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Use of Quality Measures to Identify Disparities in Health Care for Systemic Lupus Erythematosus

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Keywords

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INTRODUCTION

Health care in systemic lupus erythematosus (SLE) is complex owing to the heterogenous nature of the disease with diverse organ manifestations and unpredictable disease course. Substantial disparities exist in disease-related morbidity and mortality across genders, different age groups, ethnicities, socioeconomic backgrounds and geographic locations.[1–4] Measurement of health care quality can identify gaps in clinical care at an earlier stage, where interventions could be planned and implemented to improve outcomes and reduce disparities.

The Institute of Medicine defines quality as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”[5] Donabedian’s[6] framework of health care assessment lays out a systematic approach to measure quality of care and divides the components of care into structural, process and outcome measures with a linear relationship among them. Structural measures denote the structure of the settings in which care occurs. Examples of structural measures pertinent to SLE care are access to specialty care and insurance coverage. Process measures denote provider actions while delivering care. In SLE, process measures often reflect adherence to evidence-based clinical guidelines as well as communication with patients to ensure their understanding of recommended treatment. Lastly, outcome measures denote the effects of care on the health status of patients and populations. Important outcomes in SLE include disease activity, damage, quality of life, hospitalizations and mortality.

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This article reviews key findings from the past decade of quality measurement in SLE, which has yielded important insights into where the health care system is working and where there are disparities and need for improvement. Two types of quality measures commonly used by researchers to understand quality of care in SLE are discussed: structural measures and process measures.

STRUCTURAL MEASURES AND ACCESS TO CARE

Access to rheumatology specialty care is uneven across geographic regions and insurance coverage and can have a profound impact on the treatment and outcomes of people with SLE.[7] Given the complexity of the disease, it is not surprising that studies have shown a strong relationship between physician experience in treating SLE and outcomes. For example, data from a large sample of hospitalized patients in California (n = 9989) showed that the risk of in-hospital mortality due to SLE was much lower at centers with more experience treating the disease for women, blacks, Hispanics, and those with public medical insurance or no insurance.[8] Compared with patients hospitalized at hospitals with less experience, patients at the hospitals with more experience were younger (mean age 43.7 years vs 51.1 years, respectively) and included fewer whites (39.5% vs 60.5%, respectively) and more patients were with public insurance (28.8% vs16.7%, respectively) or no medical insurance (7.1% vs 3.9%, respectively).[9] In another large population-based sample of SLE, patients who were hospitalized in New York or Pennsylvania (n = 15,509), physician SLE volume was shown to be inversely related to in-hospital mortality after adjusting for demographic characteristics, severity of illness, and hospital characteristics, signifying a volume outcome relationship in the care of SLE.[10] Data from the National Inpatient Sample (NIS) also has shown lower mortality in SLE patients at hospitals seeing more of these patients.[11]

Similar findings have emerged from research in the ambulatory setting. Comparison of SLE care between primary care physicians and specialists (rheumatologists, nephrologists, and dermatologists) in the Indian Health Service lupus registry comprising patients from the Alaska Native population showed that specialist diagnosis of SLE was associated with a higher likelihood of having SLE classification criteria documented, being tested for biomarkers of disease, and ever receiving treatment with hydroxychloroquine.[12] Another study has shown better quality of care in a subspecialty SLE clinic in comparison to general rheumatology clinic. No demographic differences were noted in the patient population between the 2 clinics, but patients seen in the subspecialty lupus clinic had longer duration of disease and met more numbers of the ACR criteria for lupus in comparison to general rheumatology clinic.[13] Moderate correlation also was shown between physician SLE volume and performance on quality measures in this study.[13] In addition, a recent study showed that quality of care for lupus nephritis was significantly higher at academic centers specializing in SLE than in community practices,[14] even after adjusting for sociodemographic and disease differences among patients. These findings support that specialty and subspecialty care are associated with higher-quality care in SLE.

