SLE FLARES FROM THE PATIENT PERSPECTIVE: WHAT PATIENTS DISCUSS IN AN INTERNET FORUM
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Background
- Systemic lupus erythematosus (SLE) is a multi-system inflammatory autoimmune disease influenced by a variety of factors, with diverse clinical manifestations affecting multiple organ systems and variable long-term outcomes for patients (Masarwa, et al. 2012).
- Patients with active SLE experience musculoskeletal and mucocutaneous manifestations, including joint pain and swelling, skin rash, and fatigue (Hoffway, et al. 2014).
- Some studies report that flares in disease activity contribute to poor health-related quality of life (HRQoL) in patients with SLE (Oua, et al. 2013).
- Information on the diversity of lupus symptoms and the symptom experience during flares is based primarily on clinical assessment rather than on patient reports.
- Evidence of the agreement between clinical measures of disease activity and patients’ perceptions of their own disease is limited.

Objective
- To identify the key aspects of the SLE flare experience as spontaneously described by patients in their own words.

Methods
Data source
Forum posts (text entries) of patients self-reporting a SLE as a diagnosis were collected from PatientsLikeMe, an online health-information sharing platform which allows patient members to learn from each other’s disease experiences.

Sample
Forum posts were selected for analysis based on the following criteria: 1) posted by a patient with SLE, 2) posted in the immune, infections, and inflammatory forum, 3) contained the words “flare” and 4) posted within the past 5 years (July 1, 2010 through July 1, 2015). Demographic and condition data was obtained from self-reported information on patient profiles.

Analysis
Directed content analysis of posts
A directed content analysis was performed on posts by 67 members of PLM meeting inclusion criteria for the sample. Directed content analysis builds on prior theory about the subject matter to guide the development of an initial coding framework that is then applied to the text (Hsieh, et al. 2005). New codes are added, modified, or combined as analysis continues.

Using directed content analysis, broad themes for symptoms and consequences were initially identified based on a literature review. Next, posts were read in full and additional subcategories for coding themes were developed. To increase validity, the coding scheme was reviewed by a physician to ensure codes made sense from a clinical standpoint, including realignment of codes under broader themes. The final coding scheme was applied to the text to quantify the codes using ATLAS.ti for Mac, Version 10.3.18(15).

Results
A total of 99 posts from 67 patients were analyzed.
- Patients were mostly female (95.5%), White (71.4%), and from the United States (89.8%). Average age at last login was 45.2 years old with range from 22-68.
- Number of comorbid conditions was 7.5 (Table 1).
- The most common comorbidities reported by patients included fibromyalgia (n=28, 41.8%), rheumatoid arthritis (n=17, 25.4%), migraine (n=11, 16.1%), Sjogren’s syndrome (n=13, 19.4%), hypothyroidism (n=12, 17.9%), major depressive disorder (MDD) (n=9, 13.4%), and gastroesophageal reflux disease (GERD) (n=9, 13.4%) (Table 2).
- In these posts, patients shared information in general categories of symptoms (n=39, 58.2%), medications (n=28, 41.8%), comorbidities (n=27, 40.3%), consequences (n=23, 34.3%), triggers (n=17, 25.4%) and flare duration (n=15, 22.4%) (Table 3). Figure 1 includes samples of patient quotes describing the SLE experience.

Conclusions
- A flare is a cluster of symptoms which usually includes pain and fatigue at a minimum. Figure 2 includes samples of patient quotes describing the experience of a flare.
- Specific symptoms most frequently discussed in the context of flares were general pain (n=18, 27%), joint pain (n=14, 24%), rash (n=15, 22%) and fatigue (n=11, 16%) (Figure 3).
- Flare duration (n=15, 22.4%) was widely variable in this sample, ranging from days to years. Several patients commented on the unpredictability of flare duration, confusion over how long a flare could last, and difficulty distinguishing between flare symptoms and symptoms of self-reported comorbid conditions. Figure 4 includes samples of patient quotes describing flare duration and symptoms.
- The most commonly mentioned comorbidities in the context of flare included fibromyalgia (n=12), rheumatoid arthritis (n=7), Raynaud’s phenomenon (n=4), migraine (n=4), and Sjogren’s syndrome (n=3) (Table 4).

References