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Who receives contraception counseling when starting new lupus medications? The potential roles of race, ethnicity, disease activity, and quality of communication

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Abstract

Objective—Family planning discussions are an important aspect of medical care for women with systemic lupus erythematosus (SLE) as active disease is a risk factory for poor pregnancy outcomes, and the medications used for treatment can be harmful to the fetus when used during conception and pregnancy. Our objective was to examine the impact of patient perception of quality and type of communication on receiving contraception counseling.

Methods—Data were derived from patients enrolled in the University of California, San Francisco Lupus Outcomes Study. Subjects participate in yearly structured telephone interview, which included assessment of contraception counseling when starting new medications, and measures of communication and decision-making. Logistic regression was performed to identify predictors of not receiving contraception counseling.

Results—Of the 68 women included in this analysis, one third did not receive contraception counseling when starting new medications. Older age, white race, depressive symptoms, and higher SLE disease activity were independently associated with not receiving contraception counseling. Participants who did not receive contraception counseling rated their physicians lower in shared decision making communication.

Conclusions—This study demonstrates a gap in family planning counseling among women with SLE starting new medications. Future studies to address these potential areas of intervention, including education about the need for contraception through menopause, and mechanisms to engage in SDM surrounding contraception are needed to improve quality of care for women with lupus.

Background

Systemic lupus erythematosus (SLE) often affects women in their reproductive years, making family planning and pregnancy discussions an important aspect of medical care. (1) Many of

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the immunosuppressive medications used to treat the manifestations of SLE have demonstrated or theoretical harm to the fetus. Prior to starting these medications, patients should be counseled about these risks, and a plan for contraception should be made and documented.(1) Despite general consensus there are known gaps in implementing this standard in clinical practice.(2)

An analysis of a large health maintenance organization demonstrated that women who filled prescriptions for medications with demonstrated human fetal risk, were no more likely to have received contraception counseling, or to have filled a contraception prescription than those using lower risk medications.(3) Conversely, some medications widely regarded as low risk for causing fetal harm are discontinued during pre-conception or pregnancy, likely due to unawareness that the risk of exacerbating their disease may outweigh the risks of using the medication during pregnancy.(4)

Women with SLE face a higher risk of pregnancy complications including preterm delivery, pre-eclampsia, and pregnancy loss. This risk can be mitigated by timing pregnancy for periods of lower disease activity, a process that relies on a clear understanding of a woman’s pregnancy intention and timely and appropriate counseling.(5,6) Despite these risks many women with lupus remain unprotected from the possibility of unintended pregnancy. One clinic-based study found that over half of sexually active patients with SLE failed to use a highly effective form of contraception.(7)

Opportunities for counseling are often missed. A survey of physicians treating women with systemic inflammatory diseases found that only 32 – 56% of physicians reported having talked about family planning and pregnancy with their female patients of reproductive age.(8) Most patients reported that their family planning and pregnancy concerns were not adequately addressed or settled during their appointments.(8) When discussion does occur patients often report inconsistency in the advice they receive from different providers.(8,9)

In this study, we investigated rates and predictors of not receiving contraception counseling in women with lupus starting new medications with known or potential risks to the fetus when used during pregnancy. Sociodemographic factors were investigated as predictors of not receiving contraception counseling due to the well-described disparities in health associated with race, income and class in the United States.(10) Patients report significantly lower rates of family planning counseling discussions during clinical encounters than clinicians (8) therefore of interest was whether patient perception of the quality and type of communication with their physician could predict receiving contraception counseling. We hypothesize that patients who rate their physicians lower in communication are less likely to report contraception counseling when starting new potentially teratogenic medications.

Methods

Data Source

Data derived from the University of California Lupus Outcomes Study (LOS), a prospective observational study of individuals with lupus, previously described in detail.(11) Briefly, LOS participants were recruited from an existing cohort of individuals with physiciandiagnosed lupus, confirmed by chart review. Enrollment began in 2003, and continued through 2010, with 80% of individuals enrolled prior to 2006. Subjects participate in an annual structured telephone interview conducted by experienced survey workers that average 50 minutes in length. The interview includes validated measures of SLE disease activity and manifestations, general physical and mental health status, medications, health care utilization, health insurance coverage and sociodemographic characteristics. Recruitment for the LOS occurred in several different settings in an effort to capture the full spectrum of SLE, including academic and community practices (33%), lupus support groups and conferences (26%), and newsletters, websites and other forms of publicity (41%). Over the course of the study, there have been 1,349 persons in the LOS and 8,358 person years of observation (6.2 years per person). Year to year re-interview rates have averaged 93% including deaths, or 95% excluding them.

