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Current Opinion in Rheumatology Review

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Abstract

Purpose of Review—Systemic lupus erythematosus (SLE), an inflammatory rheumatic disease characterized by autoantibody production and diverse clinical manifestations, disproportionately affects vulnerable groups: women, racial and ethnic minorities, the poor, and those lacking medical insurance and education. We summarize the current knowledge of the disparities observed in SLE and highlight recent research that aims to dissect the causes of these disparities and to identify the potentially modifiable factors contributing to them.

Recent Findings—Several remediable causes, including lack of education, self-efficacy, and access to quality, experienced healthcare, have been found to contribute to observed disparities in SLE prevalence and outcomes.

Summary—SLE is associated with alarming disparities in incidence, severity and outcomes. The causes of these disparities are under study by several research groups. Identifying potentially correctable contributory factors should allow for the development of effective strategies to improve the healthcare delivery and outcomes in all SLE patients.

Keywords

Systemic lupus erythematosus; health disparities; socioeconomic status; heath care access

Introduction

Health disparities, according to the National Institutes of Health (NIH) Working Group on Health Disparities, have been defined as, “differences in the incidence, prevalence, mortality and burden of diseases and other adverse health conditions that exist among specific population groups in the US”[1]. The study of disparities in health outcomes and their causes is now a national priority. Sociodemographic disparities in the incidence and severity of many chronic diseases, including obesity, hypertension, diabetes mellitus, and chronic renal disease, have been observed[1–3]. Vulnerable populations may be defined by age, race/ethnicity, sex, sexual orientation, socioeconomic status, geographic residence or other characteristics[1].

Of the numerous conceptual frameworks describing determinants of health outcomes disparities, a conceptual model articulated by House includes sociodemographic factors that are relatively fixed, such as age, sex, race, ethnicity and geographic location, and those that are potentially modifiable[4, 5] (Figure 1). The NIH Strategic Plan on Health Disparities focuses on differences in health care delivery[6], an important potentially modifiable factor in the pathway between belonging to a specific sociodemographic group and ultimate healthcare outcomes. Healthcare system factors, medical insurance, and psychosocial factors, including adherence, education, and social support, are also potentially modifiable factors that may

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interact with fixed sociodemographic factors or act independently and influence long-term outcomes, creating health outcomes disparities.

Health Disparities in SLE

Among the rheumatic diseases, SLE is the most strongly associated with disparities in its incidence, prevalence, and long-term outcomes[7, 8]. SLE incidence appears to have increased in the general U.S. population over the past four decades[9] and SLE has one of the highest mortality rates of the rheumatic diseases[9, 10]. Prognosis is improved by prolonged, complex and potentially toxic therapies. For unknown reasons, SLE is most prevalent among women and those of non-Caucasian descent; those of African heritage are the most affected population. Lupus incidence rates among Black females, for example, are 3–4 times those of white females. Mean age at onset of lupus is younger among Blacks[11, 12], and disease damage accrues more quickly[13]. Non-whites with lupus have mortality rates at least > 3 times as high as whites[10, 14–17]. The Centers of Disease Control documented that lupus mortality rates from 1979–1998 were more than 5 times higher for women than for men[10]. The highest and fastest increasing SLE mortality rates in the U.S. from 1979–98 were observed among African American women aged 45–64[10]. In this population, a 69.7% increase in mortality was seen. (Figure 2). Other racial and ethnic minorities, including Hispanics, Asians and Native Americans, the poor, those lacking medical insurance and education, are also at increased risk of developing SLE and of poor outcomes from the disease.

The root causes of these disparities and the potentially remediable factors contributing to them remain poorly understood. The disparities observed in SLE are likely to be explained only partially by genetic, hormonal and biologic factors. Genetic and biologic differences between racial and ethnic groups and between males and females cannot explain the socioeconomic “gap” in SLE incidence, severity and outcomes, nor the widening of this gap over time.

Several research groups are investigating the underlying causes of disparities in the incidence, prevalence and health outcomes among individuals with SLE. In particular, we reviewed those that have focused on healthcare system factors. The studies reviewed herein have significantly contributed to our growing understanding of the multiple causes of SLE disparities and have helped to identify potentially correctable contributory factors. Although lupus does affect some males, it is predominantly a disease of women. Before puberty, lupus is approximately twice as common in girls. At the onset of puberty, the rate in females begins to climb, reaching a peak ratio of 8–9:1 from ages 15–45. After menopause, the disproportionate incidence rates in women decline to approximately twice those in men[18, 19]. Rates of lupus nephritis and lupus nephritis end-stage renal disease, necessitating renal dialysis or transplantation, are also much higher among women compared to men[20]. Genetic and/or hormonal differences may underlie much of the female predominance in SLE, but have yet to be well quantified[21].