Data from different studies suggest that low socioeconomic status, as proxied by insurance status or measured by self-reported income, is associated with lower quality of care. The incidence of end-stage renal disease (ESRD) due to lupus nephritis (LN) and its association with age at onset, type of insurance, and socioeconomic status were studied in a cross-sectional study using the US Renal Data System (n = 7971). Among patients with LN who developed ESRD, those with private medical insurance were older when they began ESRD treatment than those with Medicaid or no insurance. These findings suggest that progression to ESRD varies with medical insurance status, possibly because of differences in quality of care or access to care.[15] In a population-based ecological study, the incidence of ESRD due to SLE was found higher in zip codes with higher proportions of hospitalizations with Medicaid ($P<.0001$) and higher rates of hospitalizations for ambulatory care-sensitive conditions (thus avoidable hospitalizations), again suggesting that limited access to care may contribute to this complication of SLE.[16]

Racial/ethnic minorities and those with low socioeconomic status are less likely to receive timely specialty care. Using data from Medicare claims in the states of Colorado, Massachusetts, and Virginia, researchers found that African American women were less likely to receive referrals to rheumatology care for SLE.[17] Data from the Lupus Outcomes Study, which is a large, longitudinal cohort of physician-confirmed SLE, showed that Medicaid patients with SLE traveled longer distances to see an SLE physician, especially rheumatologists, and reported more visits to a general practitioner and emergency room for their SLE.[18] Assessment of the predictors of utilization of rheumatology subspecialty care in this cohort showed that older age, lower income, and male gender were associated with absence of rheumatology visits.[19] Data from the 2004 to 2007 interview wave of Lupus Outcomes Study participants showed that the number of physician visits for SLE varied by education level and neighborhood poverty.[20] Finally, among Medicaid recipients with lupus nephritis nationally, 1 in 8 patients were found to use the emergency room as a usual source of care, suggesting barriers to accessing appropriate ambulatory specialty care.[21]

Delays in initial SLE diagnosis and in receiving life-saving therapies, such as kidney transplantations, also have been documented. Low household income predicted delayed presentation (≥1 year) to a pediatric rheumatologist in childhood SLE in a study using a large registry of pediatric SLE patients (n = 598).[22] In another study, 64% of African Americans and 66% of Asians saw a specialist within 3 months of diagnosis, compared with 92% and 85% for whites and Hispanics, respectively. For those with a high-school education or less, 45% were referred to specialty care in the first 3 months compared with 81% of those with a higher level of education.[23] Predictors of kidney transplantation among children with ESRD due to lupus nephritis were studied using the US Renal Data System demonstrating significant inequalities. There were fewer kidney transplants among African American versus white patients (odds ratio [OR] 0.48; $P<.001$), Hispanic versus non-Hispanic patients (OR 0.63; $P = .03$), and those with Medicaid versus those with private insurance (OR 0.70; $P = .03$). Mortality among African American children was found almost double that among white children (OR 1.83; $P<.001$).[24] These studies build a compelling picture that access to care is uneven across racial/ethnic and socioeconomic groups with SLE in the United States and point to quality of care as 1 potential root cause of disparities in the disease.

Although no quality measures that examine structures of SLE care have been developed, the research, discussed previously, suggests that measures that monitor access to specialty care could help track and address health care disparities nationally. Moreover, given multiple studies showing that racial/ethnic minorities, those with public insurance and those with low socioeconomic status are at highest risk for poor access to care, such measures could provide data to target programs that aim to expand access. Examples of structural measures include the proportion of patients who are seen by a rheumatologist within 30 days of a suspected diagnosis of SLE or rheumatic disease or the proportion of patients with SLE who are seen by a specialist in the disease at least once per year. Beyond tracking measures, education programs should target primary care providers and insurance policy makers in areas with low performance on access measures, and telehealth programs should be explored to expand the reach of high-volume SLE centers.[25]