Variables

Primary outcome: assessing contraception counseling—Each year, patients are asked whether they have started new medications for their lupus using a pre-selected list of medications commonly used to treat the manifestations of SLE. For the past 5 years, participants were asked the question “At that time, were you also given information about birth control, contraception, or not getting pregnant?” when they endorsed starting azathioprine, mycophenolate, methotrexate, cyclosporine, leflunomide, cyclophosphoide, rituximab, abatacept, or belimumab.

Measures of assessing communication between patients and providers: Beginning in 2012, we included components of the Consumer Assessment of Healthcare Providers and Systems (CAHPS)(12) and the Interpersonal Processes of Care (IPC) assessment(13) to evaluate how participants viewed interaction with their physicians. The Agency for Healthcare Research and Quality designed CAHPS items to evaluate interactions between patients and health care systems in such domains as provider communication, promptness, timeliness of care, and care coordination as a large-scale assessment of the health plans. The IPC scale was developed to assess how quality of interpersonal process of care might affect technical process and outcomes, incorporating issues that are important to minority and low socioeconomic populations using a validated self-report instrument. Communication with their provider was assessed using 15 items, shared decision making assessed by 6 items, and trust was assessed using 6 items. Items were coded differently in the CAHPS assessment and the IPC assessment, and were therefore transformed to a 0 to 100 scale for uniformity using a strategy discussed by Morales and colleagues(14), and in another publication using the LOS(15). Only patients who had seen the primary provider who treats their lupus within the past year were asked these questions. Appendix 1 includes a complete listing of items from CAHPS and IPC included for this analysis to assess communication.

Education and income—Education level was assessed each year as less than high school, high school graduate, some college, associate/trade degree, bachelor’s degree, and post-bachelor degree. This was later dichotomized into high school education or less, and above high school education. Household income was also assessed each year, and for this analysis dichotomized into less than 125% of the Federal poverty line, or at or above 125% of the federal poverty line.

Health literacy—Health literacy was measured using a single item literacy screener, a self-report question created by Morris and colleagues.(16) The question "How often do you have someone like a family member, friend, hospital or clinic worker or caregiver help you read health plan materials, such as written information about your health or care you are offered? Possible answers were never, sometimes, usually, or always. Patients answering "sometimes", "usually", or "always" were considered as demonstrating limited health literacy.

Disease status—SLE disease status was evaluated using two measures, the Systemic Lupus Activity Questionnaire (SLAQ), and the Brief Index of Lupus Damage (BILD). The SLAQ , a 24- question inventory of self-reported signs and symptoms is a validated measure of SLE disease activity over the preceding three months, used with research when a clinical examination is not possible.(17) It is scored on a scale of 0 to 47. The BILD is a patient reported, 41-item assessment designed to evaluate cumulative lupus damage involving 12 organ systems.(18) It has been previously validated, and found to have good agreement with the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SDI), a measure requiring the assessment of a clinician.(19)

Depressive symptoms—The Center for Epidemiologic studies Depression Scale (CESD) is a commonly used 20 item assessment of depression symptoms that is patient reported. (20) Scores range from 0 – 60 with higher scores reflecting increased severity of depression. It has been previously used with SLE, with cut points of 24 consistent with major depression, and 20 and above consistent with any depressive mood disorder.(21)

Statistical Analysis

This analysis includes women who started new medications with known or theoretical harm to the fetus when used during pregnancy who were less than 45 years old at that time, and had not had prior hysterectomy or premature ovarian failure. We report patient provider communication, provider trust, shared decision-making, clinical and sociodemographic characteristics for these participants.