By most measures, including income, educational level, wealth, medical insurance, occupation and area-based socioeconomic measures, individuals with lower socioeconomic status (SES) have higher rates of incidence, severity and mortality from SLE than do those of higher SES [16, 22–33]. SLE mortality is highest in the U.S. South and associated with poverty and Hispanic ethnicity[34, 35]. Women also earn substantially less income than men and more women than men live below the Federal poverty level in the U.S. (22.5% of women vs. 18.3% of men in 2004)[36]. SES may thus be contributing to observed disparities in SLE incidence and outcomes with regard to sex.

SLE incidence, morbidity and mortality are all much higher among non-white than white racial and ethnic groups in the U.S[10, 37]. Constituted in 1994, LUpus in MInorities: NAture vs. nurture (LUMINA) is a multi-ethnic (Hispanic, African American and Caucasian), longitudinal SLE cohort study based in Alabama, Texas and Puerto Rico [28–33]. It currently has 636 participants who meet the American College of Rheumatology (ACR) criteria for the classification of SLE[38, 39], have disease duration of at least 5 years, and are at least 16 years of age[40]. The relationship of race/ethnicity and SES to the increased SLE incidence and poorer survival in African and Hispanic-American patients have been studied in LUMINA [28–33]. An early analysis followed 288 SLE patients for 5 years from study onset. During this time, 34 (11.8%) patients died and LUMINA investigators have attempted to disentangle race/ethnicity from SES as predictors of SLE mortality[28]. Those with incomes below the Federal poverty level were four times more likely to die than were those with higher incomes[28, 41]. After adjustment for poverty and medical insurance, the risk of SLE progression was greatly reduced among both African American and Hispanic participants[24]. Significant predictors of poor outcomes and disease progression in this cohort have included Hispanic and African American ancestry, as well as poverty, lack of education, and lack of social support (not married or living together) [33].

The LUMINA cohort has also allowed the investigation of racial and ethnic disparities in specific SLE manifestations and outcomes, including renal disease, myocarditis, hypertension, and work disability[31, 42–45]. LUMINA participants who developed renal disease were younger, had more hypertension and more were African American or Texan Hispanic [31, 42, 43]. African American and Texan-Hispanic ethnicity and obesity were also risk factors for developing hypertension in LUMINA[46]. Abrupt SLE onset, as opposed to a more insidious subacute onset, was associated with younger age, lower SES and predicted more severe ongoing clinical manifestations and higher disease activity[40]. African Americans in LUMINA had a strikingly higher risk of developing myocarditis (60.9%) compared to (1.9%) of Hispanics from Puerto Rico[44]. LUMINA investigators found that age, smoking, alcohol intake, education, poverty and health insurance were not associated with the risk of myocarditis however. In addition, LUMINA SLE patients from lower socioeconomic backgrounds were more likely to become disabled[45]. Lotstein and colleagues found in past work that women with SLE of lower SES as captured by the Hollingshead Index, which incorporates educational level and occupational prestige, had more functional disability and more cumulative organ damage[47]. In LUMINA, poverty, total disease duration, disease activity and damage accrual were predictors of work disability[45].

In the Hopkins Lupus Cohort of 1378 individuals with SLE, low SES, defined as a household income less than $25,000, had a 70% survival compared to an 86% survival rate for those with a higher household income[48]. African American background was associated with decreased survival in univariate analysis, but was not an independent predictor after adjustment for income and education[48]. This suggests that SES influences SLE severity and mortality independently of race/ethnicity.