PROCESS QUALITY MEASURES

Process measures denote health care provider actions in delivering care for SLE. Assessment of process measures provides actionable targets for quality improvement given care of SLE patients often is fragmented among different specialists and primary care providers. Quality indicators assessing processes of care are defined as "retrospectively measurable elements of practice performance for which there is evidence or consensus that can be used to assess the quality of care provided and hence change it."[26] Different sets of quality indicators have been developed for use in SLE utilizing standardized development techniques, including systematic literature reviews, expert panels, and Delphi interviews. A brief description of these quality indicators along with the recommending study groups is summarized in Table 1.[27–32]

DISPARITIES IN PERFORMANCE ON QUALITY MEASURES

Application of quality measures in SLE across several studies provides insight into gaps in SLE care and factors accounting for the disparities in quality of care. Data from self-report of 13 of 20 SLE quality indicators[27] showed an overall performance rate of 65%, with variable performance on the individual measures[33] (Table 2). Factors associated with poor performance included younger age, fewer physician visits, and lack of health insurance. As discussed previously, higher SLE patient volume and care in subspecialty SLE clinics have been shown associated with better performance on quality indicators.[13] This study analyzed performance on 20 measures with significant differences in 8 of them between SLE clinics and general rheumatology clinics, suggesting the roles of physician expertise and SLE volume in providing better quality of care in SLE.

Studies of quality measures in lupus nephritis have shown similar results, with better performance at academic centers[14] and for those patients with more specialist visits.[21] Data from the Medicaid program across 47 US states and the District of Columbia showed that performance of quality measures for lupus nephritis was low especially for use of immunosuppressive agents (see Table 2).[21] In this cohort, younger individuals, African Americans, and Hispanics were more likely to receive immunosuppressive therapy and hydroxychloroquine; however, younger individuals were less likely to receive renalprotective antihypertensive medications. Researchers also found that a significant number of patients used the emergency department as their usual source of care, defined as having greater than 50% of their yearly health care encounters in that setting. Not surprisingly, this group was less likely to receive recommended care.

Preventive measures play a significant role in the care of SLE patients and have been found uneven across populations (see Table 2). Having a primary care provider increases the likelihood of getting preventive services, including measures related to bone health[34] and vaccinations against influenza and pneumococcal infections.[40] Younger women, nonwhite patients, and those with shorter disease duration get these recommendations less often.[35,41] Study of reproductive health measures, another important issue in SLE, has shown that rates of contraceptive counseling are low: 30% to 60% across studies (see Table 2). In a retrospective cohort from Denver (n = 122), younger age (R 0.93), and those who did not describe English as their primary language (OR 0.29) were more likely to have received counseling on drug teratogenicity.[37] A study of factors associated with contraception counseling in the Lupus Outcomes Study cohort showed that older age, white race, those with depressive symptoms, and higher SLE disease activity were less likely to get contraception counseling.[42]

Gaps in quality of care also have been demonstrated among children with SLE. Evaluation of quality indicators in a cohort of 75 childhood SLE patients showed especially low rates of bone mineral density evaluation (28.6%) and pneumococcal vaccination (31.7%).[39] In a large sample of childhood-onset SLE patients (n = 783), care differed markedly for several quality indicators addressing lupus nephritis, bone health, vaccinations, education on cardiovascular risk, and transition planning across different centers in the United states, Brazil, and India.[38] Access to kidney biopsies was found to be lower in Brazil than in the United States and, irrespective of the country, larger centers more often met the measures than smaller centers, reinforcing the volume-quality relationship seen in multiple US studies.

As evident from these study findings, process measures help identify gaps and disparities in care of SLE. SLE measures, however, are not deployed routinely in rheumatology clinics or federal programs. Using an online survey of 32 questions mailed to rheumatologists seeing adult SLE patients in academic settings, two-thirds of respondents reported being familiar with quality indicators in SLE, but only 18% reported using them in daily practice.[43] Most rheumatologists (81%) had a positive perception of the SLE quality indicators and agreed that their implementation could improve quality care in SLE, but they identified time as a barrier to implementation. Strategies to incorporate these measures in daily practice, such as alerts or checklists in electronic medical records, have been suggested. For instance, quality improvement methodology was applied in a study of 123 childhood SLE patients where a standardized previsit planning process to electronically pend orders for the needed screenings prior to a scheduled clinic visit was performed. This intervention increased the percentage of patients with completed screenings from 54% to 92% for annual vitamin D, 55% to 84% for annual lipid profiles, and 57% to 78% for bone density screening.[44] Such interventions may be beneficial in providing recommended care as well as saving time.

