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Primary preventive services in patients with systemic lupus erythematosus: Study from a population-based sample in Southeast U.S.☆

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ABSTRACT

Objectives: Systemic lupus erythematosus (SLE) patients are at risk for complications that can be mitigated by appropriate preventive care. We examined the receipt of immunizations, cancer screening, and cardiovascular risk preventive services in a predominantly Black cohort of SLE patients from the Southeast U.S. To identify gaps in primary preventive services (PPS) that might be specific to SLE as opposed to local health system factors, we used as reference a population-based sample from the same area.

Methods: A cross-sectional design was used to characterize the percentage of PPS received by 751 SLE patients from Atlanta, GA, and 9040 subjects from the same community, of whom 938 had diabetes. Factors associated with the receipt of PPS were examined with multivariable analysis of variance.

Results: Approximately 65% of recommended PPS were provided to the SLE, overall community (OC), and diabetes samples. However, only 22.5%, 45.7%, and 27.6% of SLE, OC, and diabetes subjects, respectively, received all recommended services. Factors associated with a higher percentage of PPS received by SLE patients included older age (63.6% if age ≥65 years, 45.8% if age between 18 and 35 years), having medical insurance (61.1% for insured, 49.7% for uninsured), having a primary care physician (PCP) (59.0% if patient had PCP, 51.8% if patient did not have PCP), and being a non-smoker (61.9% for non-smokers, 49.9% for smokers).

Conclusions: Less than one-quarter of SLE patients from a southeast U.S. community received all the recommended services that were studied. Further research is warranted to unravel the barriers that prevent SLE patients from reaching appropriate standards of preventive care.

Introduction

The primary care system has key functions in delivering core medical and preventive care and helping patients to coordinate and integrate care across health care providers. Primary care services have been shown to improve health outcomes and reduce costs [1]. However, Americans receive only half of the recommended primary care services, and those who receive poorer quality primary care have higher mortality than those who receive higher standards of care [2–4]. Thus, adequate delivery of primary care is becoming a greater priority for U.S. policy makers [2].

The health of patients that suffer from systemic lupus erythematosus (SLE) is frequently complicated by comorbid conditions, many of which are potentially preventable. Among the range of primary prevention services recommended by national experts, immunizations, cancer surveillance, cardiovascular risk screening, and cardiovascular risk reduction are particularly relevant to SLE patients. Infections, cardiovascular disease (CVD), and cancer are among the leading causes of mortality in patients with SLE [5]. The prevalence of SLE is 3–4 times higher in Blacks than Whites; and as is the case with other chronic illnesses, SLE patients from ethnic minorities and low socioeconomic status are at high risk for multiple comorbidities and more likely to have poorer outcomes. For instance, Black SLE patients are 3–6 times more likely to develop multi-organ damage, diabetes, end-stage renal disease, and cardiovascular disease [6–9]. They also tend to develop these complications at earlier ages and have higher overall mortality rates [10].

In the overall US population, the quality of primary care services varies substantially across health conditions and across

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communities [2–4]. Gaps in the provision of primary care to patients with SLE have been identified. Data from a predominantly White cohort of insured women with SLE from California showed that 40% of SLE patients reported underuse of recommended immunizations, and about 30% were not screened for cancer [11]. Although these rates were comparable to the general population, significant variability was observed across socio-demographic factors, such as age and education. Moreover, despite the increased risk of CVD associated with SLE, only 29% of SLE patients reported annual evaluations for cardiovascular risk factors, and those of lower socioeconomic status were less likely to be screened [12]. Among 200 SLE patients followed at a university-based center in Boston, only 12.5% had a documented smoking assessment by the attending physician in the past year [13]. Factors directly associated with the health system (e.g. insurance, type of insurance, and type of physician involved in the medical care) have been shown to have the largest impact on the overall quality of care for patients with SLE [12].

The receipt of effective primary preventive services (PPS) has not been studied in a non-selected cohort of SLE patients encompassing a significant proportion of minority and socioeconomically disadvantaged individuals. This study aims to describe the rate of effective PPS in a population-based cohort of SLE patients' residing in a metropolitan area of the Southeastern U.S. with significant minority representation. We specifically examined influenza and pneumonia immunization rates, cancer screening, cholesterol monitoring, and use of aspirin for the primary prevention of CVD. To identify differences in the receipt of PPS that might be specific to SLE as opposed to local health system factors, we examined a population-based sample of the general population from the same geographic area. Because previous studies have shown differences in PPS rates between patients with and without chronic disease, we also identified a representative subsample with diabetes, a chronic disease that has high CVD, and infection risks, similar to that of SLE. Finally, we studied the effect of socio-demographics, health system factors, health status, and lifestyle factors in the overall receipt of PPS among SLE patients and the community subjects with diabetes.

Methods

Study design

A cross-sectional design was used to describe the self-reported receipt of primary preventive services among SLE patients enrolled in a cohort established in the greater metropolitan Atlanta area, Georgia.