Following the documentation of clear health disparities in SLE, the research impetus over the past few years has been to go beyond description and to address fundamental questions about their causes. In particular, what aspects of low SES are responsible for disparities in SLE, and can specific potentially modifiable factors be identified to allow the targeting of future efforts to decrease disparities in SLE? These two questions are enormously challenging. The multiple causes of poor outcomes in SLE are overlapping and interactive. Race, SES, and factors closely associated with each, such as reduced access to quality healthcare, reduced comprehension of disease and the medical system, increased competing home and work demands, and reduced self-confidence and social support, have been tightly correlated and predictive of SLE disease activity, organ damage and functional ability in past research studies[26, 27, 47, 49–51]. Genetic factors undoubtedly contribute to racial and ethnic disparities in SLE outcomes. The identification of new genetic factors involved in SLE pathogenesis promises improved understanding and identification of new molecular pathways and targets. Given the large sociodemographic “gap” in SLE outcomes that continues to grow, genetic factors alone are unlikely entirely responsible. Additionally genetic factors, like sex, are not modifiable and thus not amenable to interventions to decrease observed disparities. Current research is taking on the challenge of dissecting the overlapping, non-discrete aspects of race/ethnicity and SES, and how their components could be acting to create disparities in SLE incidence and long-term outcomes.

1. Education and self-efficacy

In several studies, the educational level of SLE subjects has been predictive of outcomes. A greater number of years of education may improve outcomes by increasing medical understanding, confidence in one's ability to manage a chronic disease, and/or the ability to communicate and self-advocate effectively in patient-doctor interactions. In a multicenter SLE study, lower self-efficacy for disease management (the belief that one has the ability to control one's disease), less social support, and younger age at diagnosis were associated with greater disease activity and cumulative organ damage [51]. Employing data from the US Multiple Causes of Death data from 1994 to 1997, Ward found that fewer years of education was associated with increased SLE-related mortality, particularly among whites[52]. This was not found among ethnic minorities, however, possibly due to under-ascertainment of lupus-related deaths in less-educated patients. Not surprisingly, lower educational level was associated with adverse SLE pregnancy outcomes in the LUMINA cohort[53].

Educational level, and related medical understanding and self-efficacy, are likely related to the quality of patient-physician interactions. Ward and colleagues audiotaped routine visits between 79 women with SLE and their rheumatologists and assessed for active patient participation and the degree of patient-centered communication of the physician[54]. Patients who had participated more actively in their visits had less permanent organ damage at the end of a median of 4.7 years follow-up. Karlson and colleagues enrolled 122 women with SLE into a 12-month randomized controlled trial of a theory-based intervention to improve patient self-efficacy and social support for management of SLE. At the end of the trial, those subjects who had received the intervention had improved significantly in measures of global mental and physical health, as well as fatigue, illustrating that self-efficacy and social support are modifiable predictors of long-term outcomes in SLE[55].

2. Depression and lack of social support

In several studies, being married or living with another person, or having identified individuals to provide social support, has been associated with better outcomes in SLE[33, 51]. In a randomized trial setting, an educational intervention involving SLE patients and an identified social support person to improve both self-efficacy and social support, improved SLE outcomes, underscoring the importance of social support[55]. Depression on the other hand, likely impedes self-efficacy, adherence, patient-physician communication and is more common in lower SES groups[47, 56].

3. Adherence and non-adherence

Lack of education and understanding, distrust in medical institutions and cultural misunderstanding may lead to non-adherence to medical therapy. In an older study, Petri and colleagues reported that while African American lupus patients in the Johns Hopkins Rheumatology Clinic had lower education, income, and job status and poorer medical insurance coverage than did white lupus patients, they also had poorer adherence to medical care as assessed by the physician[23]. In multivariable analyses, medical adherence and hypertension were more important predictors of the development of renal disease than were race or classical measures of SES. Lack of disease comprehension and reduced self-confidence and social support are related to racial/ethnic background and to SES, and are also predictive of SLE activity, organ damage and functional ability[26, 27, 47, 49–51]. In the LUMINA cohort, loss to follow up, defined as failure to attend two or more of the consecutive yearly visits, was highest among African Americans, followed by white and then Hispanic patients, who were the least likely to become lost due to follow-up[57].

4. Access to care: provider and hospital experience (volume), subspecialist care

Employing data from the U.S. Renal Datasystem, which includes approximately 94% of all individuals in the U.S. with end-stage renal disease requiring chronic renal replacement, Ward examined the age at onset of end-stage renal disease among patients with lupus nephritis according to their medical insurance [58]. He found that when analyzed within their own racial/ethnic group, those with Medicaid or no insurance were younger at onset of end-stage renal disease than those with private insurance. This illustrates that the type of medical insurance is related to the rate of progression of renal failure in SLE, but it is not clear what aspect of medical insurance or a variable closely associated with medical insurance is responsible.