Importantly, longitudinal follow-up of SLE patients has demonstrated that higher performance on process quality measures improves outcomes over time. Higher performance on quality measures resulted in less accrual of damage in the Lupus Outcomes Study.[45] In another recent study, receiving higher-quality clinical care was associated with low disease activity, less progress in disease damage, and better quality of life at 2-year follow-up.[46] The impact of improving performance on SLE quality measures, however, in reducing disparities and other outcomes, such as costs, health care utilization, and overall mortality, still remains to be ascertained in longitudinal studies.

OUTCOME MEASURES

There remain significant challenges to developing outcome performance measures in SLE and none has been developed to date. Key SLE outcomes, such as accumulated organ damage, may take years to develop and, therefore, are perceived as not entirely within the immediate control of individual providers. In addition, risk adjustment of averaged patient outcomes within a clinic or health care system is daunting in a disease that can affect virtually any organ in the body and has dramatically different levels of severity in the population. Despite these challenges, research is beginning to lay a foundation for outcomes measurement in SLE, given that the ultimate goal of quality measurement is to improve patient outcomes.

Most work on outcome measures has examined inpatient quality of care. Studies assessing in-hospital mortality due to SLE have shown lower mortality at centers with more experience and higher physician SLE volume, as described previously. Hospital readmissions also are a potentially important outcome measure, given that SLE has the sixth highest readmission rate among all medical conditions in the United States.[47] One in 6 hospitalized patients with SLE is readmitted within 30 days of discharge.[48] Using hospital discharge databases from 5 geographically dispersed states, risk-adjusted hospital readmission rates have been shown significantly higher among at-risk populations, including racial/ethnic minorities and those with lower socioeconomic status.[48]

What about patients? What do they define as high quality? In formative work, researchers engaged individuals with SLE, a majority of whom were African American women from medically underserved communities, to discuss barriers to care and strategies for quality improvement.[49] Patients identified outcome measures that they think are most important, including measures of quality of life, functioning, mental health, and self-efficacy. More work is needed, but partnering with patients to further develop these priorities into quality measures will be important.

SUMMARY

Despite significant challenges posed by the complexity and relatively low prevalence of SLE and the multifaceted health care needed to treat it, the past decade of research has overcome some of these challenges to lay a framework for quality measurement and improvement. Process measures with specifications for a variety of data sources are available for use, and preliminary data suggest that better performance on process measures are associated with improved health outcomes in SLE. Outcome measures have been applied to assess quality during hospitalizations, and the results of these studies provide benchmarking information for researchers and health systems aiming to improve SLE care. Lastly, patients have identified several areas they think are critical for quality measurement.

Importantly, it has been learned that poor access to subspecialty care is a major threat to high-quality care in SLE and that providers with more experience treating SLE generally have better outcomes. Tracking and working to improve access to care, therefore, are major priorities for improving SLE care, as is ensuring that patients can benefit more broadly from the expertise of specialty centers. In addition, significant disparities in quality of care have been identified, with racial/ethnic minorities, low-income patients, and those with lower educational attainment and public insurance consistently having lower quality of care across studies. As recently stated by Sivashanker and Gandhi,[50] "there is no such thing as high-quality, safe care that is inequitable." Future work should focus on deployment of SLE quality measures across health systems and clinical data registries, and resulting data should be used to pro-actively address gaps in care and reduce health care disparities for the disease.

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KEY POINTS

- Poor access to specialty care is a major factor driving poor outcomes in systemic lupus erythematosus (SLE). SLE patients who are racial/ethnic minorities, have low socioeconomic status, and with public insurance face difficulties in accessing specialty care.
- Application of quality measures has identified gaps in the care of SLE and disparities among different populations. Physician SLE volume and center experience are associated with better quality of care.
- Higher performance on quality measures correlates with improved outcomes in SLE.