Using univariate logistic regression models, we examined predictors of the outcome of receiving contraception counseling. Predictors examined include age, race/ethnicity (White, African-American, Asian, Latina, Other), education (high school education or less, more than a high school education), depression as measured by CES-D, disease activity using SLAQ scores, cumulative damage using BILD scores, and communication variables including patient provider communication, provider trust, and shared decision making. Finally, we constructed multivariate logistic regression models using significant predictors from the biavariate analysis to examine independent predictors of receipt of contraceptive counseling. Sensitivity analyses excluding women who started azathioprine were performed.

All data were analyzed using Stata, version 13 (Stata-Corp). The University of California, San Francisco Committee on Human Research, approved the research protocol. All participants gave their informed consent to be part of the study.

Results

A total of 68 women were included in this analysis between the ages of 20 and 45. Table 1 shows selected demographic characteristics for participants.

One third of women did not report receiving contraception counseling when starting new medications with known or theoretical harm to the fetus when used during pregnancy. In univariate analyses, women who were older, white, had higher levels of depressive symptoms and had high disease activity were less likely to receive contraception counseling (Table 2). Patients who rated their providers low on the shared decision making scale were also less likely to receive counseling. Health literacy was not associated with receiving counseling. In multivariate analyses, these factors did not retain statistical significance. Sensitivity analyses, excluding women who started azathioprine demonstrated no major differences.

Discussion

This analysis demonstrates a continued gap in adequate patient-clinician communication and discussions around teratogenic medications, family planning and pregnancy issues in women with lupus. Our study demonstrates that one third of participants did not receive adequate counseling. We found multiple significant predictors in bivariate analyses, but none of these remained significant in the multivariate model, perhaps because the small sample size did not provide enough statistical power. A sample size of at least 200 participants would be needed to achieve statistical significance.

In our study, women who were older were less likely to receive contraception counseling. Though fertility declines after age 40 pregnancy is still common. (22) The US Department of Health and Human Services has reported a 2% increase per year in the birth rate for women age 40 – 44 since 2000, and a 7% increase in births in women age 45 – 49 in 2013. (23) It is estimated that almost half of pregnancies in women who are older than 40 are unplanned.(23) It is recommended that women use contraception until cessation of menses for two years if younger than 50 and one year if over age 50.(24)

White women were less likely to report contraception counseling than women of other races. Historically, the influence of eugenics has significantly impacted public policy surrounding reproductive health and has disproportionately affected women of color, resulting in tragedies such as the forced and coerced sterilization of women. (25) Though public policy has shifted, the degree that remnants of such attitudes persist is difficult to assess. Borrero et al. using data from the National Survey of Family Growth found that Hispanic and African-American women were more likely than white women to report contraception counseling, though frequency of accessing family planning services was similar between groups.(26) They reflect on the role of clinician stereotypes in contraception counseling, noting that more counseling does not necessarily correspond to the quality of counseling provided. (26)

The women in these analyses had a clear indication for receiving counseling. This makes it a difficult task to distinguish necessary contraception counseling from potential clinician bias towards increased contraception counseling of women color, or to assume that white women do not need such counseling. It is also important to note that in this analysis, white women were older than non-white women, though no effect modification was detected.

Participants with higher CESD scores, indicating disorders on the depressive spectrum, were less likely to report contraception counseling. Depressive symptoms can be associated with impairment in cognitive functioning, particularly in the domain of executive function, impacting memory, attention, problem solving, and goal setting. It is possible that patients have been counseled regarding contraception, but due to their depressive symptoms did not recall it.(27)

We identified higher disease activity as measured by the SLAQ score is a predictor of not receiving contraception counseling. This finding is important, as patients with higher disease activity who become pregnant are at higher risk for poor pregnancy outcomes. (5,6) Additionally, patients with higher disease activity are often treated with medications that are potential teratogens in order to treat their lupus, and are therefore have a great need for family planning and contraception counseling.

