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Self-Management and Adherence in Childhood-Onset Systemic Lupus Erythematosus: What Are We Missing?

Onengiya Harry, MD, MPH¹, Lori E Crosby, PsyD^{2,3}, Amiee W Smith, PhD², Leslie Favier, MD, MSc¹, Najla Aljaberi, MD¹, Tracy V Ting, MD, MSc, RhMSUS^{1,3}, Jennifer Huggins, MD^{1,3}, and Avani C Modi, PhD^{2,3}

¹Division of Rheumatology, Cincinnati Children's Hospital Medical Center, Cincinnati, OH.

²Division of Behavior Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, Cincinnati, OH.

³College of Medicine, University of Cincinnati, Cincinnati, OH.

Abstract

Objective: The aim of this study is (1) characterize factors influencing self-management behaviors and quality of life in adolescent and young adult (AYAs) patients with cSLE and (2) identify barriers and facilitators of treatment adherence via focus groups.

Methods: AYA with cSLE ages 12–24 years and primary caregivers of the adolescents participated in this study. Recruitment occurred during pediatric rheumatology clinic visits at a Midwestern children's hospital or the hospital's cSLE active clinic registry. Information about disease severity was obtained from patient health records. Pain and fatigue questionnaires were administered. Descriptive statistics were used to analyze data.

Results: Thirty-one AYA patients and caregivers participated in six focus groups. Ten major themes emerged from sessions; four were expressed by both the AYA and caregiver groups: knowledge deficits about cSLE, symptoms limiting daily function, specifically mood and cognition/learning, barriers and facilitators of adherence, and worry about the future. Themes unique to AYA participants included: symptoms limiting daily functioning – pain/fatigue, self-care and management, impact on personal relationships, and healthcare provider communication/relationship. For caregiver groups unique themes included: need for school advocacy, disruption of family schedule, and sense of normalcy for their adolescent.

Conclusion: AYAs with cSLE face a life-long disease characterized by pervasive pain, fatigue, organ damage, isolation – social and/or physical, and psycho-socio-educational challenges. This study confirmed that continued psychosocial support, health information education, adherence interventions, and personalized treatment plans are necessary to increase self-management and autonomy in AYA with cSLE.

Address for Correspondence: Onengiya Harry, MD, MPH, FAAP, Clinical Fellow, Division of Rheumatology ML 4010, Children's Hospital Medical Center, 3333 Burnet Avenue, Phone # (513) 803-1979, Fax # 513-636-5990, Onengiya.Harry@cchmc.org.

DECLARATION OF CONFLICTING INTERESTS

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Keywords

Systemic Lupus Erythematosus; Renal Lupus; Adherence; Self-Management; Childhood-Onset SLE

Systemic lupus erythematosus is a chronic, autoimmune multisystem inflammatory disease that is associated with significant morbidity and mortality ¹. With an incidence of 0.3–0.9 per 100,000 children/year and a prevalence of 3.3–24 per 100,000 children ², childhood-onset systemic lupus erythematosus (cSLE) accounts for 10–20% of all patients with SLE. Typically, cSLE has a more severe clinical course than is seen in adults, with a higher prevalence of lupus nephritis, hematologic anomalies, photosensitivity, neuropsychiatric, and mucocutaneous pathology ^{2–4}. A major contributor to negative outcomes in patients with cSLE is poor adherence (i.e., the extent to which an individual's behavior matches treatment regimens) to therapeutic regimens ^{5–7}.

Children with cSLE have complex treatment regimens, including multiple medications, sun protection, and physical/occupational therapies. Despite symptom improvement from newer immunosuppressive medications, only 50–60% of patients take medications as prescribed^{8, 9}. Unfortunately, poor adherence is associated with increased morbidity, mortality, health care utilization, health care costs, and unnecessary medication changes ^{7, 10}. Addressing non-adherence in individuals with cSLE is important because, compared to adult onset SLE (aSLE), they have a more severe, and possibly prolonged disease course with more disease-related organ damage ¹¹.

