

Perceptions of Care and Illness of Patients with Systemic Lupus Erythematosus and adherence to therapy – a qualitative study

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RESEARCH QUESTION: A qualitative study in New York, NY, aims to understand if there are mitigating belief systems and alternative treatment modalities in the lives of patients with SLE that affect adherence to treatment and medical visits.

BACKGROUND

Although mortality rates can be reduced with treatment adherence, studies among SLE patients show high rates of nonadherence to medications. A qualitative study with 33 interviews show that nonadherence was enhanced by the “belief that lupus could and should be controlled using alternative methods” and “the belief that long-term use of drugs was not necessary.” This research conducts qualitative surveys to gauge patient understanding of their own complex disease, whether they are aware of or have implemented alternative treatment modalities, and whether this affects their attitudes towards the prescribed treatment course.

DESCRIPTION OF ORGANIZATION

The Herman “Denny” Farrell Clinic is a Community Health Clinici located in Upper Manhattan of New York City. It is a part of New York Presbyterian Hospital’s Ambulatory Care Network that aims to reduce health disparities through its programs.

OBJECTIVES

Interviews were conducted with the aims to (1) identify the impact of systemic lupus erythematosus (SLE) on patients’ lives and their beliefs and perceptions about the illness, their care, and course of treatment; and (2) understand if there are mitigating belief systems and alternative treatment modalities at play that affect adherence to treatment and medical visits.

FINDINGS

FACTORS THAT NEGATIVELY AFFECTED TREATMENT ADHERENCE	
Theme	Description
Aversion to adverse side effect profile of medication.	Medications with immediate and severe side effects, like mycophenolate and GI upset, were more prone to reduced compliance.
Poor communication between physician and patients.	The limited time in the appointment sessions and the lack of follow up questions on the doctors’ part contributed to patient dissatisfaction and distrust. Rushed appointments created a sense that the physician did not listen, understand, or was limited in the management of the patient’s concerns. This produced doubts about the necessity of taking the medications as prescribed.

FACTORS THAT POSITIVELY AFFECTED TREATMENT ADHERENCE	
Theme	Description
Drugs with little to no immediate adverse effects showed complete adherence.	Both patients showed 100% adherence to hydroxychloroquine, which has minimal immediate adverse effects in most people. It is worth noting that both patients took the drug regularly as prescribed despite perceiving <i>no</i> benefit from taking hydroxychloroquine.
Fear of worsening outcomes.	Discontinuing certain medications, only to suffer flares of disease, encouraged subsequent adherence to the medications

METHODS

Patients from the Farrell Clinic were recruited with the help of physician referrals. We set out to recruit eight women ages 18-65 who have been diagnosed with SLE. We were able to recruit two women to the study in the limited study timeline. After explaining the purpose of the study and obtaining consent, a 20-60 minute interviews were conducted via Zoom or a phone call. Each interview followed a structured outline, lasted ~30-60 minutes, and was recorded. After the interviews were conducted, the data was transcribed by the interviewer and examined for emerging themes.

Where side effects of a newly prescribed drug are a concern, expectations and management options should be thoroughly discussed with the patient. Conversations that set up expectations in advance of what to expect every time a new drug with significant side effects to consider may promote patient adherence and the therapeutic relationship.

DISCUSSION

This study is a work in progress and all current reporting in this presentation is based on preliminary findings. Our study suggests that the absence of education on the function or potential side effects of the drugs were poor indications of future drug adherence. Future quantitative studies might be performed on a larger sample size to assess the significance of this association. Where side effects of a newly prescribed drug are a concern, expectations and management options should be thoroughly discussed with the patient. Conversations that set up expectations in advance of what to expect every time a new drug with significant side effects to consider may promote patient adherence and the therapeutic relationship.

REFERENCES

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