Access to quality healthcare or, “the realized ability to receive appropriate medical care in a timely manner, free from geographic or financial barriers”[27], is a challenge for minority and disadvantaged groups, and a potentially remediable factor that is associated with outcomes in SLE. Care for patients with lupus, like that of many chronic diseases, necessitates advanced training, experience, strong physician-patient communication skills, and access to other sub-specialists and medical technology. In many complex diseases, including rheumatoid arthritis, diabetes mellitus, and chronic kidney disease, the involvement of medical specialists results in better long-term outcomes[59–66].

In California, lack of medical insurance was strongly associated with fewer physician visits for SLE patients [27]. Yazdany and colleagues conducted a telephone survey of more than 900 SLE patients concerning their subspecialty care and found that older age, lower income and being male were associated with lack of rheumatology follow-up care[67]. Medicaid SLE patients in California also traveled farther to receive SLE healthcare and were more likely to see a generalist or be seen in the emergency department compared to those with other insurance[68]. In addition, SLE patients enrolled in health maintenance organizations, compared to those in fee-for-service health plans, utilized less ambulatory care and were less likely to have outpatient surgery and hospital admissions[69]. In other diseases, lack of physician continuity and regular follow-up, which can be dictated by medical insurance plans, is associated with medical non-adherence as well[70]. Hospital and physician experience in treating SLE have been associated with SLE outcomes. In-hospital mortality was lower for SLE patients hospitalized at California hospitals with more SLE admissions per year compared to those at hospitals with less experience[71]. Ward found that the risk of in-hospital mortality for SLE patients in New York and Pennsylvania was inversely associated with the average number of SLE patients that the attending physician had recently admitted[72]. The inverse relationship between physician experience and SLE mortality was stronger for non-white than white patients. This suggests that provider volume may be an important, and potentially modifiable, barrier to better long-term outcomes among non-white SLE patients [72]. The association between physician volume and SLE patient mortality was also stronger for those patients without private medical insurance than for those having it, suggesting that for this vulnerable population in particular access to high quality care is paramount[72]. Among lupus nephritis patients, having an attending physician who was highly experienced was associated with a 60% reduction in in-hospital mortality risk[72].

In another study, Ward examined 16751 hospitalizations for patients with SLE and classified 12.3% as avoidable, an indicator of underutilization or poor access to healthcare [73]. Rates of “avoidable hospitalizations”, such as those for pneumonia, cellulitis and congestive heart disease, all potentially avoidable with prompt and correct medical attention and indicative of substandard outpatient care, were lower at medical centers in New York State with high volumes of SLE admissions[73]. These avoidable hospitalizations for SLE patients were most frequent for older patients and for those in the lowest quartile of SES quartile[73]. These findings reinforce the importance of physician and hospital experience in preventing avoidable SLE admissions.

Among 6521 hospitalized SLE patients in South Carolina, African Americans were more likely than whites to experience both in-hospital mortality and mortality after one year following hospital discharge[74]. In South Carolina where 30% of the population is African American, African Americans with SLE had lower levels of education, were more likely to have public insurance, earned lower incomes, had increased hospitalizations and also died at significantly younger ages than their white counterparts. Even after multivariable adjustment for comorbidities, which were more common in African Americans, African American lupus patients had a 15% increased mortality risk compared to whites with lupus[74].

5. Geographic and area-level factors

There is growing literature about the important effects of geographic residence and area-level factors, neighborhood poverty level, population composition, employment, educational level, dwelling type, household and family size, and housing occupancy, on a variety of health outcomes including infectious diseases, childhood asthma, orthopedic surgery, and end stage renal disease[75–80]. In many cases, one's individual behavior may be better explained by the characteristics of one's neighbors than by individual factors.

Investigators from the University of California at San Francisco utilized data from a large geographically, socioeconomically and racially diverse SLE cohort to assess the independent effects of neighborhood poverty and individual SES on SLE outcomes[56]. Both low neighborhood SES and individual SES were associated with increased disease activity, poorer physical functioning, and greater symptoms of depression. The increase in depressive symptoms suggests that SLE patients living in low income neighborhoods have more difficulty dealing with chronic disease, and this likely contributes to decreased self-efficacy for disease management.