Understanding the lived experience of adolescents and young adults with cSLE is an important first step in developing interventions to aid in self-management and adherence. Identifying factors that influence participation in age-appropriate activities (e.g., school, work, self-care), as well as those that contribute to self-management (e.g., taking medications) is critical ¹². For adolescents with rheumatic diseases broadly, adherence barriers include forgetfulness, more than three drugs, financial difficulties, personal problems, and/or refusal ^{9, 13}; however, it is unclear if these barriers translate to adolescents and young adults with cSLE. For example, multiple cSLE medications have strict administration instructions that may make adherence difficult compared to other conditions. Studies have demonstrated both common (e.g., forgetting⁹) and unique barriers (e.g., worry about future consequences of taking biologics for juvenile idiopathic arthritis ¹⁴) across diseases. These barriers can have variable influence on outcomes including adherence, symptoms, and health-related quality of life ¹⁵. Adherence and self-management barriers are often stable and unlikely to improve without interventions, which are lacking for adolescents and young adults with cSLE.

Assessing perceptions of living with and managing lupus could shed light on ways to improve quality of life and self-management skills of these adolescents and young adults. Qualitative research methods allow for a deeper exploration of the complicated, multifaceted issue of self-management in cSLE that may not be readily elicited by direct, closed-ended quantitative methods ¹⁶. Thus, the objective of the current study was to (1) characterize factors influencing self-management behaviors and quality of life in adolescents and young

adults with cSLE and (2) identify barriers and facilitators of treatment adherence via focus groups. The long-term goal is to develop tailored evidence-based self-management interventions.

2. Patients and Methods

2.1. Participants and recruitment

Study participants included adolescents with cSLE ages 12–17 years, their primary caregivers, and young adults with cSLE ages 18–24 years. Participants were recruited during routine pediatric rheumatology clinic visits at a Midwestern children's hospital or from the hospital's cSLE active clinic registry. Inclusion/exclusion criteria were: 1) confirmed diagnosis of cSLE via chart or registry review, 2) patient between ages 12 and 24 years 3) English-speaking, and 4) no significant developmental delay or cognitive dysfunction (i.e. autism spectrum disorder). Eligible participants received a letter about the study and were approached by study staff at regularly scheduled clinic visits or by telephone. All questions were addressed, and written informed consent and/or assent was obtained.

2.2. Procedure

Study procedures were approved by the hospital's Institutional Review Board. Adolescents and young adults completed 2–3 questionnaires while caregivers completed the demographics form if the patient was <18 years of age. Measures were completed prior to participation in a focus group. Published consolidated criteria for reporting qualitative research (COREQ) guidelines¹⁷ were followed to ensure study rigor and quality.

2.2.1 Focus Groups—Focus groups were separated into three groups: caregivers of adolescent participants, adolescents with cSLE, and young adults with cSLE. A total of six separate focus groups comprising of 12 young adults, 10 adolescents, and 9 caregivers were held, with each lasting 90 minutes. Focus group sample size was based on the literature recommendation of 4–12 or until saturation of content is reached¹⁸. Focus groups were conducted by trained moderators (doctoral level psychologists and medical fellows). A focus group discussion guide was developed following a comprehensive literature review on PubMed and Google Scholar to generate the conceptual outline for the focus groups (focus group guide information is available from the corresponding author upon request). Questions focused on knowledge about lupus, impact on quality of life, barriers and facilitators of treatment adherence, how healthcare team can help with adherence, and any additional information for healthcare team to know. All focus groups were video and audio-taped.

2.3. Measures

Demographics.—A demographic information questionnaire completed by young adults and caregivers included patient's age, work history, family composition, socio-economic status, family history of lupus, and co-morbid disorders.