Description of the GOAL cohort

The Georgians Organized Against Lupus (GOAL) Cohort is a longitudinal study of consented adult patients with a validated diagnosis of SLE. The primary source of SLE patients is the Georgia Lupus Registry (GLR), a CDC-funded population-based registry designed to estimate the incidence and prevalence of SLE in Atlanta, Georgia. The GLR was implemented between 2003 and 2010 through a partnership between the Georgia Department of Public Health (GA DPH) and Emory University. Acting as “public health authority” (under the Health Insurance Portability and Accountability Act Privacy Rule, 45 CFR parts 160 and 164), the GA DPH enabled Emory investigators to collect protected health information and clinical data from medical records without written patient consent [14]. Furthermore, the GA DPH authorized Emory investigators to recruit and consent adult SLE patients into the GOAL Cohort. The overall aim of the GOAL Cohort is to examine the impact of socio-demographic and health care factors on outcomes of SLE patients. SLE patients were recruited into the GOAL cohort by mail, phone, and in person to complete annual self-administered surveys. Of 910 SLE patients who had consented to participate in the GOAL cohort by June 2012, over 70% were ascertained from the GLR. Other patients came from lupus clinics at Emory University, the indigent care hospital in Atlanta (Grady Memorial Hospital), and community rheumatologists from the great metropolitan Atlanta. Trained abstractors collected clinical data from medical records and the diagnosis of SLE was validated according to the GLR case definition [15]. Briefly, validated cases fulfilled either four or more of the American College of Rheumatology (ACR) Classification Criteria for SLE [16] or three ACR criteria with a final diagnosis of SLE by a board-certified rheumatologist.

Among 840 GOAL participants with a validated diagnosis of SLE, 751 responded to the survey delivered between August 2011 and June 2012, and were examined in this study. The Emory University Institutional Review Board, Grady Health System Research Oversight Committee, and the GA DPH Institutional Review Board approved the GOAL study protocol. All GOAL participants gave informed and signed consent.

Data collection

The GOAL survey includes questions on socio-demographics, access to health care, lifestyle factors, lupus outcomes, health status, and utilization of primary preventive care services. Survey questions related to preventive services, health care access, lifestyle factors, and overall health status were worded the same as those in the Behavioral Risk Factors Surveillance System (BRFSS) survey, which was used as the comparative samples.

The BRFSS is an ongoing survey administered by the Centers for Disease Control and Prevention (CDC) that uses a random-digit dial landline telephone survey to collect data on health conditions and behaviors associated with the leading causes of morbidity and mortality among the non-institutionalized US population [17]. The core survey uses a stratified, multistage probability sampling design and is administered to a nationally representative sample of US adults from all 50 states as well as the District of Columbia, Puerto Rico, and US Virgin Islands. Most measures are of moderate or high reliability and validity, and reliability has been demonstrated in multiple ethnic groups [18].

PPS data collected from the BRFSS survey between 2005 and 2010 was used as reference. We analyzed de-identified BRFSS-weighted responses of residents drawn from Public Health District 3, the same geographic area as GOAL participants (the “overall community”). A total of 9040 respondents aged 18 years or older from the BRFSS survey, including 938 who self-reported a diagnosis of diabetes made by a doctor, were examined in this study. SAS-Callable SUDAAN version 10.01 was used to calculate sampling weights for the BRFSS data. For each survey year sample weights were constructed to ensure the respondents were representative of the population from which they were drawn.

Recommended primary preventive services

The receipt of influenza and pneumococcal immunizations were evaluated according to CDC recommendations for all adults [19–21]. Screening for cervix, breast, and colon cancer (Papanicolaou test, mammogram, and colonoscopy, respectively), cholesterol monitoring, and aspirin for primary prevention of myocardial infarction and strokes were examined according to recommendations graded A or B by the US Preventive Service Task Force (USPSTF) [22]. Because immunization and cancer screening recommendations were modified during the study period, we used the guidelines that were applicable when the surveys were administered. For cholesterol monitoring among GOAL participants, we examined recently developed recommendations for SLE, which endorsed annual lipid screening for all SLE patients [23,24]. Detailed descriptions of recommended services, eligibility criteria, and number of eligible participants for SLE and BRFSS samples are available in the Appendix.

Study outcomes

Proportion of eligible individuals who received recommended PPS

We calculated the unadjusted percentage and 95% confidence intervals (CI) of eligible GOAL participants who received each of the seven PPS assessed in this study. BRFSS-weighted data was used to calculate the percentage and 95% CI of eligible subjects who received each of the seven PPS in the overall community and the subsample with diabetes. We further created binary variables to examine the proportion of eligible participants from the GOAL Cohort and the BRFSS samples that received care consistent with the guidelines for: (i) immunizations, (ii) cancer screening, (iii) CVD risk screening/reduction, and (iv) overall guidelines (i-iii). Receiving care consistent with guidelines within a particular category required that all recommendations for which each individual was eligible were reported as received. For example, if an individual was eligible for pneumonia and influenza immunizations and he/she received both vaccines, this person was classified as receiving care consistent with immunization guidelines. Anything less would be considered failing to receive care consistent with the guidelines.

Percentage of recommended PPS received by eligible individuals

We calculated the percentage of each category of PPS received: immunizations, cancer screening tests, CVD risk screening/reduction, and overall PPS. For each PPS category, numerators were the sum of services reported as received by eligible individuals, and denominators were the sum of services that individuals should have received based on the recommendations described in the previous subsection and the Appendix.