Employing the US Renal Data System, Ward examined the influence of area-level SES on the incidence of end-stage renal disease due to SLE, diabetes mellitus and autosomal dominant polycystic kidney disease[81]. He used an area-based measure of SES based on subjects' zip codes of residence, encompassing area poverty, household income, house value, employment and education levels. Among whites, the risk of developing end-stage renal disease from lupus nephritis for those in the lowest compared to highest category was 50–60% higher. For African Americans, however, there was no statistically significant change in risk related to this SES measure. Thus, while this area-based SES measure was associated with SLE renal outcomes among whites, it was not independently predictive among African Americans. When comparing different disease causes of end-stage renal disease, area-based SES had a more important influence on outcomes for SLE renal disease than for polycystic kidney disease, where genetic factors may play a larger role, but less so than for diabetic renal disease, where area SES factors had an even larger influence.

6. Environmental exposures

Factors responsible for the increased incidence and severity of SLE in disadvantaged populations may also be driving increased severity of disease and poorer survival in these groups. As with many complex diseases, environmental exposures likely trigger disease development, in particular in individuals who are genetically predisposed[82]. Disadvantaged groups may have higher rates of incident SLE and of SLE progression due to both genetic and environmental factors. Cigarette smoking and exposure to occupational and agricultural silica, as well as use of exogenous reproductive hormones among women, have been associated with increased risk of developing SLE in epidemiologic studies[83–86]. Smoking is associated with more severe SLE and worse outcomes from lupus nephritis in several studies[87–89], as has hypertension[87, 90, 91]. Differential rates of comorbidities such as smoking, obesity and hypertension may explain some of observed sociodemographic disparities in SLE. Exposures to infectious agents, occupational hazards, pollutants, drugs, dietary, cosmetic or recreational factors that could heighten SLE risk could very likely be related to socioeconomic position.

Conclusion

Alarming sociodemographic disparities in the incidence and severity of SLE have been documented. Their causes are multifactorial and SES-related factors play a large role. The complex effects of SES include access to appropriate medical care with delayed and poorer quality healthcare, poor medical understanding and medication adherence, and lower self-efficacy and confidence in the healthcare system and its providers.

W. E. B. Du Bois prophetically declared at the beginning of this century that, “the problem of the twentieth century is the problem of the color line”[92]. DuBois also wrote, “To be a poor man is hard, but to be a poor race in a land of dollars, is the very bottom of hardships”[92]. Belonging to a racial or ethnic minority group and having low socioeconomic status are significant predictors of increased risk of SLE and poor SLE outcomes even today.

Recent research has identified factors that may contribute to these observed disparities in SLE, including, but not limited to education, adherence, social support, medical insurance type, geographic area of residence, access to high volume hospitals and physicians, and potential environmental exposures. This research suggests we should focus on healthcare access, education and increasing disease awareness and adherence among high-risk patients, concentrating on regular follow-up and adherence to therapy. We should also develop strategic interventions designed to eliminate these disparities aimed at the barriers research has shown to exist. Developing teams of experienced physicians, educators and caregivers, working with patients and their loved ones to strengthen social support, enhance self-efficacy, decrease comorbidities such as smoking, hypertension and obesity, and increase adherence would be a good start [50].

