

The meeting of interpersonal and psychosocial needs in the context of clinic encounters

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Abstract

Systemic lupus erythematosus (SLE) is a chronic inflammatory rheumatic disease that is characterized by autoantibody production and multiple organ system involvement. Disease complications and treatment side effects can lead to significant functional and emotional challenges. Unmet needs related to adverse psychological sequelae have often included patients' negative perceptions of their health care experiences. This may be particularly important to address in African American patients since they are at highest risk for SLE and dually exposed to a unique trajectory of stressors throughout the life course, this paper details a series of routine clinic encounters between lupus patients and rheumatologists at the Medical University of South Carolina (MUSC). The MUSC team can serve as a model for other healthcare providers and practices in their demonstrated excellence in meeting needs with proven connections to the psychosocial well-being of their patients.

Abbreviations: SLE: Systemic Lupus Erythematosus; MUSC: Medical University of South Carolina

Introduction

Systemic lupus erythematosus (SLE) is a chronic inflammatory rheumatic disease that is characterized by autoantibody production and multiple organ system involvement, including a high prevalence of polyarthritis [1-4]. SLE can lead to an array of clinical presentations, making it difficult to diagnose early (Heinlen *et al.*, 2007) [5]. In the United States, over the past four decades, SLE incidence has increased and claims one of the highest mortality rates among rheumatic diseases [6,7]. Treatment for SLE patients can be complex and potentially toxic, yet some of these treatments have been shown to improve prognosis (Demas and Costenbader, 2009) [8]. SLE can result in extreme joint discomfort, fatigue, and diminished psychosocial functioning [9-12]. Complications from the treatment of SLE are also common, especially infections due to the use of immune suppressing medications, and adverse effects of corticosteroid use such as weight gain, osteoporosis, osteonecrosis, and accelerated atherosclerosis [13,14]. Many of these side effects can lead to significant functional and emotional challenges [9]. Patients often experience a high degree of psychological symptoms, including anxiety, depression, mood disorders, and decreased health-related quality of life [15-20].

Unmet needs related to these psychological sequelae can be interpreted in reference to patients' perceptions of their health care. In a qualitative study of patients with SLE in the United Kingdom, investigators illustrated the connection of unmet needs related to psychosocial well-being to unmet needs related to health services and health information [21]. Some observations were that participants did not know which health care providers could help them with psychosocial needs and they did not believe that health care professionals fully understood the psychosocial impact of SLE [21]. For patients with SLE, the perception of not having their experience understood by others may lead to social isolation and otherwise negatively affect personal and professional interactions [22], and these trends may be more

pronounced in African-Americans who face documented incidences and perceptions of discrimination and racism. In a study of the unmet needs of patients with SLE, Danoff-Burg and Friedberg [18] found that African-American patients were more likely than white patients to have higher levels of unmet needs related to health services and information. Domains included issues such as getting adequate information from medical staff about treatment side effects, having access to telephone support and advisory services, and needing assistance with knowing when to see the doctor when changes in symptoms occur [18].

In addition to managing disease-specific stressors, it has been suggested that African-Americans are exposed to a unique set of risk factors that lead to a pattern of cumulative disadvantage over time. High rates of unemployment, poverty, violent crime, incarceration, and homicide among African-American adults reflect this accumulation of disadvantage at multiple transition points during their development and across the life course [23-35]. It is highly likely that early childhood exposure to segregated, economically impoverished neighborhoods created by institutionalized racism adversely affects child health and growth and sets the Black child on a low education and economic trajectory that increases the risk of poor physical and mental health in adulthood [23]. Additional stressors include deprivation of resources and facilities, differential exposure to health risks in the physical environment because of economically disadvantaged neighborhoods

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Key words: African-Americans, Interpersonal, Holistic, Psychosocial, Systemic lupus erythematosus, Unmet needs

Received: November 22, 2015; **Accepted:** December 17, 2015; **Published:** December 20, 2015

and poor quality housing, higher costs of goods and services in deprived areas, as well as roles of social networks and social capital, which often give rise to peer pressure against academic achievement and in support of crime and substance use [25,26,28,29]. Due to the exposure of African-Americans to a unique trajectory of stressors throughout the life course, it may be critical to address modifiable risk factors for SLE that may be further exacerbated by this trend in an effort to improve health status and reduce health disparities in this high risk group.