Statistical analysis

Confidence intervals (95%) based on Wilson's score method for a single sample proportion [25] were calculated for the proportion of participants who received recommended PPS. The confidence intervals (95%) were calculated separately for each study group (GOAL, BRFSS overall community, and BRFSS diabetes) for each of the 11 categories of PPS reported in Table 2. Confidence intervals (95%) were also calculated for the percentage of recommended PPS reported as received by categories of PPS (immunizations, cancer screening tests, CVD risk screening/reduction, and overall PPS) within each study group (Table 3). Univariable (one-way analysis of variance; data not shown) and multivariable analyses (multifactor analysis of variance using SAS Proc GLM, Table 4) were performed separately for SLE and diabetes patients to identify categorical prognostic factors independently associated with the percentage of recommended PPS services that were received. The multivariable results were summarized with adjusted means and 95% confidence intervals.

Table 1
Description of SLE (GOAL cohort) and community samples (BRFSS)

Descriptor	GOAL cohort (N = 751)	BRFSS Overall community (N = 9040)	BRFSS Diabetes (N = 938)
Socio-demographics			
Age, mean ± SD	46.0 ± 13.4	44.1 ± 22.7	57.0 ± 26.0
Gender			
Male	47 (6.3)	3122 (49.2)	370 (50.0)
Female	704 (93.7)	5918 (50.8)	568 (50.0)
Race			
White	146 (19.4)	5509 (53.7)	506 (47.3)
Black/AA	584 (77.8)	2853 (35.7)	366 (43.1)
Asian	9 (1.2)	211 (5.4)	14 (5.6)
Others	12 (1.6)	253 (5.1)	32 (4.0)
Educational attainment			
≤ High school	267 (35.6)	2243 (25.0)	370 (35.0)
Some college	241 (32.1)	2308 (24.1)	253 (25.4)
≥ College	243 (32.4)	4455 (50.9)	313 (39.5)
Living below poverty level	326 (45.9)	696 (11.0)	110 (13.7)
Marital status			
Married or cohabitated	260 (34.6)	4767 (60.6)	444 (60.3)
Single/separated/ widowed	491 (65.4)	4218 (39.4)	489 (39.7)
Work status			
Employed	258 (34.4)	5316 (66.6)	337 (46.4)
Unemployed or disabled	327 (43.6)	907 (10.5)	159 (16.1)
Student, retired, homemaker	165 (22.0)	2785 (23.0)	440 (37.5)
Health system factors			
Insured	615 (81.9)	8058 (86.1)	854 (89.9)
Limited access to see a doctor	266 (35.5)	1134 (14.2)	138 (17.2)
Annual routine checkup	549 (73.1)	6864 (72.3)	830 (87.2)
Lifestyle factors			
Current smoking	98 (13.1)	1017 (14.5)	113 (16.4)
Physical activity	424 (56.8)	6976 (79.3)	578 (65.8)
Health status			
Obesity	283 (37.8)	2507 (26.5)	491 (51.7)
Hypertension	488 (65.5)	1452 (25.6)	326 (70.1)
Overall health			
Excellent/very good/good	362 (48.3)	7743 (89.1)	552 (63.4)
Fair/poor	388 (51.7)	1260 (10.9)	380 (36.6)

Table entries are frequency (%) for categorical variables. BRFSS estimates are weighted based on BRFSS stratified multistage probability sampling design.

Results

Description of the GOAL cohort and BRFSS samples

The survey response rate among GOAL participants was 89.4% (751/840). Reflecting the demographic characteristics of SLE patients from the GLR [15], respondents from the GOAL cohort were mostly women (93.7%) and Black (77.8%), with a mean age of 46.0 years (Table 1). Over 35% had high school education or less, 43.6% were unemployed or disabled, 45.9% were living below the Federal poverty level, and 18% were uninsured. Among those GOAL respondents who were insured, 41.6%, 27.8%, and 30.6% had private insurance, Medicare, and Medicaid, respectively (data not shown). In contrast, overall community subjects were evenly distributed in terms of gender (50.8% females); 53.7% were White, and 35.7% Black. Overall community subjects reported higher educational attainment and fewer barriers to seeing a doctor than SLE patients. Subjects with diabetes were older than SLE patients, 50.0% were females and 43.1% Blacks. Levels of education were comparable between those with SLE and diabetes, but SLE patients reported higher rates of both unemployment and living below the Federal poverty level. Seventy-three percent of SLE patients reported having an annual routine checkup in the past year compared to over 87% of individuals with diabetes. The proportion without medical insurance and facing barriers to seeing a doctor was higher among those with SLE than those with diabetes. The group with SLE was less likely to perform physical activities or exercises (other than their regular job) than the other two groups. Almost 52% of SLE patients reported poor or fair health status compared to less than 37% of individuals with diabetes and 11% of the overall community.

Table 2
Proportion of SLE (GOAL cohort) and community (BRFSS) individuals who received recommended primary preventive services

