HHS Public Access

Author manuscript

Rheum Dis Clin North Am. Author manuscript; available in PMC 2022 February 01.

Published in final edited form as:

Rheum Dis Clin North Am. 2021 February ; 47(1): 41–53. doi:10.1016/j.rdc.2020.09.004.

Disparities in Lupus and Lupus Nephritis Care and Outcomes among U.S. Medicaid Beneficiaries

Katherine Pryor, MD, MS,
Brigham and Women's Hospital, Department of Medicine, 75 Francis Street, Boston, MA 02115

Medha Barbhaiya, MD, MPH,
Hospital for Special Surgery, Division of Rheumatology, 535 E. 70th Street, New York, NY 10021

Karen Costenbader, MD, MPH*,
Brigham and Women's Hospital, Division of Rheumatology, Inflammation and Immunity, 60 Fenwood Road, Office 6016X, Boston, MA 02115, 617-732-6088

Candace Feldman, MD, MPH, ScD*
Brigham and Women's Hospital, Harvard Medical School, 60 Fenwood Road, Office 6016P, Boston, MA 02115, 617-525-1035

Keywords

SLE; LN; Medicaid; disparities

I. Introduction

Systemic lupus erythematosus (SLE) is a heterogeneous chronic systemic autoimmune disease affecting patients of different ages, ethnicities and racial backgrounds worldwide. SLE is associated with substantial morbidity and mortality. SLE Patients have a 3-fold increased risk of death, particularly from renal and cardiovascular disease and infections.[1,2] Up to 40% of SLE patients develop lupus nephritis (LN), a severe disease manifestation that disproportionately affects children and adults living in poorer geographic areas despite adjustment for age, gender, and race/ethnicity.[3] LN is a risk factor for progression to end stage renal disease (ESRD). A large meta-analysis demonstrated that renal involvement is associated with the highest mortality rates (standardized mortality ratio 7.9, CI 5.5-11.0)[1] and increased risk of all-cause mortality. Although improved diagnostics and therapeutics have contributed to declining mortality rates, important disparities exist in SLE survival rates by race, ethnicity, gender, age, country, and social disadvantage.[4]

Corresponding Author: kpryor@bwh.harvard.edu, 617-525-1035.
*contributed equally

Disclosure statement:
The authors do not have any commercial or financial conflicts of interest.

In the United States (U.S.), a large proportion of SLE patients receive their health insurance coverage through Medicaid, the largest public health insurance program in the country. Medicaid is operated as a federal-state partnership and provides coverage to 65.3 million qualifying beneficiaries (roughly 1 in 5 Americans), including low-income adults, children, and people with disabilities.[5] Medicaid provides health care to some of the most vulnerable populations in the U.S. and is an important safety net ensuring critical access to health care for high risk individuals. However, despite efforts to improve quality of care, studies continue to show that across a large range of diseases and procedures, Medicaid patients have worse outcomes compared to privately insured patients across a spectrum of medical and surgical diseases.[6–9]

The purpose of this review is to highlight the burden of SLE and LN in the U.S. Medicaid population, discuss sociodemographic disparities in access to care, medication adherence and adverse outcomes, and to identify opportunities for improvement.

II. Burden of SLE and LN among Medicaid Beneficiaries

Within the adult Medicaid population between 2002-2004, Feldman et al. reported an overall SLE prevalence of 143.7 per 100,000 individuals, and an annual incidence rate of 23.17 per 100,000 person-years.[10] 38.5% of affected individuals were African American or Black (referred to as Black hereafter), 36.2% white, 13.9% Hispanic, 4.2% Asian, and 1.5% American Indian/Alaska Native. SLE was defined as having ≥3 ICD-9 codes for SLE (710.0) at least 30 days apart from either hospital discharge paperwork or physician office visit claims. At least 3 codes were required to eliminate “rule-out” SLE cases. SLE prevalence was 6 times higher in women than in men; among women, the prevalence was nearly double in Blacks at 286.4 per 100,000, and incidence was also highest (38.62 per 100,000 person-years) compared to white women.[10]

Geographically by US region, SLE prevalence was highest in the South (163.5 per 100,000) and lowest in the Northeast (125.2 per 100,000). Incidence rates were also highest in the South. Incidence of SLE was also highest among the two older age strata (together encompassing ages 30-64 years) when compared to the youngest adults (ages 18-29 years). The lowest quartile of socioeconomic status (SES) zip codes, as defined by a composite index, had the highest prevalence of SLE and the two highest SES quartiles had the lowest prevalence.[10]

The overall prevalence of LN was 30.9 per 100,000. LN was identified in SLE patients who had ≥ 2 additional ICD-9 codes from hospital discharges or physician claims for nephritis, proteinuria, and/or renal failure (on or after the SLE diagnosis) at least 30 days apart. The prevalence of LN mirrored that of SLE, with higher rates seen in the South and in older individuals, and a prevalence rate four times higher among females compared to males and among Blacks compared to whites. The average number of ACR member rheumatologists per state was inversely associated with the prevalence of both SLE and LN, suggesting underdiagnosis and likely undertreatment of both conditions in these states.[10] The prevalence of LN was lower than anticipated in this vulnerable population and may have been due to the use of a validated algorithm to identify cases,[11] which requires the

accumulation of a number of codes, and thus a number of health care encounters and continuous enrollment in Medicaid, in order to meet criteria. As such, the most vulnerable patients who may also be at higher risk of this complication, may not be fully represented in these estimates.