Results

Observations of the team of rheumatologists that care for the more than 1000 patients with lupus currently being followed at the Medical University of South Carolina (MUSC) weekly Lupus Clinics, revealed a group passionate about and committed to the holistic health of their patients, including not only careful assessment of symptoms and courses of treatment, but also thoughtful attention to and consideration of the lives and needs of their patients outside of the clinic encounter.

With regard to health information needs, providers took the time to explain treatment mechanisms, various issues symptoms could indicate, and expected outcomes. It was obvious that this was usual as many patients knew medical terminology, various conditions, things to be looking out for, how to assess symptoms, and when next appointments were. One patient sent pictures of rashes ahead of her visit and her doctor commented that they were impressed with her engagement in her disease and treatment. Patients also felt comfortable asking any kind of question, from foods to be avoiding to whether they could wear a girdle. This type of ease was also evident in the way patients felt comfortable enough with providers to joke and share milestones and life events. One patient excitedly told a provider about a recent wedding and new grandchild, another talked about pursuing her Masters in mental health counseling. Patients were noticeably encouraged by doctors' memory and inquiries about family members and details of their lives they may have shared during previous visits. One doctor asked a patient about her daughter and the patient talked about her daughter beginning college. Another doctor asked about a patient's business venture and brother who recently had a transplant and sister who donated the kidney. Still another asked a patient if she was excited about teaching and about her mom and their routine of eating out on the way home from clinic visit. Doctors also shared details of their own lives with patients (one patient asked her doctor questions about work he was doing outside of the hospital) and joked with them in a warm and friendly way. One doctor joked with a senator's wife about politics and another doctor came in and teased a patient about looking terrible, which made her smile.

Providers clearly conveyed an understanding and consideration of life circumstances of patients. One doctor noticed and inquired about a patient's insurance status and the patient shared that she had left her job, leaving her without insurance coverage and unable to pay for recommended labwork. The doctor recommended speaking with the hospital financial advisor and referred the patient to a discount program for assistance with labs. The doctor also suggested low-cost alternative(s) to the patient's regimen. Another doctor noticed a blood pressure cuff on a patient's chart, and upon asking about it, the patient shared that medicare doesn't cover it so she had to let it go. The doctor also asked about physical therapy goals and the patient said she just wants to get her legs moving. The doctor wrote a physical therapy referral and mentioned Arthritis Foundation exercise classes for when physical therapy coverage runs out. The doctor asked the patient about her computer capacity for accessing her online chart and the patient

talked about her son's playful teasing for how technologically behind she is.

A recurring theme throughout encounters was the desire of patients to have a "normal" life and providers conversed with them in such a way as to convey respect, sincere concern, and willingness to do whatever they could for this to happen. Doctors attempted to simplify medication regimens whenever appropriate and safe, and assured patients that all potential interactions are considered. One patient shared about wanting to slim down to "snag a man" and joked about online dating. Another patient had one child, a recent miscarriage, and is currently trying to get pregnant, so voluntarily taking folate. Yet another patient, excited about her pregnancy, offered to show the doctor her ultrasound and expressed interest in breastfeeding. The doctor explained to her that if she were doing well after birth, she could breastfeed for 6-12 months, but if not doing well, she wouldn't be able to. The patient was aware that she would probably experience a flare after birth, and the doctor shared the possibility of the baby's response to pain medications including risks of withdrawal and autism.

Discussion

Although such natural response to documented unmet needs is something that can't be taught and obviously inherent to the characters of this group of providers, the MUSC team can be a model for other healthcare providers and practices in their demonstrated excellence in areas of health services and health information, understanding the psychosocial impact of SLE and the experiences of their patients, and providing adequate information about treatment side effects, ancillary services, and when to see the doctor when changes in symptoms occur, which all contribute to the meeting of needs with proven connections to the psychosocial well-being of patients.

Funding information

Research reported in this publication was supported by the National Institute of Arthritis And Musculoskeletal And Skin Diseases of the National Institutes of Health under Award Number K01AR060026. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Competing Interests: The author declares that she has no competing interests.

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