Primary Preventive Service	GOAL cohort		BRFSS			
			Overall community		Diabetes	
	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)
Immunizations						
Influenza vaccine	428	57.1 (53.5–60.7)	2684	43.1 (41.3–45.0)	547	52.5 (47.6–57.4)
Pneumonia vaccine	300	49.1 (45.1–53.1)	1609	45.4 (42.8–48.0)	507	46.6 (41.8–51.4)
RCC immunization guidelines	302	40.5 (37.0–44.2)	2206	34.1 (32.5–35.9)	372	32.9 (28.9–37.2)
Cancer screening						
Cervical cancer screening	426	83.2 (79.7–86.3)	3106	86.6 (84.9–88.1)	171	77.4 (68.1–84.5)
Mammogram	225	84.3 (79.3–88.4)	3387	79.5 (77.8–81.2)	412	81.4 (75.7–85.9)
Colonoscopy	239	81.3 (76.4–85.6)	1996	66.4 (64.2–68.6)	310	69.6 (63.6–74.9)
RCC cancer screening guidelines	520	78.0 (74.6–81.1)	3849	73.4 (71.8–74.9)	353	66.2 (60.5–71.5)
CVD risk screening and reduction						
Cholesterol monitoring	485	65.0 (61.5–68.4)	2709	81.5 (79.0–83.7)	414	87.3 (80.4–92.0)
Aspirin for primary prevention	70	51.5 (42.8–60.1)	632	38.9 (35.8–42.1)	127	61.9 (53.2–69.8)
RCC CVD risk screening and reduction guidelines	423	57.5 (53.8–61.1)	1958	61.9 (59.4–64.4)	311	70.3 (63.5–76.4)
Overall PPS						
RCC overall guidelines	169	22.5 (19.6–25.7)	3464	45.7 (44.1–47.3)	302	27.6 (23.8–31.7)

Abbreviations: RCC, received care consistent with.

Proportion of individuals who received PPS in GOAL and BRFSS samples

Table 2 shows that the proportion of those with SLE who received recommended PPS varied according to the subtype of services. The lowest rates of individual services were for pneumonia immunization and aspirin, with 49.1% (95% CI 45.1–53.1) and 51.5% (95% CI 42.8–60.1) of eligible SLE patients receiving each of these, respectively. When we analyzed the proportion of SLE patients who received care consistent with guidelines for PPS categories, the highest rates were for cancer screening services (78.0%; 95% CI 74.6–81.1), followed by 57.5% (95% CI 53.8–61.1) receiving recommended services related to CVD, while 40.5% (95% CI 37.0–44.2) reported adequate immunizations. Only 22.5% (95% CI 19.6–25.7) of SLE patients received all the PPS for which they were eligible.

Among residents from the overall community, 73.4% (95% CI 71.8–74.9) received the recommended cancer screening services, followed by CVD-related services in 61.9% (95% CI 59.4–64.4), and immunizations in fewer than 35% (95% CI 32.5–35.9) of eligible individuals. The rate of those who received all recommended PPS was 45.7% (95% CI 44.1–47.3) in the overall community sample. Among BRFSS individuals with a diagnosis of diabetes, 70.3% (95% CI 63.5–76.4) received the recommended CVD preventive services, followed by 66.2% (95% CI 60.5–71.5) of cancer screening and 32.9% (95% CI 28.9–37.2) of immunizations. Within this sample, 27.6% (95% CI 23.8–31.7) of eligible subjects received all recommended PPS.

Receipt of preventive services by GOAL and BRFSS individuals

Table 3 shows the receipt of PPS in the GOAL and BRFSS samples. The denominators in the table represent the number of PPS that GOAL and BRFSS subjects should have received based on each individual's eligibility, by category of PPS. Numerators represent the number of recommended services reported as received by eligible individuals. SLE patients received 53.5% (95% CI 50.8–56.1) of recommended immunizations, and similar or slightly higher percentages were estimated for BRFSS samples. Eighty-three percent (95% CI 80.7–85.2) of recommended cancer screening services was reported as received by SLE patients, compared to less than 80% (95% CI 77.9–79.6) by BRFSS respondents. SLE patients received a relatively lower proportion of recommended services for CVD risk screening/reduction than those from the overall community and the diabetes subsample. When all combined recommended services were assessed, eligible SLE patients received 65.4% (95% CI 63.8–67.1) of overall PPS, in contrast to approximately 67% of subjects from both the overall community and those with diabetes (95% CI 65.9–67.2 and 65.5–68.7, respectively).

Percentage of overall recommended PPS as function of sociodemographics, health status, lifestyle, and health system

Table 4 depicts lower receipt of overall PPS among younger individuals with chronic disease, either SLE or diabetes. The adjusted percentage of overall PPS received by SLE patients was 45.8% (95% CI 39.1–52.5) for those younger than 35 years old and 63.6% (95% CI 54.8–72.4) for those 65 years old or older ($p < 0.0001$). The gap between the youngest and the oldest group was even greater for community subjects with diabetes. Among individuals with diabetes, females received significantly higher proportion of PPS (66.3%; 95% CI 62.7–70.0) than males (54.1%; 95% CI 48.3–59.8). Although non-whites received a lower percentage than

Table 3
Receipt of recommended primary preventive services by SLE (GOAL cohort) and community (BRFSS) samples

	Immunization		Cancer screening		CV risk screening/reduction		Overall PPS	
	n/N	% (95% CI)	n/N	% (95% CI)	n/N	% (95% CI)	n/N	% (95% CI)
GOAL cohort	725/1356	53.5 (50.8–56.1)	885/1067	82.9 (80.7–85.2)	546/872	62.6 (59.4–65.8)	2156/3295	65.4 (63.8–67.1)
BRFSS community	4242/8275	51.3 (50.2–52.3)	7106/9026	78.7 (77.9–79.6)	3293/4705	70.0 (68.7–71.3)	14641/22006	66.5 (65.9–67.2)
BRFSS diabetes	1039/1798	57.8 (55.5–60.1)	704/927	75.9 (73.2–78.7)	527/655	80.5 (77.4–83.5)	2270/3380	67.2 (65.6–68.7)

Abbreviations: n, number of primary preventive services reported as received; N, number of primary preventive services recommended.

