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Understanding the disease burden and unmet needs among patients with cutaneous lupus erythematosus: A qualitative study[☆,☆☆]

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ABSTRACT

Background: Cutaneous lupus erythematosus (CLE) is a rare dermatologic autoimmune disease marked by photosensitive lesions that can vary in appearance depending on the subtype. The extent to which CLE affects a patient's quality of life (QoL) has not been fully characterized. Focus groups were conducted to explore patients' perspectives of how CLE has affected their lives and to understand the unmet needs in regards to CLE treatment and care.
Methods: This qualitative study involved three focus groups with a total of 19 patients with CLE. A moderator guide containing open-ended questions was used to assess how CLE affects overall QoL. The focus groups were audio-recorded with notetaking. Data were content-analyzed to identify emergent themes.
Results: Four themes emerged as important to patients with CLE: disease sequelae, social interactions, functioning, and unmet needs. Most patients reported decreased QoL due to signs and symptoms such as dyspigmentation and scarring. Having CLE negatively affected patients' mental health and personal relationships and led to negative coping strategies, such as recreational drug use. Issues related to body image were also elicited by patients. Patients cited unmet needs including lack of treatments to improve chronic skin lesions of CLE and inadequate patient education on living with CLE.
Conclusions: Providers can look for signs of QoL impairment in patients with CLE by asking questions related to body image, mental health, social isolation, and coping mechanisms. Future QoL measures can include the effect of CLE-specific attributes such as scarring and dyspigmentation to empower patients' voices in determining therapeutic efficacy in future clinical trials. Findings from our study have added a new understanding of daily experiences that were elicited directly from patients with CLE.

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Introduction

Cutaneous lupus erythematosus (CLE) is a chronic and rare dermatologic autoimmune disease that affects more than 200,000 adults in the United States (Durosaro et al., 2009; Jarukitsopa et al., 2015). CLE disproportionately affects more women than men (Klein et al., 2011; Vasquez et al., 2013). The prevalence of CLE ranges from 70.4 (Jarukitsopa et al., 2015) to 73.2 (Durosaro et al., 2009) per 100,000 with an incidence rate that ranges from 4.2 (Jarukitsopa et al., 2015) to 4.3 (Durosaro et al., 2009) per 100,000.

Treatment options available to patients with CLE are limited due to toxicities (Klein et al., 2011). Common symptoms experienced by patients with CLE include photosensitivity, itching, burning, and alopecia (Eastham and Vleugels, 2014; Hansen and Dahle, 2012). These manifestations vary on the degree of severity and persistence depending on the stage and progression of the disease. Painful skin lesions and disfigurement are considerable sources of morbidity among patients with CLE (Kole and Ghosh, 2009). Studies have reported that patients with CLE fare worse than their counterparts with other dermatological conditions such as acne or nonmelanoma skin cancer (Klein et al., 2011; Vasquez et al., 2013) and experience

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a high burden of psychiatric morbidity, especially anxiety and depression (Achtman et al., 2016; Ferraz et al. 2006; Ishiguro et al., 2014).

Because patients' perceptions can differ from clinicians', it is important to use subjective measures, such as patient-reported outcomes (PROs), to capture quality of life (QoL) in patients (Ogunsanya et al., 2017). However, current QoL measures do not capture all issues relevant to CLE because patients with CLE were not well represented in the development of the current instruments (Chren et al., 1996; Finlay and Khan, 1994). For example, the Skindex (Chren et al., 1996), a commonly used QoL questionnaire for skin diseases, lacks questions that address concerns unique to patients with CLE such as avoidance of sun exposure. To improve assessment of therapeutic efficacy in CLE, a better understanding of the disease burden of CLE is required.

Little is known about the subjective experiences of patients with CLE. Such information would be vital for providers to optimize patient care, advise patients on appropriate coping strategies, and develop better PROs. Thus, focus groups (FGs), a well-known approach to elicit perspectives from patients (Rabiee, 2004), were used to explore patients' views on how CLE has affected their lives and the unmet needs with regard to CLE treatment and care.

Methods

Patients were recruited via the University of Texas (UT) Southwestern Cutaneous Lupus Registry. Patients from this registry were invited to participate in the study by phone, e-mail, or in person. Due to concerns with regard to transportation to the data collection site at the UT Southwestern Medical Center, only patients who lived in the Dallas-Fort Worth metroplex were contacted.