While challenging to compare across studies due to differences in case definitions and methods, the incidence and prevalence of SLE appear to be higher in the Medicaid population than by most other national estimates.[12–14] To help delineate the burden of SLE in the U.S. the Centers for Disease Control and Prevention (CDC)-funded population registries between 2002-2004 and 2007-2009 across the country, including Manhattan, San Francisco, Georgia, Michigan, and a registry of three Indian Health Services (IHS) sites in Alaska, Phoenix, and Oklahoma. National estimates mirror trends seen in the Medicaid population, including greater prevalence in the South, in women, and particularly in Black women relative to white women with greater burden of ESRD among minority populations. They also highlight burden of disease among other minority groups, including American Indian and Alaska Native populations whose disease prevalence and severity may be similar to Black women, a demographic more likely to be recognized as a high-risk group.[15–19]

III. Access to High Quality SLE Care and Medication Adherence in the Medicaid SLE Population.

The foundation of SLE management includes appropriate and timely access to high quality care and to subspecialty care when indicated. Within a national Medicaid population (two-thirds residing in California), Gillis et al. observed that while patients with Medicaid insurance were just as likely to have seen a rheumatologist in the past year as patients with other forms of insurance, they traveled farther distances to get care.[20] Medicaid beneficiaries traveled 11.5 more miles than those with other insurance (either dual coverage with Medicare/Medicaid or other forms of insurance), and 19.8 more miles to see a rheumatologist. Although patients enrolled in Medicaid were more likely to live in a nonurban locale, travel differences persisted even when controlling for urban vs nonurban locale. Since the Medicaid and dual coverage groups were demographically similar, increased distance for either primary or sub-specialty care suggest insurance coverage may be a predictor of access to care.[20] In an ecological study using “ambulatory care-sensitive conditions” as a surrogate for access to care, Ward noted higher rates of ESRD and of ambulatory care-sensitive conditions among patients living in ZIP codes with higher rates of Medicaid coverage.[21]

Challenges relating to access to care and other treatment barriers partially explain higher rates of acute care use (emergency department (ED) visits and hospitalizations) among Medicaid patients with SLE. This was studied in the University of California San Francisco (UCSF) Lupus Outcomes Study cohort, a national cohort of 957 participants meeting full ACR criteria for SLE. Participants in this cohort were required from clinics, community sources, conferences, and newsletters and live in 41 states. The majority (75%) resided in California. Sub-analysis of this cohort demonstrated that frequent ED users, defined as 3 or

more visits in the past year, were more likely to have Medicaid insurance, have had a recent SLE flare and increased disease activity and live below the poverty level.[22]

In a separate study of patients with incident LN within a U.S. Medicaid population, quality was assessed by performance on three measures: receipt of an immunosuppressive, an anti-malarial medication, and a renal-protective anti-hypertensive agent.[23] More than 1 in 8 patients in this study used the ED as their primary source of care (with no difference by geographic region), and quality of care as assessed by the above metrics was lower in those receiving their care in the ED.[23]

Finally, in a study of the Nationwide Inpatient Sample (NIS) between 1998-2002, all hospitalizations for adults with SLE (primary or secondary diagnosis) were analyzed.[24] Patients with private insurance were less likely to die (OR 0.85) compared to patients with public insurance (Medicare and Medicaid).[24]

Medication Adherence

Ongoing improvements in medications available to treat SLE have improved survival rates in SLE, reduced treatment toxicity, frequency and severity of flares, and decreased the development and progression of renal disease. However, medication nonadherence, the failure to take medications as prescribed, is a serious challenge in all SLE populations and adherence is estimated between 30-60% for prescribed therapies.[25–27] Nonadherence has been seen more often in people of non-white race/ethnicity and individuals of lower SES, and high rates of nonadherence have been documented using pharmacy dispensing data among Medicaid beneficiaries.

Hydroxychloroquine (HCQ), the backbone of SLE management, was associated with very low rates of adherence within the Medicaid population. In a study of 10,268 patients between 2000-2010 who newly initiated hydroxychloroquine (HCQ), fewer than 20% of patients adhered to their HCQ (adherence was defined as ≥ 80% proportion of days covered by medication refills and drug dispensings). Notably, lower odds of adherence were associated with younger age, Black race and Hispanic ethnicity, higher acute care use (ED visits and hospitalizations), diabetes mellitus, and antidepressant medication use. Lower odds of adherence were also observed in zip codes with higher percentages of Black residents, even when controlling for individual race and zip code-level income and education. HCQ adherence was also noted to decline over the first year of use for most patients regardless of initial adherence, with dynamic patterns observed.[28–31]

Within the Medicaid population, adherence to azathioprine and mycophenolate mofetil (MMF), two of the most commonly used immunosuppressive agents for SLE, was also poor.[32] Of 2,309 azathioprine initiators and 2,070 MMF initiators, only 17% of azathioprine and 21% of MMF initiators were adherent. Several demographic factors were associated with azathioprine non-adherence including Black race (OR 1.67), Hispanic ethnicity (OR 1.58), and younger age (OR 1.6 for ages 18-35 years compared to ages 51-65 years). No association with race or ethnicity was seen for MMF. The MMF had more severe disease at baseline, and lupus nephritis was associated with lower odds of nonadherence (OR 0.74). Female sex was associated with lower odds of adherence to both medications with a clearer

pattern seen among azathioprine initiators.[32] This study illustrated that predictors of adherence may differ depending on the medication prescribed.