Table 4
Multivariate analysis of the effect of socio-demographics, health status and health system factors on the percentage of overall PPS received by GOAL and BFRSS (diabetes) individuals

Characteristic	GOAL cohort		BRFSS diabetes	
	Percent (95% CI)	*p* Value	Percent (95% CI)	*p* Value
Socio-demographics				
Age				
18–34	45.8 (39.1–52.5)	< 0.0001	43.3 (26.5–60.1)	0.0005
35–54	52.2 (46.4–58.0)	< 0.01	45.3 (39.1–51.6)	< 0.0001
55–64	60.1 (53.0–67.3)	0.67	67.6 (61.4–73.7)	0.07
≥65 *(referent)*	63.6 (54.8–72.4)		74.8 (70.2–79.4)	
Sex				
Male	55.8 (47.0–64.5)	0.87	54.1 (48.3–59.8)	0.0007
Female *(referent)*	55.1 (50.4–59.8)		66.3 (62.7–70.0)	
Race				
White	54.6 (47.6–61.6)	0.56	63.7 (59.1–68.3)	0.06
Non-white *(referent)*	56.2 (50.6–61.8)		57.3 (52.5–62.0)	
Federal poverty level				
Below poverty	56.3 (49.8–62.7)	0.50	63.1 (54.9–71.3)	0.47
Above poverty *(referent)*	54.6 (48.6–60.6)		59.7 (56.0–63.3)	
Education				
High school or less	53.5 (47.4–59.7)	0.11	57.3 (51.7–62.9)	0.13
Some college	54.1 (47.6–60.5)	0.14	59.0 (53.2–64.9)	0.30
College or higher *(referent)*	58.7 (51.9–65.5)		63.2 (58.0–68.4)	
Marital status				
Married or cohabitated	54.0 (47.5–60.4)	0.21	60.8 (56.4–65.3)	0.66
All others *(referent)*	56.9 (51.0–62.8)		59.2 (53.9–64.5)	
Health/lifestyle factors				
Health status				
Fair/poor	56.5 (50.5–62.5)	0.33	62.5 (57.3–67.8)	0.28
Ex/VG/good *(referent)*	54.3 (48.1–60.6)		58.8 (54.5–63.1)	
Obesity				
Yes	56.9 (50.5–63.4)	0.15	60.1 (55.7–64.5)	0.97
No *(referent)*	53.9 (48.1–59.7)		60.2 (55.4–65.0)	
Physical activity or exercise*				
Yes	59.3 (53.4–65.2)	0.0003	60.1 (56.1–64.1)	0.95
No *(referent)*	51.5 (45.1–57.9)		60.3 (54.8–65.8)	
Smoking status				
Not current smoking	60.9 (55.4–66.4)	0.0003	62.0 (58.7–65.4)	0.04
Current smoking *(referent)*	49.9 (42.6–57.3)		50.9 (40.9–60.9)	
Health system factors				
Having insurance				
Yes	61.1 (55.4–66.8)	< 0.0001	60.5 (56.8–64.2)	0.57
No *(referent)*	49.7 (42.7–56.7)		57.4 (47.9–67.0)	
Limited access to see a doctor				
Yes	53.8 (47.6–60.1)	0.16	64.7 (55.5–74.0)	0.28
No *(referent)*	57.0 (50.9–63.2)		59.1 (55.5–62.7)	
Rheumatologist involved in MC				
Yes	56.3 (50.7–61.9)	0.53	NA	
No *(referent)*	54.5 (47.5–61.6)			
PCP involved in MC				
Yes	59.0 (53.1–65.0)	0.0023	NA	
No *(referent)*	51.8 (45.3–58.3)			

Multivariable analyses were performed separately for each group. Multivariable results are summarized with adjusted means and 95% confidence intervals. Abbreviations: Ex, excellent; VG, very good; MC, medical care; PCP, primary care physician. *Other than their regular job.

Whites, the difference was not statistically significant. Neither gender nor race impacted the receipt of PPS within the cohort of patients with SLE. Health status, education, and living below the poverty level had no effect on PPS received by SLE or diabetes subjects. Healthy lifestyle factors impacted positively the percentage of PPS received by both SLE patients (physical activity or exercises other than regular job, and current non-smoking) and those with diabetes (non-smoking). SLE patients with health insurance received 61.1% (95% CI 55.4–66.8) of PPS compared to 49.7% (95% CI 42.7–56.7) among uninsured ($p < 0.0001$). In contrast, insurance status did not impact PPS rates among individuals with diabetes. SLE patients who had a primary care physician involved in their care received 59.0% (95% CI 53.1–65.0) of PPS, as compared to only 51.8% (95% CI 45.3–58.3) among those without a primary doctor ($p = 0.0023$). Having a rheumatologist did not modify the overall rate of PPS received by SLE patients.

Discussion

This is the first study to examine the rates of recommended preventive care in an ethnically and economically diverse cohort of patients with SLE. Our findings show that, overall, SLE patients received only 65% of the seven recommended PPS.