Inclusion criteria included patients who had a diagnosis of CLE, were age ≥18 years, and were able to understand written and spoken English. The institutional review boards at UT Austin (2015-09-0041) and UT Southwestern (STU 102015-056) approved this study. Participants received a $50 VISA gift card for their time.

Data collection

FGs were utilized to a) better understand the impact of CLE on patients' lives within the context of lived experiences (Rabiee, 2004) and b) build upon the limited knowledge of issues that are relevant to PRO measures in CLE (Wackerbarth et al., 2002). To this end, three FGs were conducted in February 2016. Two trained individuals experienced in qualitative interviews served as the moderator (M.E.O.) and assistant notetaker (D.L.).

FG discussions were audio-recorded and transcribed verbatim (M.E.O., C.M., and F.I.) for data analyses. After verbal consent had been obtained, patients completed a brief demographic survey (e.g., age, sex, years since diagnosis, race/ethnicity, and smoking status) for descriptive purposes. Patients then verbally answered questions about CLE's impact on their QoL and unmet needs with regard to treatment and management (Table 1). FGs were conducted until the point of saturation was reached.

Data analysis

Demographic responses were analyzed using descriptive statistics (e.g., frequencies, means, and standard deviations) on SPSS version 23. FG transcripts were reviewed and content-analyzed to identify emerging themes related to overall QoL using Braun and Clarke's (2006) approach for content analysis. The first step in this process was familiarization with the data through repeated active readings of the entire transcript prior to identification of possible patterns and codes. Then initial codes were derived by working systemically through the entire data set to identify concepts that could be collapsed to form recurring patterns (themes). Validity checks were conducted throughout the data analysis by checking and rechecking the concepts. Using topic coding, recurring concepts and phrases were grouped into codes, and subthemes were placed under overarching themes/categories. The themes were refined, categorized, and renamed in a meaningful way. Qualitative data analysis was supported through the use of Dedoose Version 6.1.18, 2015.

To ensure accuracy and reliability of the identified themes, three coders (M.E.O., F.I., and C.M.) independently pretested the definitions of the themes/categories by thoroughly reviewing the transcripts. Results were compared among the three coders, and any coding discrepancies were resolved through discussion. The final themes, subthemes, and representative quotes were presented to the research

Table 1
Focus group discussion guide

Understanding the impact of CLE on patients' lives
1. Briefly tell me/write down all the ways that CLE affects you.[a]Probe: Kindly tell me how CLE affects your work life, daily activities, social life, personal relationships, leisure activities, or any other ways possible. Also tell me the impact of CLE on photosensitivity, alopecia, and your mental health.
2. Which other areas can you think of that has been affected by CLE?

Unmet needs with regard to CLE treatment and care
3. Thinking about your treatment for CLE, what types of issues are important to you? Why is that?
[a]Probe: What attributes would you like to see in a future therapy for CLE that isn't currently available in your current regimen?

CLE, cutaneous lupus erythematosus
[a] Probes were used as necessary and appropriate.

Table 2
Braun and Clarke (2006) thematic analysis guidelines and role of authors

1. Familiarizing yourself with your data	The accuracy of the transcripts was checked. Transcripts were read by M.E.O., C.M., and F.I., and initial thoughts were written down and discussed as a team.
2. Extracting initial codes	After transcription, the FG data were de-identified into Dedoose (Dedoose Version 6.1.18, 2015), where the data were analyzed for themes All transcripts were coded systematically using inductive methods. The three interviews were coded by M.E.O., C.M., and F.I., and inconsistencies were resolved by rereviewing the transcripts until a consensus was reached. Using Dedoose, representative quotes were added to the initial codes extracted.
3. Generating themes	From the initial codes extracted by M.E.O., C.M., and F.I. and by thorough review of the transcripts, meaningful themes were created. A preliminary description of the main and subthemes was made.
4. Reviewing themes	To achieve this step, M.E.O. checked the preliminary description of themes with the original data (transcripts). Inconsistencies were discussed in the research group. The themes and subthemes were also rereviewed by M.E.O., C.M., and F.I.
5. Defining and naming themes	The thematic content was created by M.E.O. initially, who then worked with C.M. and F.I. to generate the storyline. The results generated from this step were presented to qualitative research experts and cutaneous lupus erythematosus health care providers to obtain feedback on refining the output.
6. Producing the report	The first draft of the report was written by M.E.O. who, together with F.I. and C.M., also selected representative quotations to illustrate the themes. B.F. and C.B. reviewed the draft and provided input on necessary adjustments to be made. Finally, all members of the research team reviewed the report for accuracy, and their responses were recorded.

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