Electronic medical chart review.—Information regarding cSLE diagnosis, SLE Disease Activity Index (SLEDAI), Systemic Lupus Erythematosus International Collaborating

Clinics American College of Rheumatology (SLICC ACR) Damage Index, treatment regimen, and medical and psychosocial co-morbidities were abstracted from the electronic medical record (EMR). The SLEDAI is completed through a standardized process where all key elements are documented by every provider within the division at the time of patient visit. The total SLEDAI score is then calculated in a flowsheet in the EMR after lab data are entered. SLEDAI scores from clinic visit preceding focus group sessions were reported for this study. The Revised Duncan score (TSEI2), an occupation-based measure¹⁹, was calculated as a proxy for SES. Scores range from 15–97, with higher scores reflecting higher occupational attainment. For two-caregiver households, the highest Duncan score was used.

Fatigue.—Adolescents completed the PROMIS Pediatric Short Form v1.0 – Fatigue 10a while adult patient participants completed the PROMIS Short Form v1.0 – Fatigue 8a. The Patient-Reported Outcomes Measurement Information System (PROMIS®) is a set of validated, person-centered measures that standardize patient reported outcome assessment for use in both research and health care settings²⁰. PROMIS consists of item banks with variable number of questions that can be combined to form multi-item measures of varying length and complexity^{20, 21}. This measure employs a Likert-type scale with 5 points. A T-score is calculated, in which 50 is the mean of a relevant reference population and 10 is the standard deviation of that population^{20, 22}. For example, a higher T score represents greater fatigue.

Pain.—The Pain Intensity Visual Analogue Scale (VAS) is a validated measure of pain in patients > 7 years of age²³. This instrument is comprised of three questions describing pain intensity over the preceding week, with a 10-point Likert scale with higher scores representing more severe or intense pain²⁴.

2.2.2. Data analysis—Focus groups were transcribed verbatim. Three members of the research team developed an a priori coding framework based on a directed thematic analysis. Coding was independently conducted by three additional coders (LF, NA, & AS) using the a priori coding framework. Coders were instructed to include any new themes that emerged from the data. Theme consensus was achieved through an in-person discussion by the three original coders and included resolution of any discrepancies. Major themes were identified based upon congruency and similarity of content across groups and coders to reach saturation. Descriptive statistics were used to summarize demographics, medical characteristics, and symptom data (e.g. fatigue and pain measures).

3. Results

3.1. Participant demographics and characteristics

Overall, 66 cSLE patients and adolescent caregivers were approached for participation and 40 consented to participate. Twenty-six individuals declined study participation (10 young adults, 8 adolescent-caregiver pairs) yielding a recruitment rate of 61%. Of the 40 who consented, 31 adolescents, young adults, and caregivers participated in focus group sessions (77.5% participation). Reasons for non-participation included scheduling conflicts (e.g., could not attend scheduled focus group dates), family emergencies, and being lost to follow-

up (e.g., called to schedule but no return calls). All patient participants had at least 4 of the 11 ACR classification criteria for SLE at time of diagnosis. No differences were found between participants and non-participants on age, ethnicity, SLEDAI score, or co-morbidities. However, mean SLICC scores were higher for young adult participants (0.6 vs 0.1 for adolescents). Both adolescent and young adult participants reported mild to moderate fatigue; while on average, adolescents reported mild to moderate pain. Demographics and disease characteristics for participants is provided in Table 1.

3.2. Focus group results

Ten major themes emerged from the focus group discussions (Figure 1 and Table 2). Of the ten major themes, four were expressed by both the adolescent, young adult, and caregiver groups: knowledge deficits about cSLE, symptoms limiting daily function -- specifically mood and cognition/learning, barriers and facilitators of adherence, and worry about the future. The remainder were unique to one group. Themes and illustrative quotes are outlined in Table 2.

3.2.1 Knowledge Deficits about cSLE—All groups discussed a need for more disease-specific education for two broad groups: friends/family and the public which included school officials. Adolescent and young adult participants also stressed the need for caregiver education regarding the unpredictable impact of pain and fatigue on their daily functioning. Some wished for more public exposure as seen for children with cancer, as they believed this fosters an “automatic sympathy or empathy” that is missing for those with cSLE.