When we examined residents drawn from the same community as our SLE patients, a very similar proportion of PPS had been received. These findings indicate that although patients with SLE are at risk of inadequate preventive care, they are not at a disproportionate disadvantage, despite the demographic and health differences between the samples. However, when we analyzed the proportion of individuals who received all the recommended PPS, only 22.5% of SLE patients and 27.6% of those with diabetes were up to date on the combined recommended standards, as compared to 45.7% of people from the same community (Table 2). Our findings are consistent with those from the Community Quality Index Study, which in 2004 assessed the extent to which recommended care was provided to a representative sample of the U.S. adult population for a broad range of conditions in 12 metropolitan areas [2]. Whereas approximately half of a set of 38 recommended indicators of preventive care were delivered to the US adult population across metropolitan areas, medical conditions, and socio-demographic groups; quality of care varied substantially across conditions. Considering that SLE and diabetes are serious chronic diseases associated with high morbidity and mortality, our findings are alarming. It is noteworthy to acknowledge here that the risk for receiving inadequate preventive care in our study could be underestimated because we only tested seven out of 20 preventive recommendations graded as A or B by the USPSTF [22]

Only 53.5% of recommended immunizations were provided to SLE patients, similar to the rates for the general community including individuals with diabetes (Table 3). These findings suggest that factors related to the health system or medical providers, rather than disease-specific factors, might explain the poor quality of immunization care among those at risk. It was estimated that if the Healthy People 2010 goal of 90 percent influenza vaccination coverage were achieved in the U.S., 3750 and 11,840 deaths could be prevented annually among minorities and Caucasians, respectively [26]. In 2008, pneumonia and influenza combined ranked as the nation's eighth leading cause of death [27]. Although no national estimates of mortality attributable to influenza and pneumonia are available for patients with SLE, avoidable hospitalizations for pneumonia occur frequently in people with SLE [28]. When looking at the proportion of SLE patients who received immunizations consistent with guidelines (Table 2), it is striking that only 41% were up to date on both vaccines; while only half received the pneumonia vaccine and less than 60% the influenza vaccine. Yazdany et al. reported that 70% and 80% of SLE patients in California received pneumonia and influenza vaccines, respectively [12]. Higher representation of minority, low income, and uninsured patients might account for the lower rates observed in the GOAL cohort compared to Californian SLE patients.

When we examined the proportion of individuals who received specific categories of preventive care, almost 80% of SLE patients received all recommendations for cancer screening services compared to less than 60% for CVD preventive services and 41% for immunizations. These differences might be related to more effective dissemination and more clear guidelines for cancer surveillance than for CVD and immunization among SLE patients.

It is striking that patients with SLE received only 62.6% of services recommended for monitoring lipids or reducing the risk of primary cardiovascular events, whereas 70% of these services were provided to the overall community and 80% to those with diabetes (Table 3). The risk for CVD in people with diabetes is reported to be increased two- to three-fold in men, and three- to five-fold in women; whereas in women with SLE the risk is between10 and 50 times higher than the general population, with higher relative risk at younger ages [29]. The increased risk of CVD in SLE is not completely explained by traditional risk factors [30] and there is ongoing research to identify disease-specific risk factors, such as inflammation, that may account for the increased risk. Despite the fact that lupus experts have advocated for serial measurement and aggressive management of traditional risk factors [29,31,32], no SLE-specific recommendations to reduce CVD risk have been developed to date. The USPTF encourages aspirin use for primary prevention of CVD in men aged 45–79 years and women aged 55–79 years, when the potential benefit due to a reduction in CVD outweighs the potential harm due to an increase in gastrointestinal hemorrhage [22]. Although these recommendations do not differ for medical conditions known to have increased risk, such as diabetes or SLE, they should be considered as the minimally acceptable standard of care until specific standards are developed for SLE [33].

We did not examine potential predictors of specific subtypes of primary preventive care services (e.g. CVD, infections, or cancers screening) within SLE patients. Data from the LOS study in California indicated that younger age, lower education, and poverty had a significant negative effect on the quality of lipid screening services delivered to patients with SLE [12]. Studies among SLE patients from tertiary centers suggest that deficiencies in preventive care of CVD are more likely to be related to the provider or health system issues than to patient socio-demographic characteristics [13,34]. Thus, it is plausible that patient–provider unawareness of CVD risks, lack of nationally endorsed guidelines specific to SLE, ineffective coordination between specialists and primary care providers, and barriers to health care access might play significant roles in the gaps of primary preventive care in SLE [11–13,34]. We contrasted patient, provider, and health system features in SLE and diabetes subjects to gain insights on causes that might differ between these two chronic conditions. The major factor that impacted the quality of the overall preventive services assessed in our study was age, for both SLE and diabetes groups (Table 4). In SLE, patients younger than 35 years only received 46% of recommended services, while those aged 65 years or older received 64%. The gap among those with diabetes was even greater. These findings are consistent with previous studies that showed higher rates of primary care services among older patients with diabetes and SLE [11,35]. Longstanding U.S. health system policies that do not fully cover preventive care, or only allow for provider reimbursement once the disease is well established, may explain lower rates among younger individuals across different chronic conditions. Whether new policies being implemented through the Affordable Care Act will lead to contribute to higher rates of preventive services remains to be seen [36]. We found gender gaps in the overall quality of preventive services among patients with diabetes, but not in those with SLE. However, we must consider that the lack of similar findings for SLE might be associated with the small number of males in the GOAL cohort.