Nonadherence in the Medicaid population was also associated with acute care utilization.[33] In a study of new initiators of hydroxychloroquine (HCQ) or immunosuppressive medications, Feldman *et al.* demonstrated that SLE patients nonadherent to HCQ had 1.55 times higher rates of ED visits and 1.37 times higher rates of hospitalizations. Adherence was equally as poor among immunosuppressive medication initiators and similar rates of acute care utilization were seen comparing nonadherers to adherers.[33]

Retinal Examinations among Hydroxychloroquine Users

Baseline retinal examinations within the first year of HCQ use are considered standard of care for all SLE patients.[23] However, a study by Lin *et al.* demonstrated that only 32.5% of patients with SLE enrolled in Medicaid received baseline dilated eye examinations, with no improvement in frequency seen between 2000-2010. Screening rates were lower in Black and American Indian/Alaska Native patients.[34]

Quality of Care for Renal Disease Associated with SLE

Medicaid beneficiaries are also less likely to receive adequate care for LN and ESRD, including access to pre-ESRD nephrology care, access to transplant, and placement of permanent vascular access.

Yazdany et al. found low performance on three measures of health care quality (receipt of immunosuppressive, renal-protective anti-hypertensive, and anti-malarial medications).[23] In their study of 1711 Medicaid enrollees with incident LN, the authors noted low performance at 90 days for these three measures (21.9%, 44.0%, and 36.4%, respectively). However, these did increase by one year (to 33.7%, 56.4%, and 45.8%), highlighting both low quality of care and delays in accessing appropriate care. Both younger patients, as well as Black and Hispanic patients, were more likely to receive immunosuppressives and HCQ. Younger patients were less likely to receive renal-protective anti-hypertensive medications, possibly due to the teratogenic nature of ACE-inhibitors. A higher quality of care was observed in the Northeast compared to other regions.[23]

In a study by Plantinga et al. Black and Hispanic patients were 27% less likely to receive pre-ESRD nephrology care.[35] Compared to patients with private insurance, those with either Medicaid or no insurance were 36% and 74% less likely to receive pre-ESRD care. Having Medicaid, Medicare, or being uninsured was associated with a 32-39% decreased likelihood of transplant education, as well as a 30-51% decreased likelihood of being listed for kidney transplant during all years of follow-up. Although race and ethnicity were not associated with likelihood of receiving transplant information, Blacks and Hispanics were 22% and 18% less likely to be on the kidney transplant waitlist, though this was true only in the first year of an ESRD diagnosis.[36] Fewer than one quarter of SLE patients with ESRD had permanent vascular access in place at the start of HD relative to patients with all-cause ESRD (35-36%).[36,37]

Few patients undergo short-interval kidney transplant following progression to ESRD.[38] Blacks (OR 0.14) and Asians (OR 0.57) were less likely to receive a pre-emptive kidney transplant than whites (reference OR 1.0), as were those with Medicaid (OR 0.16) and Medicare (OR 0.42) relative to private insurance (reference OR 1.0). Patients living in the South were least likely to receive a kidney transplant (OR 0.44) compared to the Northeast (reference OR 1.0).[38] Most patients with progression to ESRD initiate dialysis through hemodialysis (HD) or peritoneal dialysis (PD). Although efficacy and safety studies comparing HD and PD are ongoing, it appears that pre-transplant PD improves allograft survival compared to HD.[39]

Significant disparities have also been found in the types of initial renal replacement therapy. Blacks had 37% lower odds of initiating PD rather than HD. Medicaid, Medicare, uninsured and unemployed patients were all less likely to receive initial PD.[40] The demographics of individuals less likely to receive initial PD mirror those who are less likely to receive a pre-emptive kidney transplant.[38]

Lipid Screening among Patients with SLE

Premature cardiovascular disease (CVD) is highly prevalent among patients with SLE, patients and may occur at even higher frequency than in patients with diabetes mellitus, a disease population well-recognized to be at high risk for CVD morbidity and mortality.[41] Despite this risk, patients with SLE enrolled in Medicaid are 66% less likely to undergo lipid screening and 82% less likely to fill a prescription for a statin compared to patients with diabetes enrolled in Medicaid.[42] Patients were more likely to undergo lipid testing if they were Asian (OR 1.86), Hispanic (OR 1.37) or Black (OR 1.09) than if they were white. Older age, Asian race, presence of Lupus nephritis, glucocorticoid use, and baseline CVD were associated with increased odds of statin prescription.[42]

IV. Disparities in Adverse Outcomes among SLE Patients Enrolled in Medicaid

Renal Disease

Renal disease, including both LN and ESRD, is a serious complication of SLE and is present in a substantial proportion children and adults upon SLE diagnosis. Renal disease is also the most important predictor of mortality in SLE. Up to 80% of children and 60% of adults will be affected by LN, and even with aggressive immunosuppressive therapy, 10-30% of patients will progress to ESRD within 15 years of onset.[43,44] As discussed, prevalence and incidence rates parallel many of the demographic trends of SLE, disproportionately affecting females, those of non-white race/ethnicity, and high-risk regions of the country including the South. Poverty, Black race, and Hispanic ethnicity are all associated with progression of lupus nephritis.[45]

Despite its tremendous clinical significance, there are substantial disparities in diagnosis, treatment and outcomes. Between 1995-2006, Costenbader *et al.* observed several important trends.[46] The standardized incidence rate (SIR) for younger patients (ages 5-19 and 20-39 years), patients living in the South, as well as Blacks and Native Americans increased over

this time period. Additionally, mortality rates did not change potentially reflecting barriers to adequate care in these vulnerable demographics.[46] Although LN disproportionately affects females, and despite differences in care utilization, Feldman *et al.* did not observe sex-specific differences in ESRD among Medicaid beneficiaries between 2000-2010.[47]