Table 1.

Quality Indicators developed for systemic lupus erythematosus

Area Covered	**Description**
Diagnosis	Initial antibody testing, including ANA, dsDNA, and aPL abs,[27,29,30] and baseline labs, including CBC, creatinine, and UA[27,30]
Disease monitoring	Regular lab monitoring,[28,29,31] regular disease activity assessment through validated indices,[28,29] damage measurement,[29] and quality-of-life measurement[29]
Medications	Counseling prior to starting drugs[27,28,30]; screening for HBV, HCV, and TB prior to immunosuppressives[29]; regular labs for drug toxicity[27,29–31]; addition of steroid sparing agent[27,30,31]; addition of antimalarials[30]; ophthalmologic examination for hydroxychloroquine[28–31]; and screening for cataracts and glaucoma while on steroids[29,30]
Renal disease	Diagnosis of lupus nephritis with renal biopsy,[28,30] regular labs for monitoring,[27,28,30,31] treatment with immunosuppressives,[27,28,30] ACE inhibitor/ARB for proteinuria,[27,30,31] and BP control[27]
Prevention	Sun avoidance counseling,[27,28,30] influenza and pneumococcal vaccination,[27,29,30] and meningococcal and *Hemophilus influenzae* vaccination (in children)[30]
Bone health	Screening for osteoporosis,[27,30] calcium and vitamin D supplementation,[27,28,30,31] and treatment of osteoporosis[27,31]
Cardiovascular screening	Annual screening and treatment of risk factors, including diabetes, hypertension, smoking, and obesity[27,28,30,31]
Reproductive health	Counseling regarding teratogenicity of drugs and contraception use[27,32]; testing for SSA, SSB, and aPL abs[27,28,30,32]; and treatment of APS in pregnancy[27,32]
Miscellaneous	Treatment of APS,[28,31] record of comorbidities,[29] immunosuppressives for neuropsychiatric SLE,[30] and transfer of care to adult providers (in adolescents)[30]

Abbreviations: ANA, antinuclear antibody; aPL abs, antiphospholipid antibodies; APS, antiphospholipid antibody syndrome; CBC, complete blood cell count; dsDNA, double-stranded deoxyribonucleic acid antibody; HBV, hepatitis B virus; HCV, hepatitis C virus; SSA, Sjögren syndrome A; SSB, Sjögren syndrome B; TB, tuberculosis; UA, urinalysis.

Table 2.

Performance on quality measures across studies in systemic lupus erythematosus between 2010 and 2019

Study	Population	Method/ Process Measure Studied	Sun Avoidance	Vaccinations	Bone Health	Medications	Lupus Nephritis	Reproductive Health	Others
Schmajuk et al,[33] 2010	n = 742 (127 eligible)	Self-report data on 3 measures of bone health	—	—	BMD screening (74%), calcium-vitamin D (58%), osteoporosis treatment (56%)	—	—	—	—
Yazdany et al,[34] 2010	n = 685	Self-report data on cancer screening and vaccinations	—	Influenza vaccine (59%), pneumococcal (60%)	—	—	—	—	Cervical cancer screening (70%), mammography (70%), colon cancer screening (62%)
Demas et al,[35] 2010	n = 200	Retrospective review of bone health measures and cardiovascular screening	—	—	BMD screening (59%), calcium-vitamin D (62%), osteoporosis treatment (86%)	—	—	—	CVD screening (5 risk factors) (3%), CVD screening (excluding smoking) (26%)
Yazdany et al,[36] 2011	n = 206	Self-report of contraceptive use and counseling	—	—	—	—	—	Contraceptive counseling (41%), consistent contraceptive use (78%)	—
Yazdany et al,[31] 2012	n = 814	Self-report data on 13 measure	Sun avoidance counseling (90%)	Influenza vaccine (80%), pneumococcal (69%)	Calcium-fitamin D (83%), BMD screening (56%), osteoporosis treatment (61%)	Counseling prior to initiation (68%), counseling on GC management plan (65%), Drug monitoring (69%), steroidsparing agent (65%)	ACE inhibitor or ARB (49%), BP control (54%)	Contraception counseling (40%)	CVD screening (29%)
Yazdany et al,[21] 2014	n = 1711	Medicaid administrative data on 3 measures for lupus nephritis at 90 days after diagnosis	—	—	—	—	Immunosu ppressives for LN (22%), ACE inhibitor or ARB (44%), antimalarials (36%)	—	—
Quinzanos et al,[37] 2015	n = 122	Retrospective review of 2 measures on	—	—	—	—	—	Antibody screening in pregnancy (SSA, SSB, and	—