Having medical insurance increased the quality of overall services received by SLE patients from 49.7% among uninsured to 61.1% among those with insurance, after adjusting for other factors. Another element of the health system that showed a positive effect on preventive services received by SLE patients was participation of a primary care physician in the medical care. Our data are consistent with previous findings from the LOS cohort [11,12]. These results suggest that potential disparities in SLE outcomes could be partially explained by system factors that preclude appropriate prevention among vulnerable groups and those who do not have access to primary care.

Finally, healthier lifestyle behaviors (being non-smoker and practicing physical activity or exercises other than regular job) were associated with higher rates of preventive services among SLE patients. Whether SLE patients who have healthier lifestyle behaviors actively seek for preventive care, or better quality of preventive care might encourage individuals to adopt healthier lifestyle behaviors, cannot be elucidated with our cross-sectional design. Nevertheless, these findings suggest that there is room to engage lupus patients in health education and awareness programs that seek to improve health behaviors while expanding on the positive impact of primary prevention on their overall care. The fact that a substantial proportion of this cohort smoke, which is known to be a risk factor for poor SLE outcomes and CVD, is notable; as is the prevalence of obesity. Addressing these risk factors should be a high priority population-health goal in SLE.

Our study has several limitations. First, receipt of primary preventive services was estimated based on patient self-reported data and not on medical record review. Although this method has been used across several chronic conditions, it has been associated with over-reporting of clinical services [37–39]. Second, due to the socio-demographic differences between the SLE and BRFSS samples, the estimates of PPS are comparable under the assumption that these are benchmarks of representative individuals drawn from the same community. Although participants of the GOAL Cohort were not randomly sampled from the base population as was the BRFSS sample, over 70% of GOAL participants were drawn from the Georgia Lupus Registry (GLR), a population-based registry of lupus patients established in two of the most populous counties targeted by the GOAL Cohort. The other participants are consenting patients from collaborating community-based rheumatology practices, a private university health care system and the major safety-net provider for low income and uninsured patients of Atlanta and around the state. Participants of the GOAL Cohort and the population-based GLR had similar socio-demographic characteristics (data not shown). Therefore, GOAL participants appear to be representative of the SLE population in metropolitan Atlanta.

Another limitation of our study is that given the potential demographic differences between SLE patients from Atlanta and those from other geographic areas, absolute risks from this research cannot be generalized to the whole US population. As discussed earlier, however, data from the LOS study in California, which is a predominantly white middle-class cohort, also revealed significant gaps (although of different magnitude) in recommended CVD prevention, vaccinations, and cancers screening [12]. Moreover, studies from university settings in Boston and Baltimore described deficiencies in the quality of primary care services provided to SLE patients [13,34]. Thus, prior findings along with our own suggest that factors directly related to the health care system might account for major gaps in preventive care among SLE patients, with socio-demographic characteristics being a contributing factor.

Conclusion

Our findings show that the overall receipt of primary preventive services among a predominantly Black cohort of SLE patients in the Southeast is suboptimal, with only 65% of the selected PPS reported as received. These estimates were similar to those found among residents from the same community, including individuals with another chronic disease, diabetes. When specific preventive services were examined, ample opportunity for improvement became evident. Despite the fact that infections and cardiovascular disease are among the leading causes of death in SLE, the proportion of lupus patients that received recommended immunizations and CVD risk screening and prevention were strikingly low, ranging from 40% to 54%, respectively. Our findings suggest a need to increase providers' awareness of SLE risks and applicability of current recommendations, along with coordination between specialists and primary care providers. At the same time, access to care is hampered by the large number of uninsured SLE patients. Hence, our study underscores the need to set an agenda for improving preventive care that moves beyond patient-specific factors to address health care delivery and financing policies with a focus on overcoming barriers that prevent SLE patients from receiving appropriate preventive care.

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Appendix

Definitions of recommended primary preventive services

Table 1A on the next page shows the guidelines applied to GOAL and BRFSS subjects for each of the seven services assessed in our study, as well as the number of eligible individuals on each sample. References of recommendations are noted at the foot of the table. Because some immunization and cancer screening recommendations varied by year, we used the most recent guidelines in place when surveys were implemented.

(1) For *influenza immunizations* we used the CDC guidelines as follows: In 2010, the CDC expanded its recommendations of the influenza seasonal vaccine for 2010–11 to include all adult individuals. Therefore, we applied these recommendations to GOAL participants who in 2011–12 were surveyed about receiving the vaccine in the previous year. Because BRFSS participants examined on this study were interviewed about receiving the influenza vaccine for the years 2004–2009, we applied the CDC recommendations implemented by 2010, which targeted healthy individuals aged >50, or those >18 with chronic conditions (diabetes, asthma, or CVD).

(2) For *pneumonia immunization* we examined GOAL participants on immunosuppressive drugs, or those aged >65, or those >18 and <65 with other chronic conditions (alcoholism, cancer, diabetes, COPD, asthma, CVD, and smoking), based on the 2010 CDC recommendations. For BRFSS samples, based on the CDC recommendations implemented before 2010, we examined pneumonia immunization among individuals aged >65 without chronic conditions, or those >18 and <65 with chronic conditions (alcoholism, cancer, diabetes, and CVD) who had ever received the vaccine.