Ward demonstrated that uninsured patients and Medicaid beneficiaries were more likely to be diagnosed at a younger age than those with private insurance, and age of diagnosis is similar between Medicaid beneficiaries and uninsured patients.[48] White patients with no medical insurance or Medicaid are diagnosed on average at ages 42.4 and 41.7, compared to with private insurance, who are diagnosed on average at age 52.9. Black and Hispanic patients with all forms of insurance are diagnosed at younger ages than their white counterparts. Black patients on Medicaid are diagnosed at an average age of 37.4 compared to those with private insurance who were diagnosed at age 41.5. Hispanic patients on Medicaid are 35.2 years-old on average at diagnosis, while those on private insurance are on average 38.2 years old. No association was seen for Asian race.[48]

Cardiovascular Disease

Racial/ethnic disparities in both CVD diagnosis, event rates/risks, and mortality are well described in the general population. Blacks have the highest rate of CVD; additionally, mortality rates are declining more slowly in Blacks than in whites, in the U.S. South, and in younger women (age < 55 years) in recent decades.[49,50] Lower SES and educational attainment are also associated with increased mortality.[49] CVD in the SLE population is accelerated and premature, as well as associated with alarming sociodemographic disparities.[51–53]

Scalzi *et al.* observed that Black females with SLE were hospitalized on average 9.6 years earlier than white females for SLE associated CVD, and Hispanic females on average 6 years earlier. Of all women with SLE who died during a CVD-related hospitalization, Black women died on average 14.3 years younger than white women and were the youngest to die a CVD-associated death with more than half younger than age 55 years.[54]

Barbhaiya *et al.* noted important racial and ethnic disparities in CVD event risks in SLE patients enrolled in Medicaid from 2000-2010. Blacks had a 14% increased overall CVD risk (including MI and/or strokes). Both Blacks and Hispanics had increased risk of stroke (HR 1.48 and 1.25, respectively) compared to whites;[55] however, Blacks had increased risk for both hemorrhagic and ischemic strokes relative to whites, whereas Hispanics had increased risk only for hemorrhagic stroke relative to whites.[56] Although MI risk was similar in Blacks compared to whites, Hispanics and Asians had reduced MI risk relative to whites (HR 0.65 and 0.57), respectively). Controlling for age, sex and region somewhat attenuated overall CVD risk and stroke risk among Blacks, but these still remained elevated.[55]

These findings suggest the importance of early recognition and screening of cardiovascular and stroke risk factors among Black and Hispanic SLE patients. Additionally, the observed racial disparities warrant further investigation into the role of genetics, biomarkers, lifestyle factors, medications, and other cardiovascular risk factors in SLE patients.

Serious Infections

Infections, particularly bacterial, are a leading cause of hospitalizations and mortality in patients with SLE. Infections affect up to 50% of SLE patients on immunosuppressive medications, with higher rates seen in those with concomitant LN. 20-30% of patients with SLE will die of a serious infection.[2,57,58] Similar to other serious complications of SLE, infections occur more frequently in vulnerable populations.

In an adult Medicaid population with SLE, Feldman et al. observed an incidence rate of infections of 10.8 per 100 person-years, reflecting bacterial infections in particular.[59] Those on immunosuppressive medications were more likely to develop infections (HR 1.11). HCQ reduced the risk of infection (HR 0.73). Those with infections were more likely to be in the oldest cohort (ages 51-64) than the youngest, to be Black (IRR 1.23) or Native American (IRR 1.40) compared to white, to come from lower socioeconomic status neighborhoods (IRR 1.14) and to have higher risk SLE (IRR 2.68). Men were also more likely to develop a first infection than women.[59] Although immunosuppressive medications increase the risk of infections for patients with SLE, there does not appear to be a higher risk associated with specific medications. In a study of new initiators of azathioprine, MMF, or cyclophosphamide, Feldman et al. found similar rates of infection and mortality over the first 6-10 months between MMF and azathioprine initiators compared to MMF and cyclophosphamide initiators.[60] Infection rates are also higher in those with LN, where Feldman et al. noted an IR of 23.9 per 100 person-years. While the risk of infection was again higher in older patients, in Blacks compared to whites, and in patients with higher disease scores, no difference was seen by SES. Interestingly, while steroids also increased risk of infection and HCQ decreased the risk of infection, as in patients with SLE without LN, immunosuppressive medications did not affect the likelihood of developing an infection in this cohort. Mortality rates were very high in both cohorts, where more than 45% of patients with serious infections died during their hospitalization or within 30 days of discharge. Patients with LN were 1.5 times more likely to die than patients with SLE.[59]

Infection rates in children with SLE and LN mirror those of adults. In a Medicaid cohort, the incidence of serious infections among children with SLE and lupus nephritis were 10.42 and 17.65 per 100 person-years, respectively. As in adults, Blacks and Native Americans had higher rates of infections. Interestingly, boys had a reduced risk of infection relative to girls.

Preventive care trends were more readily available in the pediatric population. Hiraki et al noted that only 14% of children with SLE and 20% of children with LN were receiving preventive care. Only 3% received influenza vaccines, and only 11-17% received pneumocystis jirovecii pneumonia prophylaxis despite the high use of steroids in this cohort (67% of children with SLE and 80% of children with lupus nephritis).[61]

Additionally, past studies have shown that up to 40% of patients had not received vaccinations despite broad recognition of the high rates of infection.[62] Patients were more likely to receive influenza vaccinations if they saw a rheumatologist (suggesting access to sub-specialty care is an important factor). As previously described, lower educational attainment, and living below the poverty line also reduced vital preventive services.[62] Recognizing that vulnerable populations are less likely to receive appropriate preventive

care, and that their rates of bad outcomes are substantially higher is critical in understanding and alleviating the tremendous disparities in care in patients with SLE, particularly those enrolled in Medicaid.