Study	Population	Method/ Process Measure Studied	Sun Avoidance	Vaccinations	Bone Health	Medications	Lupus Nephritis	Reproductive Health	Others
		reproductive health						aPLs ab) (100%), contraception counseling (46%)	
Mina et al,[38] 2016	n = 483	Retrospective review of 26 measures in pediatric SLE patients across 7 centers	Sun avoidance (54%–99%)	Influenza vaccination (57%–100%)	Calcium-vitamin D (59%–100%), BMD screening (7%–90%)	Antimalarials (75%–100%), Steroid sparing agent (25%–100%), counseling about drugs (60%–100%), lab monitoring for drugs (86%–100%), eye screening (72%–96%)	Lab monitoring for lupus nephritis (50%–100%), kidney biopsy (50%–100%), immunosuppressives (83%–100%), ACE inhibitor or ARB (80%–100%)	Antibody screening in pregnancy (50%–100%)	CVD screening (0%–100%), transition of care (13%–100%), treatment of neuropsychiatric lupus (80%–100%)
Harris et al,[39] 2017	n = 75	Retrospective review of 7 measures in pediatric SLE	—	Influenza vaccine (76%), pneumococcal (32%), meningococcal (67%)	Vitamin D recommendation (84%), BMD screening (29%)	HCQ use (94%), eye screening (49%)	—	—	—
Arora et al,[13] 2018	n = 150	Self-report and retrospective review on 20 measures	Sun avoidance (lupus clinic vs general rheumatology clinic; 99% vs 84%, respectively)[a]	Influenza vaccine (lupus clinic vs general rheumatology clinic; 98% vs 88%, respectively), pneumococcal (lupus clinic vs general rheumatology clinic; 85% vs 49%, respectively)[a]	Calcium-vitamin D (lupus clinic vs general rheumatology clinic; 78 vs 72%, respectively), BMD screening (lupus clinic vs general rheumatology clinic; 94% vs 54%, respectively),[a] osteoporosis treatment (100% in both clinics)	Counseling prior to drugs (lupus clinic vs general rheumatology clinic; 92% vs 81%, respectively) steroidsparing agent (lupus clinic vs general rheumatology clinic; 100% vs 82%, respectively)[a]	ACE inhibitor or ARB (lupus clinic vs general rheumatology clinic; 94% vs 58%, respectively),[a] BP control (lupus clinic vs general rheumatology clinic; 94% vs 100%, respectively), immunosuppressives (100% in both clinics)	Contraception counseling (lupus clinic vs general rheumatology clinic; 90% vs 65%, respectively)	CVD screening (lupus clinic vs general rheumatology clinic; 40% vs 15%, respectively),[a] aPLs ab testing (lupus clinic vs general rheumatology clinic; 72% vs 37%, respectively)[a]
Aggarwal et al,[14] 2019	n = 250	Retrospective review of 8 measures for screening and treatment of lupus nephritis	—	—	—	—	Urine screening for nephritis (42%), kidney biopsy (67%), immunosuppressives (81%), BP control (78%)	—	Overall performance 85% at academic centers vs 60% at community centers[a]

Abbreviations: aPLs ab, antiphospholipid antibodies; ARB, angiotensin receptor blocker; BMD, bone mineral density; BP, blood pressure; CVD, cardiovascular disease; GC, glucocorticoid; HCQ, hydroxychloroquine; LN, lupus nephritis.

[a] P value <.05.