(3) For *cancer screening*, when guidelines varied by year and across different expert organizations (e.g. breast cancer screening), we used the most recent update of the USPSTF recommendations available by 2011 among GOAL participants and for BRFSS samples, we used the most recent guidelines in place when surveys were administered: (i) For *cervix cancer screening* we examined all women age 18–65 who received a PAP smear in the past 2 years and had no history of hysterectomy; (ii) For *breast cancer screening* we examined all women from the GOAL cohort age 51–76 who received a mammography within the past 2 years, based on the USPSTF 2009 guidelines. Whereas within the BRFSS samples, women 40 or older who received a mammography within the past 2 years were eligible, based on the USPSTF 2002 recommendations. (iii) For *colon cancer*, we examined

all individuals age >50 who ever received a colonoscopy within GOAL and BRFSS samples.

(4) For *cholesterol monitoring* among participants of BRFSS samples, we examined the 2008 USPSTF recommendations, which are the first USPSTF guidelines that explicitly advice for cholesterol monitoring based on age, gender, and presence of specific traditional risk factors. We examined whether cholesterol was ever checked among males aged >35 or individuals who self-reported tobacco use, hypertension, obesity (BMI $\geq$ 30), diabetes or coronary heart disease. Among those who self-reported diabetes or coronary heart disease, we determined the percentage of individuals who had their cholesterol checked within the past year. For GOAL participants we examined cholesterol monitoring in the past year for all SLE patients, based on the recommendations of European League Against Rheumatism (EULAR) and the quality indicators for SLE by Yazdany et al.

(5) For *aspirin for primary prevention of cardiovascular disease* among both, BRFSS and GOAL samples, we examined men aged 45–79 and females aged 55–79 who were on aspirin after excluding those subjects who self-reported a medical history of coronary heart disease or stroke. Although SLE patients are at higher risk for cardiovascular disease than the general population, no formal recommendations on the use of aspirin for SLE have been released by the time the GOAL cohort was surveyed.

See Table A1.

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Table A1

Primary preventive services (PPS): recommendations, intervals and eligible individuals in the GOAL cohort and BRFSS samples

PPS		BRFSS	
	GOAL cohort (N = 751)	Overall community (N = 9040)	Diabetes (N = 938)
Immunizations			
1. Influenza vaccine, in the past year[a]	751 (100)	5568 (61.6)	938 (100)
2. Pneumonia vaccine, ever ($\geq$65 or immunosuppressed, or chronic conditions)[b]	616 (82.0)	3061 (33.9)	938 (100)
Cancer screening			
3. Cervical cancer screening, within 2 years (women18–65 with uterus)[c]	516 (68.8)	3797 (42.0)	227 (24.2)
4. Mammogram, within 2 years (women)[d]	269 (35.8)	4364 (48.3)	518 (55.2)
5. Colonoscopy, ever ($\geq$50)[e]	299 (39.8)	4873 (53.9)	771 (82.2)
CVD risk screening and primary prevention			
6. Cholesterol monitoring[f]	751 (100)	6057 (67.0)	938 (100)
7. Taking aspirin[g]	146 (19.4)	3631 (40.2)	508 (54.2)

Values represent n (%) of eligible individuals.

Abbreviations: CVD, cardiovascular disease.

[a] GOAL:$\geq$ 18 based on the recommendations of the Advisory Committee on Immunization Practices (ACIP) 2010 (http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5908a1.htm?s_cid=rr5908a1_e); BRFSS samples: $\geq$50, or $\geq$18 if diabetes, CVD or asthma, based on the Centers for Disease Control and Prevention throughout 2009 (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5753a6.htm?s_cid=mm5753a6_e).

[b] GOAL: aged $\geq$65, or those $\geq$18 and <65 on immunosuppressive drugs or with other chronic conditions assessed on the GOAL survey (alcoholism, cancer, diabetes, COPD, asthma, CVD, and smoking), based on the 2010–11 CDC recommendations (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5934a3.htm). BRFSS samples: aged$\geq$65, or those >18 and <65 on immunosuppressive drugs or with other chronic conditions assessed on the BRFSS survey (Diabetes, CVD, Cancer, and Alcoholism), based on The Centers for Disease Control and Prevention guidelines throughout 2009 (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5753a6.htm?s_cid=mm5753a6_e).

[c] USPSTF recommendation published by Agency for Healthcare Research and Quality, Rockviller, MD, Jan 2003 (http://www.ahrq.gov/clinic/pocketgd1011/gcp10s2.htm#Cervical).

[d] GOAL: aged 50–75, based on USPSTF 2009 guidelines (http://www.uspreventiveservicestaskforce.org/uspstf/uspsbrca.htm); BRFSS samples: aged $\geq$ 40, based on USPSTF 2002 guidelines (http://www.uspreventiveservicestaskforce.org/uspstf/uspsbrca2002.htm).

[e] USPSTF 2008 guidelines (http://www.uspreventiveservicestaskforce.org/uspstf/uspscolo.htm).

[f] GOAL: $\geq$18 and received in the past year, based on Yazdany et al. [23], and EULAR recommendations (Mosca, M., et al. [24]); BRFSS community: ever received if male $\geq$35, or $\geq$18 and smoking, or obesity, or hypertension, or diabetes, or CVD; BRFSS diabetes: $\geq$18 and received in the past year, based on USPSTF 2008 (http://www.uspreventiveservicestaskforce.org/uspstf/uspschol.htm).

[g] Men 45–79 without a history of coronary heart disease or stroke; women 55–79 without history of coronary heart disease or stroke, based on the USPSTF guidelines 2009 (http://www.uspreventiveservicestaskforce.org/uspstf/uspsasmi.htm).

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