Psychiatric Disease

SLE is a lifelong chronic disease associated not only with physical but also psychiatric comorbidities. Psychiatric disease is underrecognized and undertreated in patients with SLE, particularly in minority groups. In a study of children with SLE on Medicaid, Knight et al. noted that despite high rates of psychiatric disease among children with SLE that Blacks were less likely to be diagnosed with depression (OR 0.56), anxiety (OR 0.49) or be prescribed anxiolytics (OR 0.23) compared to whites.[63]

Mortality

Given tremendous disparities in access to high quality care and adverse outcomes, it is unfortunately not unexpected that there are racial and ethnic disparities in mortality rates. In a Medicaid population, Gomez-Puerta et al. noted higher mortality rates among age and sex-adjusted hazard ratios (HRs) for death among Blacks (1.36) and Native Americans (1.43) with SLE relative to whites, and reduced HRs in Hispanics (0.41) and Asians (0.30). Among those with lupus nephritis, hazard ratios remained significantly higher in Blacks (1.18) and lower in Hispanics (0.39) and Asians (0.31).[64]

IV. Conclusions

This review of the published literature describing patients with SLE enrolled in Medicaid, one of the most vulnerable populations in the U.S., demonstrates that these patients experience a disproportionate burden of SLE and of adverse outcomes, which may be tied to poor access and lower quality of care. Within this population, racial/ethnic minorities, individuals living below the poverty line, and individuals living in certain U.S. regions experience even poorer outcomes.

Data from the Systemic Lupus International Collaborating Clinics (SLICC) cohort, comprised of patients from 32 academic medical centers worldwide between 1999 and 2011, provide a stark comparison to our findings in the Medicaid population. Of the 38.3% of patients enrolled in SLICC who developed lupus nephritis (similar to rates in the U.S. Medicaid cohort), during a mean follow-up of 5.2 years, there was a greater likelihood in improvement in renal function, rather than deterioration.[64] In the SLICC cohort, patients with LN had a 10.1% 10-year incidence of ESRD, whereas in the Medicaid population, the 5-year incidence of ESRD among males was 22.3% and among females, 21.1%. In the SLICC cohort, the 10-year cumulative incidence of death in patients with LN was 5.9%. In the Medicaid cohort, the 5-year incidence of death was 9.4% (males) and 9.8% (females).[47,65]

Limitations exist in the literature reviewed. Since analyses were conducted on available claims data using ICD-9 codes, patients may be misclassified. In addition, patients had to be enrolled in Medicaid for a period of time to accumulate the codes to meet the classification algorithms. It is possible that patients with the poorest access to care were missed. Medicaid

data do not include laboratory values or clinical notes and therefore the authors were unable to assess fluctuations in disease activity, or whether certain medications were not prescribed or were discontinued due to an adverse effect or contraindication. Additionally, eligibility for Medicaid, as well as reporting to the Medicaid Analytic eXtract varies by state. There is significant turnover in the Medicaid population, though this is more likely pronounced among those who are less sick and do not get hospitalized. Policies regarding ease of Medicaid renewal vary by state as well, which may influence who is continually enrolled. Finally, the literature reviewed includes only the Medicaid population prior to the Affordable Care Act, which influenced enrollment criteria and coverage for certain states. Further studies are needed to determine how these policy changes influence care and outcomes among Medicaid beneficiaries.

Disparities in outcomes observed among Medicaid SLE patients are likely multifactorial, based on biology, sociodemographics, and access to care. Given the complex social challenges facing many Medicaid SLE patients, this population needs more support, funding, and improved allocation of resources. Earlier and improved access to physicians, including sub-specialists, and higher quality of care at all stages of the disease are warranted and would hopefully improve outcomes. A recent study of the effects of the expansion of Medicaid on hospitalizations for the SLE population, however, showed increased odds of preventable lupus hospitalizations.[66] Given the complex social challenges facing many Medicaid patients, adequate SLE care in this population will mean going beyond the care itself to address these social determinants of health.

References

1. Yurkovich M, Vostretsova K, Chen W, Avina-Zubieta JA. Overall and cause-specific mortality in patients with systemic lupus erythematosus: a meta-analysis of observational studies. Arthritis Care Res (Hoboken). 2014;66(4):608–616. [PubMed: 24106157]
2. Fors Nieves CE, Izmirly PM. Mortality in Systemic Lupus Erythematosus: an Updated Review. Curr Rheumatol Rep. 2016;18(4):21. [PubMed: 26984805]
3. Hoover PJ, Costenbader KH. Insights into the epidemiology and management of lupus nephritis from the US rheumatologist's perspective. Kidney Int. 2016;90(3):487–492. [PubMed: 27344205]
4. Demas KL, Costenbader KH. Disparities in lupus care and outcomes. Curr Opin Rheumatol. 2009;21(2):102–109. [PubMed: 19339919]
5. Centers for Medicare & Medicaid Services. https://www.medicaid.gov/medicaid/index.html. Accessed 11/15/2019.
6. Parikh AA, Robinson J, Zaydfudim VM, Penson D, Whiteside MA. The effect of health insurance status on the treatment and outcomes of patients with colorectal cancer. J Surg Oncol. 2014;110(3):227–232. [PubMed: 24810008]
7. Martin CT, Callaghan JJ, Liu SS, Gao Y, Warth LC, Johnston RC. Disparity in total joint arthroplasty patient comorbidities, demographics, and postoperative outcomes based on insurance payer type. J Arthroplasty. 2012;27(10):1761–1765 e1761. [PubMed: 22868072]
8. Giacovelli JK, Egorova N, Nowygrod R, Gelijns A, Kent KC, Morrissey NJ. Insurance status predicts access to care and outcomes of vascular disease. J Vasc Surg. 2008;48(4):905–911. [PubMed: 18586449]
9. Naghavi AO, Echevarria MI, Grass GD, et al. Having Medicaid insurance negatively impacts outcomes in patients with head and neck malignancies. Cancer. 2016;122(22):3529–3537. [PubMed: 27479362]