3.2.2 Symptoms limiting daily functioning – mood and cognition/learning—All participants endorsed cognitive problems, especially for adolescents in the school setting. Problems were often related to absenteeism for disease related issues. Caregivers expressed difficulty in differentiating lupus-derived cognitive or mood problems from their adolescent “*not trying*” or “*just being a teenager*”. Adolescents and young adults emphasized a desire for more attention and assessment of depression during the clinical visit.

3.2.3a Barriers to adherence—All participants identified forgetfulness, number of pills, and perceived or real side effects as significant barriers to medication adherence. Patient participants specifically mentioned absence of immediate, overt results as a barrier sharing “*What’s the purpose of taking it...I am going to feel the same regardless*”. Caregivers expressed frustration with getting their adolescents to understand the impact of their medication stating “*...it’s hard to get her to understand the severity of that [non-adherence] as a teenager when they don’t even understand their own mortality*”.

3.2.3b Facilitators of adherence—Flare of disease, and/or fear of disease flare, were stated as a significant facilitator of medication adherence. More common facilitators included pill boxes, reminders including family, calendars, phone alarms, or apps. Potential facilitators like individualized treatment plans were also discussed by young adult participants sharing “*...this is what your life looks like right now and these are our*

[medication] options. What do we think fits best into that? ...it would make it easier for us to take them”.

3.2.4 Worry about the Future—All participants shared worries about how lupus restricts work options, the financial burden of lupus (e.g., insurance coverage), and accomplishing autonomous goals, such as living independently, going away to college, having a relationship or children, and transitioning care to an adult provider.

3.3 Adolescent and Young Adult-Specific Themes

Major themes unique to the adolescents and young adults included: (1) Symptoms limiting daily functioning – pain and fatigue, (2) self-care and management, (3) impact on personal relationships, and (4) healthcare provider communication/relationship (See Table 2).

3.3.1 Symptoms limiting daily functioning – pain and fatigue—Adolescents and young adults felt that there is a lack of understanding about the unpredictability of daily symptoms, which vary throughout the day. Participants believed this variability contributed to the trivialization and lack of empathy they experience from those close to them or in the school/work setting. Indeed, based on self-report, our sample rated their pain and their fatigue as mild to moderate in the 7 days preceding the focus group session.

3.3.2 Self-Management and Self-Care—Adolescent and young adults desired more age and developmentally appropriate health information from their rheumatologist, as well as increased involvement in treatment decision-making. Young adult participants wanted to take a more active role than their caregivers in managing their disease sharing “*I want to get messages from my doctor directly, not through my mom*”.

3.3.3 Impact on Personal Relationships—Most of the adolescents and young adults were hesitant to share their diagnosis with friends or significant others because of worries “*they won’t be my friend anymore*” or “*I have to tell them they may have to take care of me when I am sick*”. Adolescent participants described loss of friendship(s) due to prolonged hospitalizations and feeling frustrated with well-meaning teachers who disclose their illness to the classroom.

3.3.4 Healthcare Providers Communication/Relationship—Adolescents and young adults desired more open communication with their healthcare providers; they expressed the importance of trust in making treatment-related decisions. Some stated “*I lie to my mom about taking my medicine, but I don’t lie to the doctor because they need to know*”. Young adult participants wanted a discussion with their doctor about alcohol, smoking, marijuana, college life as it relates to having lupus. Effective communication between the different specialists involved in their care was important to patients.

3.4 Caregiver-Specific Themes

Unique themes were also identified in the caregiver groups including (i) need for school advocacy, (ii) disruption of family schedule and (iii) sense of normalcy for their adolescent (See Table 2).

3.4.1 Need for School Advocacy—Caregivers shared a desperate need for physician-initiated school advocacy and believed lack of knowledge about cSLE was a fundamental challenge encountered in schools.

3.4.2 Disruption of family schedule—The impact of cSLE extends past the patient to the entire family, including healthy siblings. “*When she gets sick, it is just chaos for the family especially if she has to be admitted*”. Caregivers voiced difficulty in mitigating the impact of cSLE within the family particularly in the setting of disease flare.

