






Health Literacy and Patient Activation in the Pediatric to Adult Transition in Systemic Lupus Erythematosus: Patient and Health Care Team Perspectives

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Objective. To identify perceived health literacy (HL) and patient activation (PA) needs during the transition from pediatric to adult rheumatology among patients with childhood-onset systemic lupus erythematosus (cSLE).

Methods. Semistructured interviews of patients and health care professionals were conducted from November 2019 through May 2020, until thematic saturation was achieved. Interviews were audio-recorded, transcribed, coded, and analyzed using thematic analysis.

Results. Thirteen post-transition adult female participants with cSLE were recruited from a public safety-net hospital system or from private practice. Thirteen health care team members were recruited from two pediatric and four adult rheumatology clinical sites serving patients in the same metropolitan area. Patients and health care team members acknowledged numerous HL components as important to transition, including language fluency, education, SLE-specific knowledge, self-efficacy, and accurate knowledge of personal medical history. Our interviews found PA to be an important component of the transition process, driven by internalization of the implications of cSLE diagnosis, self-education, autonomy, introspection, and trustworthy doctor–patient relationships. Patients valued access to their online electronic medical record, recommended multimodal SLE-specific education materials, and desired increased access to social workers. Health care team members stressed the importance of early preparation for transition and use of mobile medical applications and endorsed interventions such as lupus camp and increased partnership with psychologists and social workers.

Conclusion. HL and PA are perceived by patients and health care team members as substantially influencing transition success. Further research is needed to evaluate whether interventions to improve HL and PA positively influence cSLE transition outcomes.

INTRODUCTION

Childhood-onset systemic lupus erythematosus (cSLE) is a chronic, multisystem autoimmune disease that accounts for approximately 10%–20% of total SLE diagnoses (1,2). Compared with adult-onset SLE, patients with cSLE have more severe disease with a higher incidence of lupus nephritis and greater tendency to require dialysis, cyclophosphamide treatment, or kidney transplant (3). Early recognition and advances in treatment of cSLE have ensured increased survival among patients with

cSLE, such that long-term quality of life (QoL) and disease management must be considered.

Transition to adult care is a particularly tumultuous period, with increases in new renal manifestations (4), progression to end-stage renal disease (ESRD) (5), anxiety and depression (6), and ongoing or new neuropsychiatric symptoms (7). Younger adults (ages 18–33) and those with ESRD are more likely to have increased 30-day hospitalization rates, reinforcing the concept that transition to adult care is a particularly vulnerable period (8). Among privately insured patients with cSLE, a substantial

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SIGNIFICANCE & INNOVATIONS

- Young adults whose childhood-onset systemic lupus erythematosus (cSLE) was managed at a safety-net urban hospital system who transitioned from pediatric to adult rheumatologic care expressed concern about perceived deficits in understanding the etiology, clinical course, and treatment rationale of lupus.
- Young adults with cSLE and their health care teams report substantial gaps in patients' knowledge pertaining to accessing and using insurance, an issue of health literacy (HL), which is particularly salient during transition due to many patients' shifts in coverage.
- Patient suggestions to improve disease-specific HL emphasize multimodal, jargon-free educational materials, including videos, pamphlets, drawings, and patient-facing online portals, along with more intensive interventions such as lupus camp.

proportion (26%) do not have a follow-up appointment with an adult rheumatologist within 12 months of their final pediatric rheumatology visit (9). Interventions to improve cSLE transition outcomes require an understanding of the challenges that patients and their health care teams face during this unique time.

Development of health literacy (HL) skills is critical among individuals who frequently interact with health systems, such as those diagnosed with chronic diseases in childhood. HL describes the extent to which individuals are able to "obtain, process, and understand basic health information and services needed to make appropriate health decisions" (10). Nutbeam divides HL into three major subtypes: functional, interactive/communicative, and critical (11). Functional HL describes participants' baseline capacity to understand health-related materials and is thus influenced by educational background (12), but is also greatly affected by the ability to read and speak the language(s) of the operating health care system (13). Interactive/communicative HL refers to cognitive and social skills needed to exchange information, derive meaning from communication, and apply information to changing circumstances (11). This would encompass 1) disease-specific knowledge (etiology and complications of one's disease, as well as basic treatment rationale), 2) the ability to navigate one's health care system (such as by obtaining and using insurance), and 3) knowledge of accurate personal medical history (13). Critical literacy refers to advanced cognitive and social skills applied to analyze information and used to exert greater control over life events and situations (11). Relatedly, patient activation (PA), defined by Lazaroff et al as "taking an active role in managing one's own health and health care," is important in ensuring transition success (14) and likely influences one's degree of HL. Herein, we adopt the aforementioned model as an organizational framework.