10. Feldman CH, Hiraki LT, Liu J, et al. Epidemiology and sociodemographics of systemic lupus erythematosus and lupus nephritis among US adults with Medicaid coverage, 2000-2004. Arthritis Rheum. 2013;65(3):753–763. [PubMed: 23203603]
11. Chibnik LB, Massarotti EM, Costenbader KH. Identification and validation of lupus nephritis cases using administrative data. Lupus. 2010;19(6):741–743. [PubMed: 20179167]
12. Jacobson DL, Gange SJ, Rose NR, Graham NM. Epidemiology and estimated population burden of selected autoimmune diseases in the United States. Clin Immunol Immunopathol. 1997;84(3):223–243. [PubMed: 9281381]
13. Uramoto KM, Michet CJ Jr., Thumboo J, Sunku J, O'Fallon WM, Gabriel SE. Trends in the incidence and mortality of systemic lupus erythematosus, 1950-1992. Arthritis Rheum. 1999;42(1):46–50. [PubMed: 9920013]
14. Naleway AL, Davis ME, Greenlee RT, Wilson DA, McCarty DJ. Epidemiology of systemic lupus erythematosus in rural Wisconsin. Lupus. 2005;14(10):862–866. [PubMed: 16302684]
15. Izmirly PM, Wan I, Sahl S, et al. The Incidence and Prevalence of Systemic Lupus Erythematosus in New York County (Manhattan), New York: The Manhattan Lupus Surveillance Program. Arthritis Rheumatol. 2017;69(10):2006–2017. [PubMed: 28891252]
16. Lim SS, Bayakly AR, Helmick CG, Gordon C, Easley KA, Drenkard C. The incidence and prevalence of systemic lupus erythematosus, 2002-2004: The Georgia Lupus Registry. Arthritis Rheumatol. 2014;66(2):357–368. [PubMed: 24504808]
17. Somers EC, Marder W, Cagnoli P, et al. Population-based incidence and prevalence of systemic lupus erythematosus: the Michigan Lupus Epidemiology and Surveillance program. Arthritis Rheumatol. 2014;66(2):369–378. [PubMed: 24504809]
18. Dall'Era M, Cisternas MG, Snipes K, Herrinton LJ, Gordon C, Helmick CG. The Incidence and Prevalence of Systemic Lupus Erythematosus in San Francisco County, California: The California Lupus Surveillance Project. Arthritis Rheumatol. 2017;69(10):1996–2005. [PubMed: 28891237]
19. Ferucci ED, Johnston JM, Gaddy JR, et al. Prevalence and incidence of systemic lupus erythematosus in a population-based registry of American Indian and Alaska Native people, 2007-2009. Arthritis Rheumatol. 2014;66(9):2494–2502. [PubMed: 24891315]
20. Gillis JZ, Yazdany J, Trupin L, et al. Medicaid and access to care among persons with systemic lupus erythematosus. Arthritis Rheum. 2007;57(4):601–607. [PubMed: 17471527]
21. Ward MM. Access to care and the incidence of endstage renal disease due to systemic lupus erythematosus. J Rheumatol. 2010;37(6):1158–1163. [PubMed: 20395647]
22. Panopalis P, Gillis JZ, Yazdany J, et al. Frequent use of the emergency department among persons with systemic lupus erythematosus. Arthritis Care Res (Hoboken). 2010;62(3):401–408. [PubMed: 20391487]
23. Yazdany J, Feldman CH, Liu J, Ward MM, Fischer MA, Costenbader KH. Quality of care for incident lupus nephritis among Medicaid beneficiaries in the United States. Arthritis Care Res (Hoboken). 2014;66(4):617–624. [PubMed: 24124011]
24. Krishnan E. Hospitalization and mortality of patients with systemic lupus erythematosus. J Rheumatol. 2006;33(9):1770–1774. [PubMed: 16832848]
25. Marengo MF, Waimann CA, de Achaval S, et al. Measuring therapeutic adherence in systemic lupus erythematosus with electronic monitoring. Lupus. 2012;21(11):1158–1165. [PubMed: 22588588]
26. Koneru S, Kocharla L, Higgins GC, et al. Adherence to medications in systemic lupus erythematosus. J Clin Rheumatol. 2008;14(4):195–201. [PubMed: 18636020]
27. Daleboudt GM, Broadbent E, McQueen F, Kaptein AA. Intentional and unintentional treatment nonadherence in patients with systemic lupus erythematosus. Arthritis Care Res (Hoboken). 2011;63(3):342–350. [PubMed: 21120967]
28. Feldman CH, Costenbader KH, Solomon DH, Subramanian SV, Kawachi I. Area-Level Predictors of Medication Nonadherence Among US Medicaid Beneficiaries With Lupus: A Multilevel Study. Arthritis Care Res (Hoboken). 2019;71(7):903–913. [PubMed: 30055088]
29. Petri M, Perez-Gutthann S, Longenecker JC, Hochberg M. Morbidity of systemic lupus erythematosus: role of race and socioeconomic status. Am J Med. 1991;91(4):345–353. [PubMed: 1951378]

