

Addressing Healthcare Disparities in Autoimmune Disease: A Focus On Systemic Lupus Erythematosus in the USA

by

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Abstract

Autoimmune diseases affect over 22 million Americans and are a class of disease where the immune system that defends the body against infection targets healthy cells. Examples of autoimmune diseases include lupus, diabetes and rheumatoid arthritis. Despite recent advances in treatment options, there remain measurable disparities in outcome. For example African American patients with systemic lupus erythematosus often have more severe outcomes including more severe kidney disease. There remains an unmet need to understand both the biology underlying these disparities as well as addressing the healthcare requirements of these patients. Innovative approaches to community health screens may be a useful method to reduce healthcare disparities in autoimmune diseases. The Center for Closing the Health Gap hosts an annual health expo that provides free health screenings. In this article the results of the kidney screens are presented as well as discussion of interventions that can be taken to address these wider issues of health care disparity.

Introduction

Autoimmune Diseases

Autoimmune diseases encompass a wide range of conditions that include type 1 diabetes, systemic lupus erythematosus (SLE), multiple sclerosis, rheumatoid arthritis and Crohn's disease. Despite the diverse clinical presentations and symptoms all these diseases manifest because the immune system, which is essential in protecting the human body against bacteria and viruses, attacks healthy organs and cells. In type 1 diabetes, the autoimmune reaction leads to the targeted destruction of the pancreatic beta cells that produce insulin. By contrast in SLE, multiple organs throughout the body can be targeted including the skin, kidney, digestive tract and lungs leading to often debilitating disease flares. All these autoimmune conditions have a wide range of disease severity and can cause pain, reduced quality of life, and for some conditions, an increased risk of mortality and long term disability. There are a complex range of factors that contribute to development of autoimmune disease including inherited, that is genetic, as well as environmental influences. Scientific research has transformed the outcome for patients with autoimmune diseases with an increasing range of new therapies available. These treatments vary in their precise mechanism of action but suppress the effects of the immune system to reduce inflammation.

Healthcare Disparities: a Focus on SLE in the USA

It is long been characterized that the greatest rates of SLE occur in women and also in individuals of African descent [1]. The prevalence rates for SLE were recently refined in a study where over 45,000 patients in Georgia, USA were screened across hospitals and specialist clinics including rheumatology, dermatology and nephrology [2]. When adjusted for age, the prevalence rates of SLE were over 9 times higher in women than men (127.6 cases per 100,000 in the population compared to 14.7 cases per 100,000). Black women had the highest rates, at 196.2 cases, with women between the ages of 30 and 59 at highest risk of developing SLE. Furthermore, there was a higher incidence of the more serious clinical manifestations of SLE among black patients, including severe kidney disease where there was a 7-fold greater incidence of end-stage renal disease [2].

The reasons for this are complex. Inherited genetic variations, as well as environmental and social factors are under investigation to reveal causes of these severe complications of SLE. Firstly, there is a higher risk of SLE patients of African ethnicity developing lupus nephritis - an earlier stage of renal disease [3]. A recent study of the genetics of end-stage renal disease in African Americans revealed the gene apolipoprotein L1 strongly impacted the risk of lupus nephritis [4]. The genetic variants that increased risk were nearly absent in European Americans. This exemplifies the role of inherited factors in disparities in SLE severity. When disease was severe enough to require kidney transplantation there were further differences in outcome: patients of African ancestry had a higher transplantation failure rate.

A recent study investigated the reason for this in a large cohort of American patients who received kidney transplants for SLE [5]. Transplanted kidneys that have longer cold storage and more incompatibilities between donor and recipient are more likely to be rejected. This study showed that when known risk factors that predict poor outcome are matched, then there is a similar rate of kidney transplantation failure between patients of European and African ancestry. The authors discuss that in the US population, patients of African ancestry have a higher rate of kidney transplantation from donors of European ancestry resulting in greater organ rejection and that improvement of kidney matching and organ donation among African ancestry patients would be beneficial.