HL is an important component of improving individuals' control over the modifiable social determinants of health (15). Katz et al analyzed HL among adult patients with SLE from the California Lupus Epidemiology Study and found that individuals with low HL had worse scores in all 10 Patient-Reported Outcomes Measurement Information System domains (16). Low HL has been reported among more than 25% of patients with SLE with greater than high school education, supporting the notion that formal education and HL are different (16). These studies are significant in that they point to HL as a modifiable determinant of health, which may be amenable to change more readily than other social determinants of health.

To our knowledge, few other published studies have focused on the lived experience of transition among predominantly publicly insured/uninsured patients with cSLE (2). Importantly, this demographic is likely to have different challenges with health care access and use and may receive differential treatment as compared with a privately insured population (17,18). Our interviews of lupus health care team members and post-transition, publicly or uninsured patients with cSLE yielded salient themes of HL and PA as important components of the transition process. We conclude with a series of recommendations, put forth by both groups, aimed at improving the overall transition experience.

PATIENTS AND METHODS

Setting and sample. We recruited two groups of participants through purposive sampling: 1) young adults with a history of cSLE after their transition to adult care and 2) health care teams involved in caring for patients with cSLE. A list of young adults (ages 18-24) who had transferred to adult care over the previous 5 years was obtained, and individuals with appointments over the subsequent months were invited to participate. Patient race was identified through review of the electronic health record. Racial identity was obtained because SLE is known to have varying prevalence, with higher worldwide prevalence among non-White racial groups (19) and worse outcomes among Black patients as compared with White patients in regions of the United States (20). Health care teams were recruited from two pediatric and four adult rheumatology clinical sites, all serving patients in the same large metropolitan area. At present, no dedicated transition care clinic exists in this system. Institutional Review Board approval was obtained from the University of Texas Southwestern Medical Center (UTSW) and site approval granted from Parkland Health & Hospital System for young adult participant interviews, in compliance with the Helsinki Declaration. Written informed consent was secured from all health care team members; verbal informed consent was obtained from all post-transition adult cSLE participants.

Data collection. Semistructured in-depth interviews (21) were conducted with young adults with cSLE and with health care

team members between November 2019 and May 2020, either in person or via telephone (based on participant preference). Discussion guides for young adults and health care team members were developed to query various psychosocial experiences of the transition to adult care (Supplementary Appendix A); the salient themes of HL and PA emerged as prominent influencers of transition success, rather than serving as predetermined topics of exploration. The Qualitative Research Committee (QRC) at UTSW collaborated in this process and reviewed the guides for clarity and comprehensibility. After piloting the guide on the first two participants, subsequent adjustments were made.

Interviews were conducted by two members of the QRC with formal training in facilitating one-on-one semistructured interviews. Recruitment ceased when thematic saturation was achieved in each cohort, with little to no new concepts emerging through continued interviews (22). All interviews were digitally audio-recorded and transcribed verbatim by a professional transcription service.

Data analysis. Thematic analysis, a method for identifying, organizing, describing, analyzing, and reporting themes, was used to identify emergent themes within the interview data (23). Two QRC team members trained in qualitative methodology collaboratively developed and refined a coding dictionary throughout data analysis. Transcripts were analyzed using constant comparative analysis to identify salient themes and reconcile any coding discrepancies (24). NVivo 12 Plus software was used to manage data during analysis.

RESULTS

We invited 29 patients with cSLE to participate by mail. After obtaining verbal consent, in-depth interviews were conducted with 13 young adult participants, with 6 taking place in person and 7 by telephone. Participants had the following demographic characteristics: 13 women, average age of 21 (range 18-24), 2 Non-Hispanic Asian, 6 Non-Hispanic Black, 4 Hispanic of any race, and 1 participant of two or more races. Eleven participants had public or no insurance at time of participation; the remaining two had private insurance. Interviews with young adult participants averaged 45 minutes (range 34 to 66 minutes). Final pediatric rheumatology visit occurred a mean of 2.7 years (± 1.8 years) prior to interview. Time between final pediatric and first completed adult visit was between 2 months and 24 months. Transition to adult care occurred at an average age of 18.4 years. During transition, two participants progressed from normal renal function in pediatric care to ESRD at the time of first adult rheumatology visit.

