Spanish-speaking patients is the medical provider's utilisation of a phone or in-person interpreter if the medical provider does not speak Spanish. The majority of Spanish-speaking patients prefer an interpreter for increased understanding.[20] However, medical residents often receive little to no training in the use of interpreters, and medical interpretation is often underused due to time constraints, deference of

interpretation to family members, and judgement of the perceived value of information in their clinical decision-making.[15 21] When used appropriately, interpreters could still contribute to the disparities seen in this study, as this creates a unique dynamic with a non-medical third party involved in the conversation and potentially affect the quality of the patient-provider relationship. The presence of an interpreter may influence Spanish-speaking women to forgo sensitive medical conversations topics like reproductive health.[19]

Our study offers several key strengths. This is the first study we are aware of that evaluates, from a patient perspective, just how the 2020 ACR Guidelines have been experienced 'downstream' over a 3-year period of exposure to providers and patients from a vulnerable minority patient population. Our survey was designed to target this population, helping to fill a gap in research and improve on the care of a high-risk population; it is important to note that our survey was pilot-tested and modified with input from the target population. Further, we gathered information on a wide variety of patient-reported reproductive health topics. We adopted a participant-friendly approach by compensating participants regardless of survey completion, reducing potential participation barriers, and thus had a relatively high participation rate for a survey which was well over 90%. These strengths collectively reinforce the reliability and relevance of our findings, contributing valuable insights to the existing body of knowledge.

A major limitation of our study is that the survey responses were anonymous, and we did not associate respondents' answers with clinical documentation, such as verification of medication regimen, serologic profiles, disease activity or prior pregnancy histories. Surveys were also distributed based on patient language preference which could have been influenced by factors such as the team member's role (eg, physician) potentially leading patients to choose a different language for the survey to please them. Moreover, a patient might be able to read and comprehend part of a language and therefore chose a survey in a language they are less proficient to practice. Further, although all patients are in our rheumatology clinic are staffed with an attending rheumatologist, the majority of face-to-face clinical care is provided by internal medicine residents and rheumatology fellows, all of whom have varying degrees of comfort levels and expertise with handling reproductive healthcare, and are not representative of how SLE care may be handled in the community or private practice. Therefore, our results may not be applicable to all practice settings.

In summary, we identified several potential obstacles to implementing the 2020 ACR Guidelines among participants in vulnerable, non-English-speaking population. Among these, one barrier that appears amenable to intervention is effective communication. The knowledge that Spanish-speaking patients with SLE may have lower rates of pregnancy-related and contraception-related conversations should spurn providers to proactively initiate such conversations with this specific patient population. Employing qualified language interpreters and using plain, patient-friendly language tailored to individual preferences could enhance the frequency of reproductive health discussions with SLE patients. Further, more comprehensive research is warranted to understand, and unravel further, the underlying communication barriers that reduce our ability to facilitate the successful implementation of the 2020 ACR Reproductive Health Guidelines in resource-constrained healthcare settings with non-English-speaking individuals.

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Supplemental material

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Lupus Sci Med

Appendix 1 - Lupus and Reproductive Health – English Survey

Survey purpose: Lupus is a chronic disease that can affect many parts of a person's life. Lupus can affect how women use contraception and experience pregnancy. Your experience with these issues is very valuable. We hope to use this survey to understand how we can improve our care of female lupus patients, especially for those who want to use contraception or become pregnant.

Please only take this if you are female, between the ages of 18 – 50, and have been told that you have systemic lupus erythematosus (lupus)

Where do you receive the majority of your lupus care?
- o LAC+USC Rheumatology Clinic
- o Harbor UCLA Rheumatology Clinic
- o Other:_____

1. How old are you? _____

2. What is your race?
- o White
- o Black/African American
- o Asian American
- o American Indian/Alaska Native
- o Native Hawaiian/Pacific Islander
- o Mixed race
- o Prefer not to state
- o Other (please write): _____

3. What is your ethnicity?
- o Hispanic
- o Non-Hispanic
- o Prefer not to state

4. In what language do you prefer to receive your medical care?
- o English
- o Spanish
- o Other (please write):_____

5. Education level:
- o Less than high school
- o High school diploma or equivalent

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- o Technical/vocational training
- o Bachelor's degree
- o Master's degree or above

6. Marital status:

- o Never married
- o Married, or in a domestic partnership
- o Widowed
- o Divorced or separated
- o Prefer not to state

7. Place of birth:

- o United States
- o Outside the United States

8. Religious affiliation:

- o Catholic
- o Any denomination of Christianity other than Catholic
- o Other religious group (please list): _____
- o No religious affiliation

9. Please select the following that best describes you:

- o I have never been sexually active with a male partner
- o I have been sexually active with a male partner, but I am not currently sexually active with a male partner
- o I am sexually active with a male partner, and I am currently trying to get pregnant
- o I am sexually active with a male partner, and I am currently trying to AVOID a pregnancy
- o I am sexually active with a male partner, and am neither trying to get pregnant nor trying to avoid it