3.4.3 Sense of Normalcy—All caregivers feared their adolescents were “missing out” on typical teenage experiences. They expressed a desire for their adolescent to have friends, go have fun, and their future life not being restricted by having lupus.

4. Discussion

The objective of this study was to assess self-management and the lived experience of adolescents and young adults with cSLE and their caregivers. Our study adds to the existing body of work in this area by including the caregivers’ perspective of how cSLE disrupts family dynamic and scheduling, and their desire for physician-initiated school advocacy initiatives. Focus group themes reflect both the disease-specific knowledge deficits and the psychosocial and educational issues that affect patients with cSLE. Both caregivers and patients agree that disease-specific knowledge deficits are significant issues contributing to feelings of isolation, relational conflicts, inadequate or absent school/work accommodations, and treatment non-adherence. All participants also agreed that symptoms were often dismissed by friends and families, significant others, and/or school individuals, given their imperceptible nature; this has been a consistent finding in qualitative studies involving adolescents and adults with SLE^{25, 26}

Adherence to treatment is a major facet of daily living for patients with cSLE and their caregivers. Adolescents and young adults in our study highlighted the lack of perceived improvement in their daily symptoms as a significant barrier to treatment adherence, thus hindering self-management. Other reported barriers included the high number of pills, perceived side effects, forgetting, low medication literacy, and/or taste. Additionally, caregivers expressed frustration in addressing adherence concerns with their adolescents due to a decreased appreciation of their own mortality. One strategy to address these barriers may be school-based educational activities or sessions for peers/teachers/administrators, low cost internet-based educational tools for patient and families, or individualized clinic-based education about cSLE.

Treatment non-adherence is multifactorial^{7, 9, 27}; and as such interventions targeted at improving adherence should use multi-component strategies based on the identified themes. Individualized treatment plans, tailored to fit their lifestyle, were considered a potent facilitator of adherence and self-management by adolescent and young adults. Tailoring interventions based on intentional versus unintentional non-adherence has been advocated in previous studies²⁷, although the evidence for improved adherence is lacking^{6, 13}. In addition, evidence from other pediatric conditions, such as epilepsy, suggests that adherence

interventions should be tailored to developmental stage¹⁵. All participants acknowledged that reminders such as apps, calendars, alarms, friends or family, flare of underlying disease, and fear of being hospitalized or sick were additional facilitators of adherence. Innovative interventions involving technology such as pillboxes with digital reminders and personalized treatment plans might prove more effective for adolescents and young adults with cSLE, however these require further evaluation.

Adolescents and young adults reported pain and fatigue as important factors limiting their daily functioning and negatively impacting their quality of life. This unique barrier identified by patients alone, highlights the importance of multi-method reporting from both the patient and their caregivers, when possible. As with most chronic illnesses^{27, 28}, patients conveyed the need for open, trusting communication with their healthcare provider, especially about treatment options and choices. In addition, patients expressed how living with cSLE impinges on their personal relationships and influences their decision to disclose their diagnosis to close friends and significant others. Other studies have reported a similar dilemma in adults with SLE²⁸. Taken together, themes identified from our adolescents and young adults may provide the context for the lower quality of life reported by those with cSLE compared to healthy adolescents or adolescents with juvenile arthritis^{25, 29, 30}.

While the general themes were similar between adolescents and young adults, how these translated to their lived experience with cSLE differed due to development. Adolescents reported common school-related problems like bullying, absenteeism, lack of accommodations, and falling behind academically, while the young adults were concerned with work accommodations, self-management, and transition-related problems. This age-associated difference has been described in the literature²⁵. This developmental difference underscores the importance of adherence-tailored interventions that are tailored to the developmental stage of the patient with cSLE.

