Quality of Life in Patients with Cutaneous Lupus Erythematosus (CLE)
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Background
- Cutaneous Lupus Erythematosus (CLE) is a chronic dermatologic autoimmune disease marked by photosensitive lesions that can vary in appearance depending on the subtype.  
- CLE is not fully understood, but it is speculated that genetic, hormonal, immunological abnormalities (e.g., cytokine, B-cells and T-cells dysfunction) and environmental factors (especially ultraviolet irradiation) contribute to its pathogenesis.  
- While dermatologic diseases, in general, have been shown to have a significant impact on quality of life, there is limited information as to the extent in which CLE affects a patient's quality of life.  
- Studies have reported that patients with dermatologic diseases are not only distressed about the disease itself but also how they are perceived by others as result of their appearance.  
- Consequently, dermatologic patients may experience higher rates of mental health conditions, especially anxiety and depression, with a prevalence ranging from approximately 20-40%, compared to 11-30% seen in the general population.  
- CLE is generally perceived as being less severe and having a better prognosis than systemic lupus erythematous; chronic forms of CLE, however, can last for several years and may lead to severe disability and permanent disfigurement.  
- Given the impact of CLE on the quality of life of patients and the increasing prominence of patients' involvement in their own care, it is important to assess outcomes from the patients' perspectives.

Purpose
The purpose of this study is to better understand the impact of CLE on patients' lives.

Study Objectives
- Describe focus group (FG) participants: 
  - Demographics and personal characteristics
- As part of the initial development of a CLE-specific QoL measure, a qualitative approach was utilized to:
  - Explore, describe and clarify the patients' perspective of how CLE has impacted their lives, and
  - Examine patients' perceptions of unmet needs regarding CLE treatment and care.

Methods
- Study was approved by The University of Texas at Austin IRB and the University of Texas Southwestern IRB.
- Inclusion Criteria
  - CLE diagnosis
  - Adults, age ≥ 18 years
  - English-speaking
  - Able to provide informed consent
- Study Site
  - Outpatient, University dermatology clinic in Dallas, TX
- Participants
  - Purposeful sample of patients with CLE
    - Recruited via a cutaneous lupus registry using emails or phone numbers
- Data Collection
  - Pre-FG Survey
    - Questions on demographics/personal characteristics, such as age, gender, years since diagnosis, race/ethnicity, smoking status.
  - Focus group sessions
    - Three FGs (approx. 1.5 hours long)
    - Sessions were audio-recorded with notetaking
    - Moderator guide
    - Open-ended questions to assess how CLE affects overall QoL, including work life, daily activities, social life, personal relationships, and leisure activities as well as the impact on photosensitivity, alopecia, mental health, and treatment outcomes.
    - After FGs, participants were given pamphlets on lupus information, as well as information on support groups available for lupus
    - Incentives
      - $50 VISA gift cards
    - Incentives
- Recruited via a cutaneous lupus registry using emails or phone numbers
- Participants
  - Outpatient, University dermatology clinic in Dallas, TX

Results
Several major themes emerged from the FGs that concentrated on issues that are important to patients living with CLE.

Data Analyses
- Descriptive Analysis
  - Demographic/personal characteristics were analyzed using descriptive statistics (e.g., frequencies, means and standard deviations using SPSS).  
- Qualitative Analysis
  - The transcripts were content-analyzed to identify emerging themes related to overall QoL.  
  - Using Braun and Clarke's approach for content analysis, categories were created and counted by counting the frequency of similar words and phrases throughout the transcript.
  - Inter-rater reliability
    - Two coders independently prototyped the definitions of the category by thoroughly reviewing the transcripts.
    - Compared codes generated and corroborated the frequency of each theme.
    - Generated themes will be used to populate the CLE-specific QoL measure. The data was analyzed using Dedoose.

Discussion/Conclusion
- Eleven themes emerged as important to patients with CLE: physical effects; mental effects; social effects; medication effects; disease effects; coping mechanisms; social dynamics; diagnosis; odyssey; cutaneous effect/body image; photosensitivity, and unmet needs.
- Most patients reported a negative impact of CLE on their lives, however, some patients reported some positive aspects to having CLE.
- Results from this study provide pharmacists, physicians and other healthcare practitioners a better understanding of the impact of CLE on patients' QoL.
- Treatments that improve CLE manifestations, as described by participants, may offer considerable benefit.

Study Limitations
- Social desirability bias – this may have impacted patients' responses to please the moderator and/or other patients.
- It is possible that the universe of issues that are important to patients with CLE were not captured.

Selection bias – FG participants did so voluntarily. Also, patients who were motivated to show up were more likely to have severe skin disease than those who did not.

References