Thirteen interviews were conducted with clinical care team members with 12 in person interviews and 1 via telephone. Participants included pediatric rheumatologists ($n = 4$), adult rheumatologists ($n = 4$), nurses ($n = 2$), one nurse practitioner ($n = 1$), one social worker ($n = 1$), and one psychologist ($n = 1$). Interviews with

clinical care team members averaged 56 minutes (range 41 to 66 minutes).

Herein, we report on the themes of HL and PA, both of which were deemed by patients, and their past/present health care teams, as important during the transition. We also present suggestions from both groups for an improved transition experience.

Theme 1: HL from the patient and health care team perspectives.

Both participants and health care team members described the importance of HL during the transition period. Overall, participants expressed frustration with perceived deficits in HL across multiple domains (Table 1). Attainment of post-high-school education was considered influential in improving Functional HL (Table 1, Quote 1 [T1Q1]). In the domain of Interactive HL, participants expressed frustration and hesitancy toward understanding physicians' explanations regarding the nature of lupus (T1Q2) and the mechanisms/purpose of its various treatments (T1Q3). Participants suggested that many patients "just do whatever their doctors tell them" without developing thorough understanding (T1Q4). Physician explanations, though attempted in the past, resulted in "doctor's talk," leading one patient to conclude "doctors [should] have like a cultural training and not expect for their patients to know everything about their disease" (T1Q5).

Part of HL is understanding how to navigate the health care system. Most patients interviewed reported substantial gaps in their understanding of insurance and coverage. Some did not realize they would need their own insurance post transfer (T1Q6); one believed that a diagnosis of lupus would automatically enable public insurance to continue beyond age 18 (T1Q7). Even after attaining insurance, patients were often unsure how to use their policy (T1Q8). Other areas that proved difficult in navigating the health care system included delays in obtaining appointments (T1Q9, T1Q10), forgetting to request refills (T1Q11), difficulties refilling medications (T1Q9, T1Q10), and physical distance impeding medical care (T1Q12).

Young adults viewed knowledge of their personal medical history as a skill gained over time, noting discord in that health care teams expected a more thorough knowledge of personal health history at the first adult visit (T1Q13). Other patients pointed to physiologic limitations toward recalling their past medical history (T1Q14). Post-transition patients wanted pediatric health care teams to emphasize the need to "have all your information ready about yourself because they're gonna want to know basically everything" (T1Q15).

Health care team members strongly emphasized the influence of background education level on the ability to comprehend the pathophysiology and severity of lupus (Table 2) (T2Q1). Though grateful for translation services, health care team members believed that language differences impeded personal connection (T2Q2). The scarcity of written materials for non-English, non-Spanish-speaking patients was felt to be a notable barrier