An important finding of the current study was caregivers, adolescents, and young adults worry about the future, including transitioning to adult care, self-management, and independence. These worries could be addressed via transition programming involving both pediatric and adult multidisciplinary care teams. Targeted transition programming would equip adolescents with the tools needed to achieve skills for self-management, obtain health information about their disease, all with the goal of reaching independence in self-management³¹. This study reinforces the need for transition programming, which remains a challenging issue for most pediatric rheumatology clinics^{31, 32}, despite being widely recommended for improving health outcomes for patients with rheumatic diseases^{25, 33}.

While our study used focus groups to elicit in-depth data from an understudied population, we acknowledge a number of potential limitations including that the sample was one of convenience and from a single institution. Also, our participants were predominantly Caucasian, which does not capture the ethnic groups with highest morbidity and may limit the generalizability of our results¹¹. Notably, other studies of adolescents and young adults with cSLE have reported similar themes^{34, 35}. Future studies should also include objective measures of adherence.

The current study identified perceived barriers to treatment adherence from the patient and caregiver perspective. Participants desired good self-management including adherence to their treatment and medication regimen. Overall, adolescents and young adults with cSLE face a life-long debilitating disease characterized by overwhelming, pervasive pain, fatigue, medication- or disease-related organ damage, isolation – social and/or physical, and psychosocio-educational challenges. This study informs that continued psychosocial support, health information education, adherence interventions, and personalized treatment plans are necessary to increase self-management and autonomy in those with cSLE. This multipronged approach is likely to improve not only adherence and quality of life outcomes, but also treatment satisfaction among adolescents and young adults diagnosed with cSLE.

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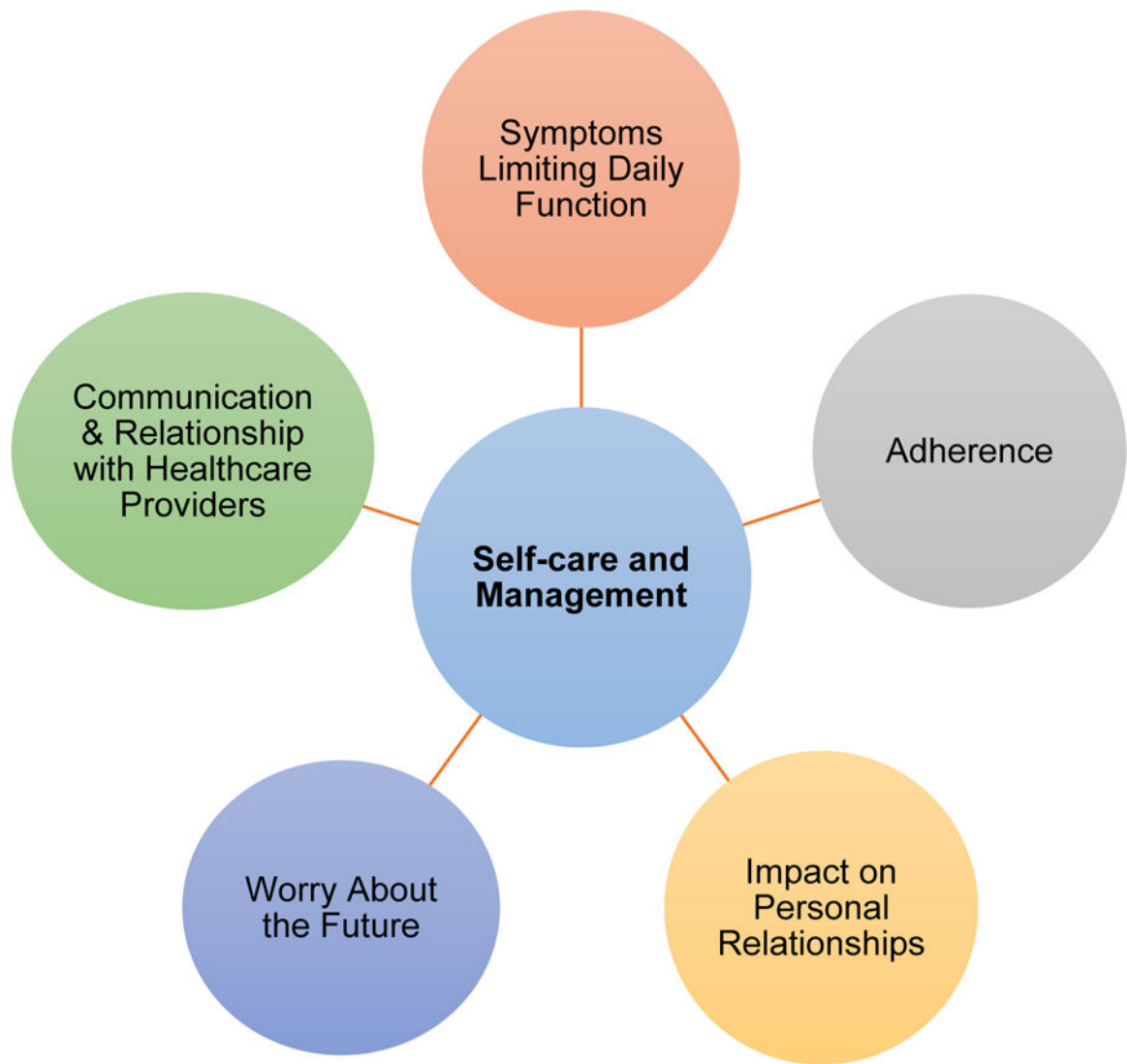