General clinician communication was rated highly amongst women who did and did not report receiving contraception counseling. Participants in both groups scored clinicians lower on shared decision making. However, patients who did not receive contraception counseling scored their physicians significantly lower in this area. Data on health literacy, which can impact communication, was available for 56 participants, with no statistical differences between the groups. Trust in the physician can also impact SDM, but was rated highly in both groups. Dehlendorf et al in their qualitative study of communication surrounding contraception also describe a paucity of SDM in their analysis of 50 taper-ecorded clinician-patient encounters in primary care clinics. In a separate study, Dehlendorf et al investigated women’s opinions and values regarding interactions with family planning providers in semi-structured interviews, and found that most women desired provider participation in the decision-making process in a context that emphasizes patient values and preferences. (28) This could be an important area of needed innovation, as there has been limited success with contraception interventions to date.(29)

Limitations of this study include the relatively small number of participants in the LOS who met criteria for the analysis and the reliance on participant recall via structured telephone interviews, which may underestimate counseling. However, participant recall may be a more meaningful measure than actual objective measurement of counseling, as only women who recall receipt of contraception counseling would be able to act on the information. We did not have data on current method of contraception, which may impact the interpretation of this data. Women with long acting reversible contraception (LARC) may not receive as much dedicated contraception counseling, though prior studies in this cohort demonstrated low rates of LARC use.(2)

Azathioprine, which is regarded clinically as acceptable for use during pregnancy for women with SLE with severe disease manifestations was included in this analysis. Reported adverse outcomes in infants exposed to azathioprine in-utero include thymic atrophy, leukopenia, anemia, thrombocytopenia, chromosome aberrations, decreased immunoglobulin levels and infection, however no specific physical malformations have been associated with its use. Some women who intended pregnancy may have been advised to stop other immunosuppressant agents associated with worse infant outcomes and start azathioprine due to its relative safety. The question posed in our study would not capture these women. We performed sensitivity analyses, excluding women with azathioprine and found no major differences in effects.

Our data suggest a gap in contraception counseling among women with lupus starting new potentially teratogenic medications who are older, who have depressive disorders, and who have higher disease activity. Though overall communication was rated highly, patients who rated their clinicians lower on SDM reported less contraception counseling. Future studies to address these potential areas of intervention, including education about the need for contraception through menopause, and mechanisms to engage in SDM surrounding contraception are needed to improve quality of care for women with lupus.

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Table 1

Sociodemographic characteristics

Characteristics	
Age, years, mean +/− sd	34.8 +/− 7.3
Race/Ethnicity, n (%)	
Caucasian	18 (26.5)
Hispanic	20 (29.4)
African American	8 (11.8)
Asian	13 (19.1)
Other	9 (13.2)
Poverty, n (%)	
Below Fed Pov	125% 21 (31.8)
Education, n (%)	
High school graduate and less	8 (17.4)
Depression (CESD), mean +/− sd	15.7 +/−14.3
SLAQ Score, mean,+/− sd	9.1 +/− 6.9
BILD Score, mean +/− sd	1.6 +/−1.8

SLAQ: Systemic Lupus Erythematous Activity Questionnaire, range 0 – 47; BILD: Brief Index of Lupus Damage range 0 – 31; CESD Center for Epidemiologic Studies Depression, range 0 – 60;

Table 2

Predictors of not receiving contraception counseling when starting new potentially teratogenic medications.

Predictor	**Patients who report contraception (n=46)**	**Patients who do not report contraception counseling (n=22)**	**Univariate (95% CI)**	**Multivariate (95% CI)**
Ag mean (sd)	33.2 (7.5)	38.0 (5.7)	**1.10 (1.02, 1.21)**	1.04 (0.95, 1.15)
Race/Ethnicity frequency (%)				
African American	7 (15.2)	1 (4.6)		
Asian	10 (21.7)	3 (13.6)		
Hispanic	14 (30.4)	6 (27.3)		
Other	7 (15.2)	2 (9.1)		
White	8 (17.4)	10 (45.5)	**3.96 (1.27, 12.3)**	3.12 (0.74, 13.1)
CESD score (per 5 units) mean (sd)	13.2 (12)	20.9 (17.3)	**1.21 (1.01, 1.47)**	1.09 (0.86– 1.4)
High school Education or less frequency (%)	5 (22.7)	4 (18.2)	1.4 (0.4, 4.9)	
SLAQ score (per 5 units) mean (sd)	8 (6.1)	12.5 (7.8)	**1.60(1.06, 2.41)**	1.50 (0.87, 2.58)
BILD score mean (sd)	1.4 (1.7)	2.1(2.1)	1.24 (0.93, 1.65)	
Provider Trust (per 10 units) mean (sd)	90.8 (12.6)	88.4 (17.3)	0.89 (0.63, 1.27)	
Patient Provider Communication (per 10 units) mean (sd)	92.9 (9.6)	90.1 (10.7)	0.77 (0.46 – 1.26)	
Shared Decision Making (per 10 units) mean (sd)	58.1 (25.8)	42.5 (32.5)	**0.82 (0.67, – 0.99)**	0.93 (0.74, 1.16)
Limited Health Literacy frequency (%)	13 (37.1)	4 (25)	1.46 (0.33, 6.51)	