Table 1. Patient perspectives on health literacy

Category of health literacy	Patient perspective
Functional health literacy	
Q1	I think people who are in college or people who have higher education I think that helps a lot...I have family members who are immigrants and...I see how hard it is for them to go to doctors and understand what's being done...I definitely think education plays a big part in being able to properly transition and understand the changes that are happening.
Interactive health literacy	
A. Knowledge/understanding of SLE	
Q2	I: When the doctor, the nurse or whoever told you it looked like you had lupus, did you understand what lupus was? P: No... I still have a hard time knowing what [is going on] I:...Did you ask your doctor about what it is...or have anyone explain to you what it is? P: They have, but since it's doctor's talk, I still don't get it that much.
Q3	I don't think doctors ever...told me what my medications do, [which] could be [helpful] if you understand [it] in layman's terms...[in a way] that makes sense...but how am I supposed to know what it actually does?...I don't even know what it's doing to me if I am taking it.
Q4	A lot of people just do whatever their doctors tell them, but they don't really understand because no one's really ever taken the time to explain...what's going on.
Q5	Doctors [should] have like a cultural training and not expect for their patients to know everything about their disease.
B. Navigating the health care system	
Q6	[The pediatric hospital] never really—they never touched base on like—Hey, you're gonna have to have insurance once you transition.
Q7	I wasn't like really thinking much about getting insurance as I got older...I thought that lupus was like a disability that would allow for state insurance always.
Q8	They didn't really explain what all comes with the [health insurance] plan like who do I talk to about making appointments, and what all doctors am I allowed to see, and what benefits I had. They didn't really tell me anything about that...I still don't know any of it. I would have to probably ask my doctor because I don't know where to find any of that information.
Q9	I: So then when you were waiting 3 months [for your next appointment], were you able to get med refills or how did that work? P: Yeah, I went to the emergency room.
Q10	The nurse she was like...since you have to wait so long [for your next appointment]...I can see if I can give you some refills, but she was only able to give me one refill... and she thought that I was going to be able to get in that day [but] I couldn't so I was like—I don't have no more refills, so I had to go to the emergency room, and they only gave me like one refill. So I was like—I hope this [lasts] me until my appointment.
Q11	I: What are some of the specific challenges or what are some of the specific different things that you are now having to do that you didn't have to do previously? P: Um, just dealing with the doctors on my own...having to remember to [ask] my doctors like can you refill my medicine? I: How long did that take you to feel comfortable with that? P: About 3 months.
Q12	I was living in East Texas and I did have to move here to be closer to the doctors...because my appointments were frequent and we used to live like 2 hours and 30 minutes from here...So it was kinda hard for my parents to come back and forth and we did move to Dallas, which is closer to the doctors.
C. Knowledge of personal medical history	
Q13	When I did transition, my first appointment here they—I mean my nurse talked to me about what medications I was taking and I personally—I don't know literally every medication I'm taking name from name, and I remember that was like—you're an adult, you should know this, your mom can't answer for you no more...and to me it was like—this is my first appointment...you have to give me time.
Q14	I wasn't able to answer all the questions [related to personal history] because when I got diagnosed with lupus, I had had a seizure, and I lost some of my memory from the first few weeks I was in the hospital.
Q15	I: Are there certain things that you think a person who's getting ready to transition should know and that would help them? P: I guess just have all your information ready about yourself because they're gonna want to know basically everything.

Abbreviations: I, interviewer; P, patient; Q, quote; SLE, systemic lupus erythematosus.

to furthering patient education in applicable populations (T2Q3, T2Q4).

Health care team members also requested certain degrees of interactive HL and preferred that patients have a “foundational literacy” toward understanding lupus (T2Q5). Health care teams report that knowledge acquisition takes time, which can be a

challenge among patients who are diagnosed in their late teens, near the time of transfer (T2Q6). Some professionals felt that the short duration of office visits limited the extent of information physicians could convey to patients for educational purposes, which resulted in limited patient knowledge of their own disease manifestations (T2Q7).

Table 2. Health care team members' perspectives on health literacy

Category of health literacy	Team member perspective
Functional health literacy	
Q1	Education level is really important...it can be difficult to communicate the pathophysiology of a certain disease, you know, and getting the patients to understand, the parents to understand—okay this is, you know, serious.
Q2	There's language barriers. We have great translators, I'd like to say, but I do feel like, you know, not speaking the same language, [we] just don't connect as well sometimes.
Q3	If they're not Spanish or English [speaking], I don't know how these families navigate it...we have some very unusual languages in our practice...it is amazing to me that they are doing as well as they are.
Q4	We have a lot [of materials] in Spanish, but I think if you're non-Spanish or English, I'm not sure we have any written materials really to provide you... [these families] get mostly verbal counseling and education...There's a few slim internet resources, but not tons.
Interactive health literacy	
A. Knowledge/understanding of SLE	
Q5	I want to know that they have...foundational literacy for their specific illness.
Q6	The ones who have been here for years, some of them their entire lives, we've had all of that time to work with them and prepare them and educate ...whereas if you get a 17-year-old that you tell all of a sudden you have lupus, there's a lot of education that has to happen in a short period of time...They just haven't had a chance to absorb all that information and then take ownership of it [prior to transitioning]...
Q7	It's a little bit sad because, [during] our office visits, we can only achieve so much. I do feel confident they know their medications and their dose and how they're gonna get the meds, but I feel less confident that they are able to fully explain their disease manifestations.
B. Navigating the health care system	
Q8	Many patients that come to me and they think they're gonna be able to keep Medicaid forever and so sometimes I've had to kind of break down that—actually, no, it's gonna cut off when you're 19.
Q9	Sometimes families don't have the funding to continue with the medication...There are programs out there that the families can apply for, but sometimes...literacy comes into play so they may not have filled out that renewal for the Medicaid form...So that comes in to play so when their kids get sick.
Q10	Does your parent have access to insurance through an employer? Some do, and the parents haven't taken it out for whatever reason...[I recommend] information on the marketplace or healthcare.gov ...advise them to understand what their insurance is going to look like after they become an adult.
Q11	This conversation I've had with people—I will say—look, it's really important as you get older...you need to take responsibility for your appointments. I'd like you to sort of keep in charge.
Q12	The difference between pediatrics and adult care is, you know, we're going to call and remind you of your appointments, we're going to call and let you know that you don't have any refills left... that kind of stops when you go into adult care, you know, the handholding kind of stops.
C. Knowledge of personal medical history	
Q13	I want to know that [patients] can independently identify their disease that they have, like an appropriate understanding of their disease, they know what the treatment for that is, they can accurately report on these are the medicines I'm taking, this is how much I'm taking, this is when I take them, these are the side effects to look out for.
Q14	It's a little bit sad because, [during] our office visits, we can only achieve so much. I do feel confident they know their medications and their dose and how they're gonna get the meds, but I feel less confident that they are able to fully explain their disease manifestations.
Q15	I'll have patients who will come in and in 5 minutes...tell me everything I need to know...I have other patients who come in and they could talk to you for 45 minutes and you have no idea what's gone on. So that's really more individualistic than I think it's being prepped by the pediatrician.