30. Pons-Estel GJ, Alarcon GS, Gonzalez LA, et al. Possible protective effect of hydroxychloroquine on delaying the occurrence of integument damage in lupus: LXXI, data from a multiethnic cohort. Arthritis Care Res (Hoboken). 2010;62(3):393–400. [PubMed: 20391486]
31. Feldman CH, Collins J, Zhang Z, et al. Dynamic patterns and predictors of hydroxychloroquine nonadherence among Medicaid beneficiaries with systemic lupus erythematosus. Semin Arthritis Rheum. 2018;48(2):205–213. [PubMed: 29458974]
32. Feldman CH, Collins J, Zhang Z, et al. Azathioprine and Mycophenolate Mofetil Adherence Patterns and Predictors Among Medicaid Beneficiaries With Systemic Lupus Erythematosus. Arthritis Care Res (Hoboken). 2019;71(11):1419–1424. [PubMed: 30354025]
33. Feldman CH, Yazdany J, Guan H, Solomon DH, Costenbader KH. Medication Nonadherence Is Associated With Increased Subsequent Acute Care Utilization Among Medicaid Beneficiaries With Systemic Lupus Erythematosus. Arthritis Care Res (Hoboken). 2015;67(12):1712–1721. [PubMed: 26097166]
34. Lin TC, Marmor MF, Barbhaiya M, et al. Baseline Retinal Examinations in Patients With Systemic Lupus Erythematosus Newly Initiating Hydroxychloroquine Treatment in a US Medicaid Systemic Lupus Erythematosus Population, 2000-2010. Arthritis Care Res (Hoboken). 2018;70(11):1700–1706. [PubMed: 29409142]
35. Plantinga LC, Drenkard C, Patzer RE, et al. Sociodemographic and geographic predictors of quality of care in United States patients with end-stage renal disease due to lupus nephritis. Arthritis Rheumatol. 2015;67(3):761–772. [PubMed: 25692867]
36. Podgorski M, Robinson B, Weissberger A, Stiel J, Wang S, Brooks PM. Articular manifestations of acromegaly. Aust N Z J Med. 1988;18(1):28–35. [PubMed: 3395299]
37. National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health. United States Renal Data System. USRDS 2013 annual data report: atlas of chronic kidney disease and end-stage renal disease in the United States. www.usrds.org.
38. Devlin A, Waikar SS, Solomon DH, et al. Variation in initial kidney replacement therapy for end-stage renal disease due to lupus nephritis in the United States. Arthritis Care Res (Hoboken). 2011;63(12):1642–1653. [PubMed: 22058067]
39. Tang H, Chelamcharla M, Baird BC, Shihab FS, Koford JK, Goldfarb-Rumyantzev AS. Factors affecting kidney-transplant outcome in recipients with lupus nephritis. Clin Transplant. 2008;22(3):263–272. [PubMed: 18482047]
40. Wang V, Lee SY, Patel UD, Weiner BJ, Ricketts TC, Weinberger M. Geographic and temporal trends in peritoneal dialysis services in the United States between 1995 and 2003. Am J Kidney Dis. 2010;55(6):1079–1087. [PubMed: 20385435]
41. Huang PL. Unraveling the links between diabetes, obesity, and cardiovascular disease. Circ Res. 2005;96(11):1129–1131. [PubMed: 15947251]
42. Chen SK, Barbhaiya M, Fischer MA, et al. Lipid Testing and Statin Prescriptions Among Medicaid Recipients With Systemic Lupus Erythematosus or Diabetes Mellitus and the General Medicaid Population. Arthritis Care Res (Hoboken). 2019;71(1):104–115. [PubMed: 29648687]
43. Maroz N, Segal MS. Lupus nephritis and end-stage kidney disease. Am J Med Sci. 2013;346(4):319–323. [PubMed: 23370533]
44. Tucker LB, Menon S, Schaller JG, Isenberg DA. Adult- and childhood-onset systemic lupus erythematosus: a comparison of onset, clinical features, serology, and outcome. Br J Rheumatol. 1995;34(9):866–872. [PubMed: 7582729]
45. Barr RG, Seliger S, Appel GB, et al. Prognosis in proliferative lupus nephritis: the role of socio-economic status and race/ethnicity. Nephrol Dial Transplant. 2003;18(10):2039–2046. [PubMed: 13679478]
46. Costenbader KH, Desai A, Alarcon GS, et al. Trends in the incidence, demographics, and outcomes of end-stage renal disease due to lupus nephritis in the US from 1995 to 2006. Arthritis Rheum. 2011;63(6):1681–1688. [PubMed: 21445962]
47. Feldman CH, Broder A, Guan H, Yazdany J, Costenbader KH. Sex Differences in Health Care Utilization, End-Stage Renal Disease, and Mortality Among Medicaid Beneficiaries With Incident Lupus Nephritis. Arthritis Rheumatol. 2018;70(3):417–426. [PubMed: 29193893]