10. I use the following for contraception (please select all that apply):

- o Abstinence; or I'm not sexually active with a male partner
- o Natural methods (pull out methods, fertility awareness)
- o Barrier or spermicidal methods (condoms, spermicide, cervical cap or diaphragm)
- o Short-acting birth control (oral contraceptive pills, vaginal ring, injection, patch)
- o Long-acting reversible birth control (intrauterine device [IUD], hormonal implant)
- o Sterilization (tubal ligation, hysterectomy, vasectomy, or post-menopausal)
- o None – I don't use any type of contraception

11. How many…

Times have you been pregnant? ____

How many miscarriages have you had? _____

How many elective (also called medical or surgical) abortions have you had? ____

12. Which of the following medications are you currently taking? (please select all that apply):

- o Steroids (prednisone, methylprednisolone [Medrol])
- o Hydroxychloroquine (Plaquenil)
- o Mycophenolate mofetil (CellCept) or mycophenolic acid (Myfortic)
- o Azathoprine (Imuran)
- o Methotrexate (Rheumatrex)
- o Leflunomide (Arava)
- o Tacrolimus (Prograf)
- o Voclosporin (Lupkynis)
- o An injection or infusion in the past 3 months (belimumab [Benlysta], anifrolumab [Saphnelo], tocilizumab [Actemra], abatacept [Orencia])
- o Rituximab (Rituxan) infusion in the past 6 months
- o Cyclophosphamide (Cytoxan) infusion in the past 3 months
- o An ACE inhibitor (benazepril, lisinopril, or captopril) or ARB (losartan, valsartan) blood pressure medicine
- o NSAIDs (ibuprofen, naproxen, indomethacin, celecoxib, aspirin)
- o I don't know
- o None
- o Other (please write): _____

Please answer the following questions as it relates to your lupus doctor and you:

13. In the past one year, my lupus doctor has had at least one discussion regarding contraception with me.

- o **Yes**
- o **No**

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Lupus Sci Med

14. My lupus doctor has explained what type of contraception I should or should not use in light of my lupus.

- o **Yes**
- o **No**

15. In the past one year, my lupus doctor has asked what my plans are, if any, for pregnancy

- o **Yes**
- o **No**

Questions 17 – 23 ONLY populate if patient answers in the affirmative to Question 16 "Yes, AFTER I was diagnosed with lupus"

16. Have you every been pregnant or have you ever tried to become pregnant? Choose all that apply.

- o **Yes, BEFORE I was diagnosed with lupus**
- o **Yes, AFTER I was diagnosed with lupus**
- o **No**

17. My lupus doctor has told me that it's important that my lupus is in remission before becoming pregnant

- o **Yes**
- o **No**

18. My lupus doctor has explained which medications I should continue when I'm trying to become pregnant or when I'm pregnant

- o **Yes**
- o **No**

19. My lupus doctor has told me that I should take hydroxychloroquine (Plaquenil) when I'm trying to become pregnant or when I'm pregnant

- o **Yes**
- o **No**

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20. I took hydroxychloroquine (Plaquenil) during pregnancy or when I was trying to get pregnant

- o **Yes, I was already on it and continued it while I was trying to get pregnant or during my pregnancy**
- o **Yes, I was not already on it, but I started it during this time**
- o **No, I stopped taking it when I found out I was pregnant or when I was trying to get pregnant**
- o **No, I was not taking it and did not start it at this time**
- o **Other**

21. My lupus doctor has explained which medications I should NOT continue during a pregnancy or if I'm trying to get pregnant

- o **Yes**
- o **No**

22. My lupus doctor has checked my blood for lupus-related risk factors that might make me or my baby at high risk during a pregnancy

- o **Yes**
- o **No**
- o **I don't know**

23. My lupus doctor has explained which medications are safe to take during breastfeeding

- o **Yes**
- o **No**

24. My lupus doctor has enough information to answer questions I have about lupus and its effect on contraception or pregnancy

- o **Yes**
- o **No**

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25. What makes it hard to discuss contraception and pregnancy questions with your lupus doctor? Please choose all that apply.

- o We don't have enough time in my appointment
- o My lupus doctor has suggested that I talk with an OB-GYN instead
- o There is a language barrier between my doctor and me
- o I don't think my lupus doctor knows enough about contraception or pregnancy issues
- o I don't feel comfortable talking about these issues with my lupus doctor
- o I don't think it's safe for me to become pregnant
- o I don't think these topics are relevant or important to me
- o Other (please write): _____
- o None

26. Who is most likely to initiate a conversation about reproductive health-related topics during an appointment with my lupus doctor?