Abbreviations: Q, quote; SLE, systemic lupus erythematosus.

Patients and health care team members alike noted the importance of communicating to patients the Medicaid cutoff age (T2Q8). Diminished insurance enrollment and diminished medication adherence were attributed to prohibitive cost (T2Q9), literacy barriers (T2Q9), and lack of knowledge of employer benefits (T2Q10). Adult health care providers longed for their patients to understand that “handholding kind of stops” once patients were of adult age, which is a systematic

cultural and resource-related difference between pediatrics and adult medicine (T2Q11, T2Q12).

Health care team members described a minimum baseline of personal medical history required for transition, including proper identification of one's disease, accurate recall of medications and dosage, knowledge of side effects (T2Q13), and ability to explain personal disease manifestations (T2Q14). Knowledge of these domains was considered highly variable both in content

and succinctness and was attributed to patient variation more so than differences in pediatric care (T2Q15).

Theme 2: PA from the patient and health care team perspectives. During interviews, patients with cSLE expressed the importance of PA as a component of their transition from pediatric to adult rheumatology care (Table 3). Understanding and internalizing the severity of SLE was identified as a key step toward patients attaining an “activated” role (T3Q1). Participants communicated the importance of achieving agency through self-education (T3Q2) and stressed the importance of increased communication with their care team post transition (T3Q3), which sometimes required a distinct change in mindset, “I changed up and got better with myself,” between pediatric and adult care (T3Q4).

Some participants recalled initial indifference toward fostering an active role in the management of their health care, which tended to give way to an overwhelmed state during transition (T3Q5, T3Q6). Others recalled their development of health care independence as a positive change, noting an altered locus of care from parent-directed instruction in pediatrics to a more patient-centric focus in adult clinics, resulting in greater depth of knowledge (T3Q7, T3Q8). Patients recalled a certain peace of mind associated with their development of informed accountability toward their own state of health: for example, one patient described feeling “complete” after taking medications (T3Q9). Another patient described having fewer suspicions as to whether medications were a conspiracy after developing an inclination toward science through her microbiology major (T3Q10).