48. Ward MM. Medical insurance, socioeconomic status, and age of onset of endstage renal disease in patients with lupus nephritis. J Rheumatol. 2007;34(10):2024–2027. [PubMed: 17696272]
49. Cooper R, Cutler J, Desvigne-Nickens P, et al. Trends and disparities in coronary heart disease, stroke, and other cardiovascular diseases in the United States: findings of the national conference on cardiovascular disease prevention. Circulation. 2000;102(25):3137–3147. [PubMed: 11120707]
50. Wilmot KA, O'Flaherty M, Capewell S, Ford ES, Vaccarino V. Coronary Heart Disease Mortality Declines in the United States From 1979 Through 2011: Evidence for Stagnation in Young Adults, Especially Women. Circulation. 2015;132(11):997–1002. [PubMed: 26302759]
51. Skaggs BJ, Hahn BH, McMahon M. Accelerated atherosclerosis in patients with SLE--mechanisms and management. Nat Rev Rheumatol. 2012;8(4):214–223. [PubMed: 22331061]
52. Roman MJ, Shanker BA, Davis A, et al. Prevalence and correlates of accelerated atherosclerosis in systemic lupus erythematosus. N Engl J Med. 2003;349(25):2399–2406. [PubMed: 14681505]
53. de Leeuw K, Freire B, Smit AJ, Bootsma H, Kallenberg CG, Bijl M. Traditional and non-traditional risk factors contribute to the development of accelerated atherosclerosis in patients with systemic lupus erythematosus. Lupus. 2006;15(10):675–682. [PubMed: 17120595]
54. Scalzi LV, Hollenbeak CS, Wang L. Racial disparities in age at time of cardiovascular events and cardiovascular-related death in patients with systemic lupus erythematosus. Arthritis Rheum. 2010;62(9):2767–2775. [PubMed: 20506536]
55. Barbhaiya M, Feldman CH, Guan H, et al. Race/Ethnicity and Cardiovascular Events Among Patients With Systemic Lupus Erythematosus. Arthritis Rheumatol. 2017;69(9):1823–1831. [PubMed: 28598016]
56. Barbhaiya M, Feldman CH, Guan H, et al. Racial/ethnic variation in stroke rates and risks among patients with systemic lupus erythematosus. Semin Arthritis Rheum. 2019;48(5):840–846. [PubMed: 30205982]
57. Gladman DD, Hussain F, Ibanez D, Urowitz MB. The nature and outcome of infection in systemic lupus erythematosus. Lupus. 2002;11(4):234–239. [PubMed: 12043887]
58. Ward MM, Pyun E, Studenski S. Causes of death in systemic lupus erythematosus. Long-term followup of an inception cohort. Arthritis Rheum. 1995;38(10):1492–1499. [PubMed: 7575699]
59. Feldman CH, Hiraki LT, Winkelmayer WC, et al. Serious infections among adult Medicaid beneficiaries with systemic lupus erythematosus and lupus nephritis. Arthritis Rheumatol. 2015;67(6):1577–1585. [PubMed: 25772621]
60. Feldman CH, Marty FM, Winkelmayer WC, et al. Comparative Rates of Serious Infections Among Patients With Systemic Lupus Erythematosus Receiving Immunosuppressive Medications. Arthritis Rheumatol. 2017;69(2):387–397. [PubMed: 27589220]
61. Hiraki LT, Feldman CH, Marty FM, Winkelmayer WC, Guan H, Costenbader KH. Serious Infection Rates Among Children With Systemic Lupus Erythematosus Enrolled in Medicaid. Arthritis Care Res (Hoboken). 2017;69(11):1620–1626. [PubMed: 28217919]
62. Yazdany J, Tonner C, Trupin L, et al. Provision of preventive health care in systemic lupus erythematosus: data from a large observational cohort study. Arthritis Res Ther. 2010;12(3):R84. [PubMed: 20462444]
63. Knight AM, Xie M, Mandell DS. Disparities in Psychiatric Diagnosis and Treatment for Youth with Systemic Lupus Erythematosus: Analysis of a National US Medicaid Sample. J Rheumatol. 2016;43(7):1427–1433. [PubMed: 27134262]
64. Gomez-Puerta JA, Barbhaiya M, Guan H, Feldman CH, Alarcon GS, Costenbader KH. Racial/Ethnic variation in all-cause mortality among United States medicaid recipients with systemic lupus erythematosus: a Hispanic and asian paradox. Arthritis Rheumatol. 2015;67(3):752–760. [PubMed: 25590668]
65. Hanly JG, O'Keeffe AG, Su L, et al. The frequency and outcome of lupus nephritis: results from an international inception cohort study. Rheumatology (Oxford). 2016;55(2):252–262. [PubMed: 26342222]
66. Brown EA, Dismuke-Greer CE, Ramakrishnan V, Faith TD, Williams EM. Impact of the Affordable Care Act Medicaid Expansion on Access to Care and Hospitalization Charges for Lupus Patients. Arthritis Care Res (Hoboken). 2020;72(2):208–215. [PubMed: 31562794]

Synopsis:

Systemic lupus erythematosus (SLE) is a serious chronic autoimmune disease with substantial morbidity and mortality. Although improved diagnostics and therapeutics have contributed to declining mortality rates, important disparities exist in SLE survival rates by race, ethnicity, gender, age, country, and social disadvantage. This review highlights the burden of SLE and lupus nephritis (LN) among Medicaid beneficiaries, outlines barriers in access to high quality SLE care and medication adherence in the Medicaid SLE population, and summarizes disparities in adverse outcomes among SLE patients enrolled in Medicaid.

Key points:

- Important disparities exist in SLE survival rates by race, ethnicity, gender, age, country, and social disadvantage
- SLE patients enrolled in Medicaid experience a disproportionate burden of SLE and of adverse outcomes, which may be tied to poor access and lower quality of care. Within this population, racial/ethnic minorities, individuals living below the poverty line, and individuals living in certain U.S. regions experience even poorer outcomes.