Race/Ethnicity: rates of contraception use reported for each group; for bivariate and multivariate regression models white race was compared to sum of all other groups. SLAQ: Systemic Lupus Erythematous Activity Questionnaire, range 0 – 47; BILD: Brief Index of Lupus Damage range 0 – 41; CESD Center for Epidemiologic Studies Depression, range 0 – 60; Physician trust, Patient Provider Communication and Shared Decision Making using Consumer Assessment of Healthcare Provider and Systems survey and the Interpersonal Processes of Care survey; responses transformed to a 0 –100 scale.

Appendix 1

Selected Dimensions of Interactions between Patients and Providers and Health Systems from the Consumer Assessment of Health Plans Survey (CAHPS) and Interpersonal Processes of Care Scale (IPC)

Dimension		**Rating Scale**
Patient-doctor communication (CAHPS)		1 to 4
1.	In the last 12 months, how often did this provider explain things in a way that was easy to understand?	Never 1 Sometimes 2 Usually 3 Always 4
2.	In the last 12 months, how often did this provider listen carefully to you?	
3.	In the last 12 months, how often did this provider interrupt you when you were talking?	
4.	In the last 12 months, how often did this doctor talk too fast when talking with you?	
5.	In the last 12 months, how often did this doctor use medical words you did not understand?	
6.	In the last 12 months, how often were the explanations this doctor gave you hard to understand because of an accent or the way the doctor spoke English?	
7.	In the last 12 months, how often did this doctor ignore what you told him or her?	
8.	In the last 12 months, how often did this doctor use a condescending, sarcastic, or rude tone or manner with you?	
9.	In the last 12 months, how often did this doctor show interest in your questions and concerns?	
10.	In the last 12 months, how often did this provider give you easy to understand information about these health questions or concerns?	
11.	In the last 12 months, how often did this provider show respect for what you had to say?	
12.	In the last 12 months, how often did this provider answer all your questions to your satisfaction?	
13.	In the last 12 months, how often did this provider spend enough time with you?	
14.	In the last 12 months, when this provider ordered a blood test, x-ray, or other test for you, how often did someone from this provider's office follow up to give you those results?	
15.	In the last 12 months, how often did this provider seem to know the important information about your medical history?	
Shared Decision-making (CAHPS & IPC*)		1 to 2; 1 to 4
1.	In the last 12 months, did anyone in this provider's office talk with you about specific goals for your health?	No 1 Yes 2
2.	In the last 12 months, did anyone in this provider's office ask you if there are things that make it hard for you to take care of your health?	
*3.**	*In the last 12 months, how often did the provider ask if you would have any problems following what he or she recommended?*	Never 1 Sometimes 2 Usually 3 Always 4
*4.**	*In the last 12 months, how often did the provider ask if you felt you could do the recommended treatment?*	
*5.**	*In the last 12 months, how often did you and this provider work out a treatment plan together?*	
*6.**	*In the last 12 months, if there were treatment choices, how often did this provider ask if you would like to help decide your treatment?*	

Dimension Rating Scale		
Trust (CAHPS)		1 to 3; 1 to 10
1.	In the last 12 months, did you feel you could tell this provider anything, even things that you might not tell anyone else?	Yes, definitely 1 Yes, somewhat 2 No 3
2.	In the last 12 months, did you feel you could trust this provider with your medical care?	
3.	In the last 12 months, did you feel that this provider always told you the truth about your health, even if there was bad news?	
4.	In the last 12 months, did you feel this provider cared as much as you do about your health?	
5.	In the last 12 months, did you feel this provider really cared about you as a person?	
6.	Using any number from 0 to 10, where 0 means that you do not trust this provider at all and 10 means that your trust this provider completely, what number would you use to rate how much you trust this provider?	0=Don’t trust at all to 10=Trust completely