Table 3. Patient perspectives on PA

Category of PA	Patient perspective
Understanding disease severity Q1	[The clinical team] can only do so much...It's really up to us because we're the ones that are going through it...if we want to be able to get better, be here with our families, we're gonna have to put everything else to the side and realize that this is very, very serious.
Importance of PA Q2	Listen and read up about your condition... Find out about yourself and be able to sit there and ask the doctor questions and tell them what you're going through...
Q3	Now [in adult care] I actually ask when I don't understand something. I'm more into the conversation than when I was at [the pediatric center].
Learned trust, self-advocacy Q4	They wouldn't prescribe it to me if it wouldn't help me. Now if I have an issue when I'm taking a medication and it makes me feel some type of way, I let it be known...I was one of those teenagers that wasn't taking it at first, so [when] I transitioned up to an adult, I changed up and got better with myself.
Indifference to self-efficacy Q5	My mom tried. She tried to help me get it on my own and tell me what to do, but I never got around to it [getting insurance]. I was just like lost...I didn't know how to, and I guess I didn't just take the time to find out...
Q6	At the beginning I didn't want to change or switch because even though I was with my mom and, she was coming back and forth to the doctor's appointments and things like that, I still felt like I had a shoulder to lean on. I felt like it was much easier because she was doing everything, and I was just attending the appointments...but now I have to sign papers, I have to do this, I have to do that by myself. She's not here with me anymore, so it kind of just felt overwhelming.
Growth beyond family involvement Q7	My mom used to go to all the appointments with me, and she really didn't understand half the things they were talking about, but I actually understood what they were talking about, I mean because it's me that they're talking about.
Q8	The doctors talk to me now [in adult care] and so I understand what's going on...but at [the pediatric hospital] they would mostly talk to my mom...
Realized responsibility Q9	When you take your medicine, you feel complete. You feel like I've done everything that I'm supposed to do. So if there was something that was to happen to me, I could say that, well, I done everything I'm supposed to do.
Curiosity, concern about conspiracies Q10	I: Do you feel like you have the skills you need to take care of your own health care? P: Yeah, I do, but I also recognize that like I have a lot of privileges that other people don't have. Like for one, I'm a microbiology major. I'm a science major, so I know how important this stuff is, and I've always had the resources to educate myself on my condition and what to do that's best for me. It takes a lot of just wanting to know like, oh, why is this happening, and ... because I'm more inclined toward science, because I know people who don't really care about science aren't gonna wonder what are the processes that are going on in my body that are making me sick or why should I take my medicine or does taking my medicine even really work or is it just a conspiracy to get more money to the pharmacy companies and stuff like that.

Abbreviations: I, interviewer; P, patient; PA, patient activation; Q, quote.

Similarly, health care team members emphasized the importance of empowering their patients to become more autonomous “so they take charge,” (Table 4) but acknowledged the wide range of baseline activation among those entering adult care (T4Q1). They acknowledged that severe lupus presentations at a young age, followed by years of clinical stability, sometimes led to complacency in transitioning teens (T4Q2). Health care teams expected independence in certain self-efficacy domains upon first visit to adult clinics, for example, an ability to schedule/cancel appointments (T4Q3) and an ability to obtain refills (T4Q4).

They stressed the importance of conversations directly encouraging self-empowerment (T4Q5), even holding private conversations with patients to communicate these transition goals around age 16 (T4Q6). Goal setting and adjustment of unrealistic expectations were noted as influential in establishing a “partnership” attitude (T4Q7). Health care teams approached patients’ resistance to active participation by addressing specific beliefs driving denial, labeling fixed attitudes, and using motivational interviewing in combination with “compassionately honest” language (T4Q8).

Theme 3: Recommendations from the patient and health care team perspectives.

The patient participants provided valuable recommendations to improve transition outcomes (Table 5). Participants stressed the importance of a patient-accessible online portal (used by health care teams at both the pediatric and adult rheumatology centers) as a means of facilitating medication and appointment adherence (T5Q1). The platform was deemed valuable because it offered a one-stop location for a variety of logistical information (T5Q2). Patients suggested that receipt of a high-quality pill box from their physician would reinforce medication adherence while demonstrating physician investment (T5Q3). Participants desired educational materials in multiple formats, including drawings (T5Q4), pamphlets, videos, and verbal explanations (T5Q5). Additionally, participants reflected on lupus camp as a source of broad education about lupus as a disease (T5Q6).