Figure 1:

Schema showing proposed interplay between self-management, adherence, and other influencing factors as described by adolescents and young adults. Absence of directional arrows indicates bidirectional influence of each theme with adherence.

Table 1:

Adolescent and Young Adult Participant Demographical and Disease Characteristics

Characteristic	Adolescent (n = 10)	Young adults (n = 12)
Demographics		
Female, No. (%)	10 (100)	11 (92)
Age, mean (SD), year	16.1 (1.6)	20.2 (1.5)
Race/Ethnicity, No. (%)		
White non-Hispanic	7 (70)	4 (33)
Black non-Hispanic	3 (30)	7 (58)
Other, non-Hispanic	-	1 (8)
Insurance coverage, No. (%)		
Public	6 (60)	6 (50)
Private	4 (40)	6 (50)
Duncan scores, mean (SD) ^a	42 (21)	22.6 (9)
eSLE characteristics		
Disease duration, mean (SD), year	2.7 (2.5)	4.4 (2.6)
SLEDAI ^b , mean (SD)	4.0 (4.2)	4.4 (4.2)
SLICC Damage Index ^c , mean (SD)	0.1 (0.3)	0.6 (0.8)
Presence of Lupus Nephritis ^d , No. (%)	2 (20)	5 (42)
Class III	1 (50)	1 (20)
Class IV	1 (50)	2 (40)
Class V	-	1 (20)
Mixed (Class II/IV)	-	1 (20)
PROMIS fatigue, T score (range)	57.5 (30.3 – 74.4)	57.4 (33.1 – 72.4)
Child pain VAS, mean (range) ^e	3 (0–8)	-
Number of all meds, mean (SD)		
Patient Reported ^f	4.6 (2.5)	3.5 (1.3)
Chart Review	5 (2)	5 (1.8)
Comorbidities, No. (%)		
Hypertension	1 (10)	5 (42)
Depression/Anxiety	5 (50)	2 (16.7)
Obesity	1 (10)	5 (42)
Other ^g	4 (40)	7 (58)
Disease Flare ^h , No. (%)		
Within Preceding 12 mos.	2 (20)	3 (25)
Positive Family History of SLE	3 (30)	4 (33)

^aRevised Duncan score, a measure of socioeconomic status. As reference, garbage collectors score 24.6 and electrician apprentice score of 42.

^bSLEDAI 2K score from clinic visit preceding focus group session. Range of scores is 0–14 for adolescent and young adult group respectively.

^cSLICC Damage Index obtained from annual calculated score within 12 months of focus group session. Scores ranged from 0–1 and 0–2 for adolescents and young adults respectively.