A national study published in 2013, analyzed 23.9 million individuals between the ages of 18-65 across the USA and revealed that locations with the lowest socioeconomic status had the highest SLE prevalence [6]. The authors highlight that there are multiple environmental factors including cigarette smoke, environmental and workplace exposures to air pollution which have been proposed as risk factors that are more prevalent in patients of low income [6, 7]. A study of 982 patients with SLE described that lower income was a factor associated with decreased visits to a specialist rheumatologist [8] and that barriers to accessing this care may exist in these patients. A survey of community health center physician medical directors, who are not rheumatology specialists, showed that 94% would not start an SLE patient on an immunosuppressant therapy [9]. In another study the need for rheumatology specialists was further demonstrated by rheumatoid arthritis, another autoimmune disease. African American arthritis patients were less likely to receive the treatment of disease-modifying antirheumatic drugs (DMARDs) when not seen by a rheumatologist [10]. However there was no significant difference when patients were seen by a specialist rheumatologist.

A recent report shows that a new cost-effective tool called (self-administered Brief Index of Lupus Damage, SA-BILD) to help patients collect data on disease involvement of organs has been validated for use in American patients of African descent [11]. While the SA-BILD should not be a replacement to specialist care, where there are barriers to physician assessment, this low-cost tool may be an asset in monitoring serious SLE disease manifestations.

Given the multi-layered need for addressing health disparities in this article we investigate if access to mobile health screening can bridge the gap for effective diagnosis and disease awareness among patient populations in areas with reduced life expectancy. In patients with SLE one of the serious disease manifestations is impaired kidney function caused by the autoimmune disease reaction. Free, rapid kidney screenings were performed by the Kidney Trust at the one day Center for Closing the Health Gap Expo in 2014. This screening event was designed to benefit American adults with, or at risk of, chronic kidney disease. The goal is to delay or prevent progression from chronic kidney disease to kidney failure. We report the findings of this patient population and discuss if these strategies are appropriate for autoimmune diseases such as SLE.

Methodological Construct

Study Population

Anonymized data were collected from individuals who had mobile kidney screens performed at a one day health event: the 2014 Closing the Health Gap Expo in Cincinnati, Ohio, USA. Data were collected as part of clinical care and all participants gave informed consent to participate in the 2014 Health Expo with local ethical approval provided by hospitals conducting the intervention in accordance with the Declaration of Helsinki [11]. Anonymized data were provided by the Center for Closing the Health Gap and were classified as exempt from human subject research.

Kidney Screening and Patient Demographics

Screenings were performed for blood creatinine levels: an indicator of kidney function. Kidney screen results were categorized as either “normal” or “recommendation” for further consultation by a physician. No primary screening data were used in this study. Body mass index (BMI) data were provided as “normal” or “recommendation”.

Results

Demographics of Individuals with Kidney Screen Data and of the Local Population

Data were collected on 177 individuals who had kidney screenings at the one day event hosted by The Center for Closing the Health Gap in 2014. Of these people, 146 (82.5%) were African American, 117 (66.1%) were female and overall the median age was 52 years. Data from the 2010 census demonstrates 72.4% of residents were African American in the location of the expo [12]. Residents of this neighborhood have a life expectancy at birth of 70.6 which is in the lowest quartile for the city [13] and are a good candidate population for health intervention with mobile health screening.

Outcome of Kidney Screen Data for African American Participants

The analyses in this study are focused on African American individuals, a population at high risk of severe kidney disease in SLE. Individuals at risk of chronic kidney disease include African Americans and individuals over the age of 60. Of the 146 African American patients, age, gender and kidney screening outcome data were available for the vast majority (95%) of data points. There was a wide age range of adults who participated in the kidney screening: participants were aged from 22 to 82 with a median age of 53. Of these patients nearly a fifth of individuals with screening data had a result of “recommendation” to seek further advice from a physician. Without this health screen, these 25 individuals may not have a reason to prioritize seeking further advice from a physician on their kidney function.

Physician Follow-Up Indicated in Greater Percentage of Patients Without Health Insurance

Patients without health insurance to pay for health visits and screenings may be more at risk for abnormal kidney function due to not getting adequate preventative health screenings and clinical care. While there were missing data, of those individuals with a “recommendation” status for their kidney screen a remarkable 41% (7 of 17 with data) did not have health insurance which contrasts with only 24% of those with “normal” kidney screens. This data does not indicate causality but is a notable association between lack of health insurance and poorer kidney health.