- o I am
- o My lupus doctor is
- o My lupus doctor and I are equally likely to initiate a conversation about reproductive health-related topics
- o My lupus doctor and I have never discussed reproductive health-related topics

27. Where do you get most of your information regarding lupus and reproductive health? Please choose the top three.

- o My OB-GYN
- o My lupus doctor
- o Another doctor
- o Significant other
- o Family member
- o Friends
- o Lupus support group
- o Information found on an internet site
- o Social media
- o Television
- o Other (please write): _____

28. *Please let us know anything else that's important to you regarding reproductive health:*

_____

_____

_____

Supplemental Table 1. Multivariable logistic regression with having had discussion about pregnancy plans ("One Key Question") in past year as outcome

Variable	Estimate	Odds Ratio (95% CI)	P-value
Survey Language			
English	Reference	Reference	
Spanish	-0.564	0.57 (0.23 – 1.43)	0.231
Marital Status			
Never married	Reference	Reference	
Married/in a domestic partnership	-0.077	0.93 (0.36 – 2.41)	0.875
Widowed	-15.189	0.001 (0.00 – inf)	0.988
Divorced or separated	0.198	1.22 (0.35 – 4.25)	0.756
Age	-0.099	0.91 (0.86 – 0.96)	<0.001*
Education	-0.107	0.90 (0.57 – 1.42)	0.645

*Significant at $p<0.05$

- After adjusting for survey language, marital status, and education, for every one-year increase in the age, the odds of having a discussion regarding pregnancy plans in the past year was 9% lower (OR[95%CI]=0.91 [0.86-0.96]; p-value<0.001).

Supplemental Table 2. Multivariable logistic regression with having contraception discussion in the past year as outcome

Variable	Estimate	Odds Ratio (95% CI)	P-value
Survey Language			
English	Reference	Reference	
Spanish	-1.718	0.18 (0.07 – 0.47)	<0.001*
Marital Status			
Never married	Reference	Reference	
Married/in a domestic partnership	0.495	1.64 (0.59 – 4.58)	0.345
Widowed	-15.868	0.001 (0.00 – inf)	0.992
Divorced or separated	0.050	1.05 (0.28 – 3.89)	0.941
Age	-0.069	0.93 (0.89 – 0.98)	0.009*
Education	-0.155	0.86 (0.54 – 1.35)	0.504

*Significant at $p<0.05$

- After adjusting for age, education, and marital status, Spanish language participants had 82% lower odds (0.18 times lowers) of having a discussion regarding contraception with their lupus doctor in the past one year (OR[95%CI]=0.18 [0.07-0.47]; p-value<0.001).

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Lupus Sci Med

- After adjusting for survey language, marital status, and education, for every one-year increase in the age, the odds of having a discussion regarding contraception with their lupus doctor in the past year was 7% lower (OR[95%CI]=0.93 [0.89-0.98]; p-value=0.009).

Supplemental Table 3. Barriers by survey language group

Variable	Survey Language Group		Adjusted p-value
	English Survey (n=86)	Spanish Survey (n=65)	
What makes it hard to discuss contraception and pregnancy questions with your lupus doctor?			
Not enough time in my appointment	5 (5.8%)	9 (13.9%)	0.693
My lupus doctor suggested I talk to OB-GYN instead	16 (18.6%)	11 (16.9%)	0.999
There is a language barrier between doctor and me	1 (1.2%)	0	0.999
I don't think my lupus doctor knows enough about contraception or pregnancy	3 (3.5%)	2 (3.1%)	0.999
I don't feel comfortable talking about these issues with my lupus doctor	1 (1.2%)	2 (3.1%)	0.900
I don't think it's safe for me to become pregnant	19 (22.1%)	14 (21.5%)	0.999
I don't think these topics are relevant or important to me	11 (12.8%)	4 (6.2%)	0.693
Other	5 (5.8%)	5 (7.7%)	0.990
None	36 (41.9%)	21 (32.3%)	0.639

Supplemental Table 4. Sources of information by survey language group

Variable	Survey Language Group		Adjusted p-value
	English Survey (n=86)	Spanish Survey (n=65)	
Where do you get most of your information regarding lupus and reproductive health?			
My lupus doctor	59 (68.6%)	39 (60.0%)	0.601
My OB-GYN	24 (27.9%)	15 (23.1%)	0.776
Another doctor	11 (12.8%)	3 (4.6%)	0.315
Significant other	1 (1.2%)	5 (7.7%)	0.315
Family member	4 (4.7%)	7 (10.8%)	0.572
Friends	1 (1.2%)	2 (3.1%)	0.776
Lupus support group	7 (8.1%)	3 (4.6%)	0.777
Information found on an internet site	37 (43.0%)	10 (15.4%)	0.002*
Social media	8 (9.3%)	7 (10.8%)	0.842

Television	0	0	0.999
Other	3 (3.5%)	1 (1.5%)	0.776

*Significant at p<0.05 (adjusted using Benjamini-Hochberg correction)