^dBased on International Society of Nephrology/Renal Pathology Society (ISN/RPS) classification system.

^eAverage pain in preceding two weeks.

^fTwo patients did not report any medications on questionnaire

^gdyslipidemia, hypovitaminosis D, ADHD, anti-phospholipid abs+.

^hpatient-reported worsening of symptoms requiring hospitalization or escalation of medication management.

Table 2:
Major themes identified for Adolescent, Young Adult and Caregiver Participants with Illustrative Quotes

Theme/Subtheme	Adolescents	Young Adults	Caregivers	Illustrative Quotes
Knowledge Deficit				
Friends and Family	✓	✓	✓	It's almost like a ghost disease...I've had to check myself, because I'm like, "she looks fine, she is taking her medicine, well, Why are you still hurting? Why are you still tired?" (Caregiver)
Public	✓	✓	✓	When I got diagnosed, I got bullied bad by my classroom...my teacher decided to tell all of them I had lupus, and they thought they could catch it. So they wiped the seats off with cleaning wipes...trying not to catch the lupus. (Adolescent)
Symptoms Limiting/Daily Function				
Pain	✓	✓		I want to be 17 like everybody else. I'm supposed to be having fun...I'm doing fun things, but I can't enjoy it because my legs hurt, or my head hurts.... (Adolescent)
Fatigue	✓	✓		Fatigue is the most difficult part of having lupus. Lupus is an evil disease that makes you sleep a lot. (Young Adult)
Mood	✓	✓	✓	I think sometimes mental health is overlooked. It's hard because some of us...might have mental health problems going into it. Some of us, mental health caused by it. Or made worse because of it. (Young Adult)
Cognition and Learning	✓	✓	✓	We're having problems with her in school passing. She can't concentrate...which is it, the lupus or is it her just not trying? (Caregiver)
Adherence				
Barriers	✓	✓	✓	<ul style="list-style-type: none"> • All the medicine I have to take, I don't see results right then and there.... What's the purpose of taking it? I'm going to feel the same regardless. (Young Adult) • My hardest thing with her is getting her to take her medication. And it's hard to get her to understand the severity of that as a teenager when they don't even recognize their own mortality. (Caregiver)
Facilitators	✓	✓	✓	...Doctors can take in the big picture. Instead of just picking one [med], maybe stepping back and saying, "This is what your life looks like right now. And these are our options. What do we think fits best into that?"...it would make it easier for us to take them (Young Adult)
Other				
Worry About the Future	✓	✓	✓	<ul style="list-style-type: none"> • I need to know if I am living past 40. So maybe talking [more] about transition. (Young Adult) • It's...devastating as a parent. What is she going to be? What is she going to do? How is she going to provide for herself? (Caregiver)
Self-Care and Management	✓	✓		...you can't be a kid think in the moment, you have to think weeks and months...I know if I do this, I can't do this the next night. And a lot of kids don't have to do that. (Adolescent)
Impact on Personal Relationships	✓	✓	✓	Isolated, even though you are with the people you care about, you just still feel isolated, because you can't do what they are doing. (Adolescent)
Healthcare Providers' Communication/Relationship	✓	✓	✓	<ul style="list-style-type: none"> • Less science-y talk. [When my doctor] explain it, it's cells and stuff, and I'm like, "I'm only 17 years old." (Adolescent) • I hate going to the emergency. I feel like they don't understand lupus patients. (Young Adult)

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Theme/Subtheme	Adolescents	Young Adults	Caregivers	Illustrative Quotes
Need for School Advocacy		✓		Just to be able to educate the kids and the staff at the schools, all from top to bottom, what lupus is and what it looks like. And the main thing for the kids to understand ...it's not contagious because that is what they are afraid of. (Caregiver)
Sense of Normalcy		✓		She tries to live her normal life. And I try to facilitate that. (Caregiver)
Disruption of Family Schedule		✓		She doesn't feel good, and so there's more burden put on the rest of the people within the household. (Caregiver)