Testing for Known Risk Factors of Kidney Disease: Age and BMI

Older age is a known risk factor for an abnormal kidney screening result [14] and was investigated in this population. In the cohort of 25 people with a “recommendation” status for their kidney screen, their age range was not significantly different compared to that of the 105 individuals who had a “normal” kidney screening result. Being overweight or obese is an important risk factor for chronic kidney disease [15]. Body mass index (BMI) is an indicator of body fat content from height and weight. Over half (53.1%) of those individuals with body mass index data had a “recommendation” for further consultation with a physician due to an abnormal BMI. Even though not all people with high BMI had an abnormal kidney screening result, these individuals are at risk for kidney disease.

Discussion

The majority of individuals with kidney screen data in The Center for Closing the Health Gap expo kidney were African American which was unsurprising given the demographics of the neighborhood that the expo was based. The increase in the worse kidney screen results in those individuals who reported a lack of health insurance was striking even with a relatively small cohort. Since these individuals have no health insurance, adequate access to physician follow-up is likely to be limited and further impact on health. In the USA ‘no single system provides insurance for everyone’ [16] which contrasts with other systems such as the United Kingdom’s National Health Service which is ‘free at point of use for anyone who is a UK resident’ [17, 18]. The introduction of the Patient Protection and Affordable Care Act in 2010 was intended to improve access to health insurance in the US [16]. As this study is cross-sectional it was not possible to determine if improvements in access to health insurance have been made since the introduction of the Affordable Care Act 4 years ago. Future investigations will be important to determine if more participants have access to health care in subsequent years.

A major limitation of this research area is that no single test is diagnostic for SLE. A normal kidney screen result does not exclude the presence of lupus as the patient may have other manifestations of SLE which have not impacted on their kidney function. However, for those individuals with a kidney disorder, the possibility of SLE should be noted by the presenting clinician for further investigation. Diagnosis criteria for lupus was developed by the American College of Rheumatology where the presence of 4 of 11 criteria is strong evidence of the patient having lupus [19]. These clinical criteria include: photosensitivity, kidney disorders, abnormal antinuclear antibody (ANA), malar rash. To diagnose lupus according to those criteria an abnormal ANA result is mandatory and can be assessed by a blood test. To facilitate early SLE diagnosis in underserved, at-risk populations mobile health screens that can conduct ANA tests would be beneficial. New guidelines to diagnose lupus have been recently published by the Systemic Lupus International Collaboration Clinics (SLICC) [20]. Under the new SLICC guidelines, kidney screening for proteinuria, which is the presence of protein in the urine, and blood levels of ANA are important for lupus diagnosis. If these tests were more widely available to individuals at risk of SLE, for example innovative ways to enable access through free health screening events; this would be a beneficial step in early diagnosis. Once an individual has been diagnosed with lupus the challenges are great to maximize the chances of a favorable outcome. New tools such as the Lupus Health Passport may have a beneficial outcome for ethnic minority groups [21]. Briefly, the Lupus Health Passport helps SLE patients in several areas including how to identify a lupus flare and take actions to overcome it [21]. Multiple approaches to improve outcome are needed and finding resources to improve healthcare access for all individuals remains a priority.

A review by Thomas et al [22] indicates that to eliminate health disparities requires ‘comprehensive, multilevel interventions’. Several of the proposals for intervention include interactions with the community to identify problems relevant to the target population, and to include ‘culturally appropriate’ lifestyle interventions for preventing conditions such as diabetes and obesity [22]. This is corroborated by a recent study of 29 women with SLE from medically underserved areas who indicated benefits in quality of life where interventions were designed as collaborations between the community and researchers [23]. While there is currently no known way to prevent diseases such as SLE, early diagnosis, effective management of symptoms and appropriate access to healthcare specialists could improve the long term outcome for patients especially for African Americans who are at greater risk of life-threatening outcomes. Achieving health equity for all remains a goal that the US Director of the National Institute on Minority Health and Health Disparities states is “a moral obligation in our society to do what is necessary to improve health”[22].

Conclusions

African American SLE patients are at increased risk of severe disease manifestations. For patients in medically underserved areas, free mobile health screens are an effective way to target populations who would otherwise have inadequate health care. In a one day health screening expo, patients without health insurance were found to have more recommendations to see a physician about their kidney screen results, this may be challenging without health insurance. Although kidney disease is one manifestation of SLE, it is not diagnostic. The possibility exists to modify mobile kidney screening to aid with SLE diagnosis and monitoring of serious disease manifestations. Providing sufficient access to specialist healthcare remains a priority in improving the outcome for all SLE patients.

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