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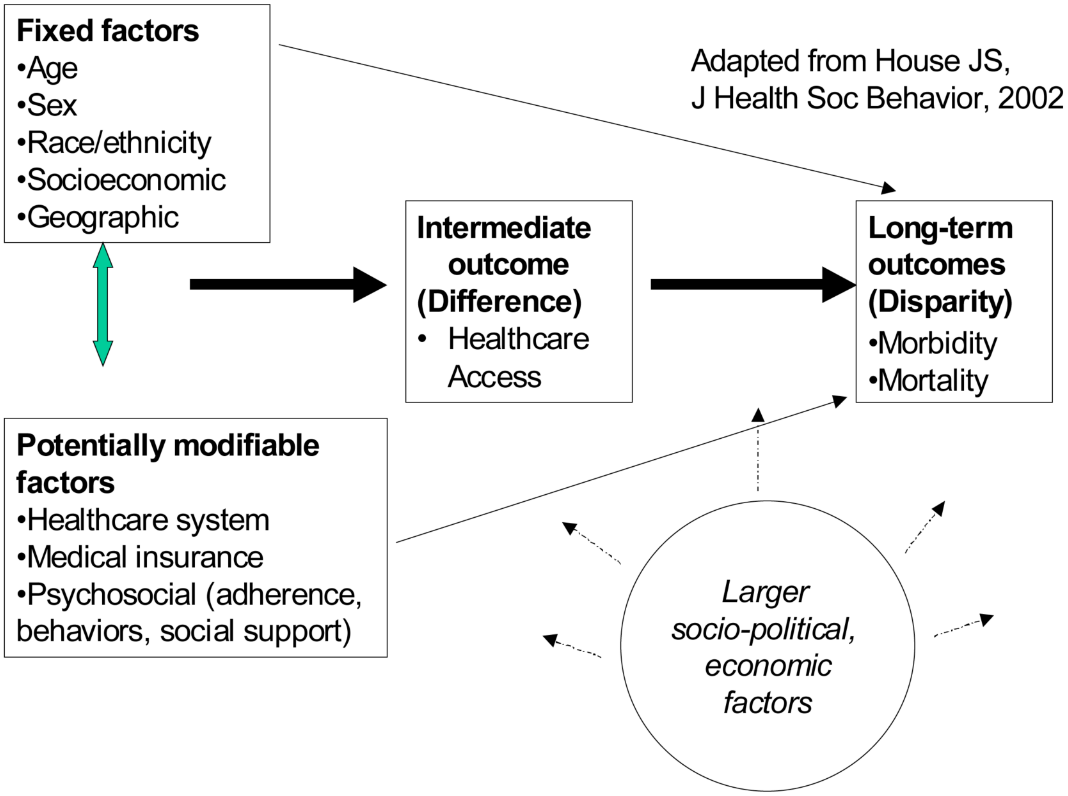

Figure 1.

Conceptual Framework For Understanding sociodemographic Differences and Disparities in SLE

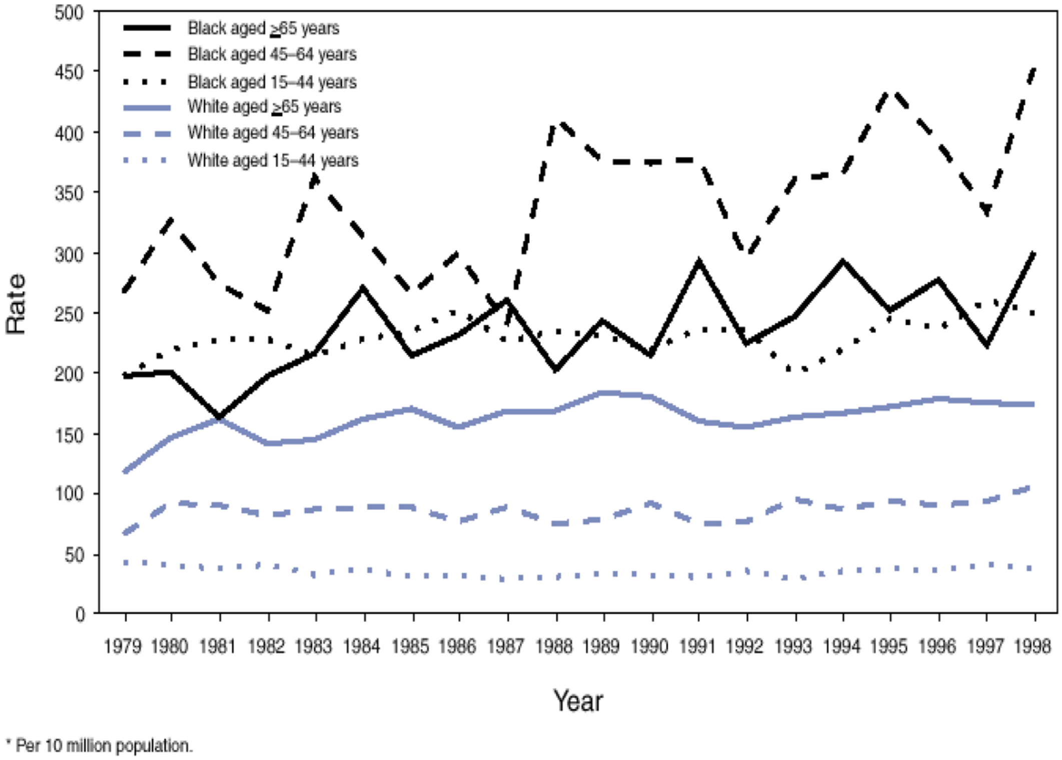

Figure 2.

Systemic lupus erythematosus death rates* among females, by age group and race – United States 1979–1998

*per 10 million population