Participants desired a quick introduction to their adult care team prior to transition (T5Q7). They valued empathy and hoped that their health care team members would appreciate the gradual pace at which individuals mature from children into adults

Table 4. Health care team members’ perspectives on patient activation

Category of patient activation	Team member perspective
Range of activation Q1	Some [patients] are very responsible, and they want to be well, so they take charge, and they know about their symptoms, they're good about telling you how they feel, but others are just not that interested.
Understanding severity, complacency Q2	Pediatric lupus can present terribly... so when they first present to the pediatric rheumatologist, it's gonna be like, Oh my god, this is life or death. And so they take the disease very seriously...But as kids get older, they do tend to be a little bit more complacent.
Skill-based activation Q3	At the very first visit, if the parent is there or a caregiver is there, one of the first things I always say is, Now that you're an adult, you have to be in, you know, full charge of your own health ... I want you to be the one to make the appointment; don't rely on mom to do it. If you have to cancel an appointment, I want you to be the one to cancel the appointment and reschedule. Don't make mom do it, because this is your health.
Q4	I always say to my patients, you know, your family's going to be here to help you if you have a question about how to do X, Y, Z, they're here, but I want you to work on making the phone call to get your refills for the medicines.
Reframing locus of control Q5	I usually empower [patients]. I want them to know about their health history without relying on the parents. So I tell them they're in control.
Q6	Around the age of [...] 16, I try to have a private conversation with the patients and talk to them about taking control of their management, their medications...on being an advocate for themselves.
Goal setting, partnership attitude Q7	I do go over the disease process...I do tell them worst case scenario, best case scenario and then I want to know exactly [...] what their goals are and if some of their goals are to get off of all medicines completely I might say, hey, that's not a realistic goal...because this is a lifelong chronic disease, but what we can do is control it with the medicines that you have...When they go into an adult practice, it's going to end up being more of a partnership.
Addressing fears, acknowledging limits Q8	Choosing to accept information is a choice, and people have a variety of reasons why they won't, so sometimes if you can kind of get down to the heart of it, like are you convinced that it won't matter what you do, it's not gonna change the outcome?...What's that belief that's kind of driving that denial behavior?...I just try to be as compassionately honest and, you know, there's motivational interviewing as a technique that can be helpful...But at the end of the day, you can't force anyone—no matter how many years of school you go to—you can't force anyone to do anything that they don't want to do or believe anything they don't want to believe.

Table 5. Patient suggestions to improve cSLE transition

Category for improvement	Patient suggestion
Patient-facing online portal	
Q1	I use MyChart to refill my prescriptions, to look at my labs...My doctors message me on there, and I message them back on there, so like after my appointment, [my rheumatologist] will hit me back up on MyChart to let me know if my lab's okay or just to let me know about my appointment period...You gotta be on top of it, but MyChart is a really good help.
Q2	I usually just check MyChart, which is really helpful. It tells me the appointments, the floor where it is, the phone number, the time—that's very helpful and I can order my medicine from there.
Pillbox	
Q3	When I was younger, one thing that like encouraged me to take my meds a lot was having a pillbox...a nice one...it does encourage you to take your meds.
Education suggestions	
Q4	I like people to talk to me, explain the paper to me, and maybe just like a few drawings like on the consequences like flareups or your muscles being icky...
Q5	[On education about medications] I think another way would probably be a pamphlet and the doctors just kind of summarize it a little bit, but the pamphlet will be for the teenager to have and, you know, to read it on their own time, and I think a video's also helpful too, if they don't want to read a pamphlet.
Q6	When I was a child, I thought lupus was just something to make my bones hurt...but finding out it really affects people's body and their organs in their bodies and I didn't know that until I went to lupus [camp] and got all those facts.
Introduction to adult staff	
Q7	I think just a simple, you know, like—'Hey...this is so and so from [the adult rheumatology clinic]. We're excited...you're coming over...hope to see you'—You know, just something really small, just a little...a little cheer up...at least I know somebody over here before I did transition.
Physician empathy	
Q8	It could be really helpful for the adult rheumatologist to be receiving some kind of like training on empathy or like how to better suit children, because even though it's like, okay, now you're an adult—like, that's not the reality of it...After being somewhere for a long time, you can't expect someone's mindset to just switch to—okay, I'm an adult now and this is how it's gonna be.
Q9	I just want to say how [important] it is that doctors [try to be] empathetic...If we're being honest, most doctors that these people are seeing probably don't look like them, and so it's hard to know that someone cares about you or understands what you're going through if they don't even look like you and you know that they haven't had the same experiences as you.
Personal support networks	
Q10	It's very important that you make sure that...you have a support group, a support system...because they are the ones that's gonna be there, you know, when everything goes left and right.
Q11	It's important that you do have a helping hand...I may be going through this, but at least I have someone there...to help me, to encourage me to keep going, to strive to keep going forward.
Q12	When I transitioned, I mean I didn't want to at all—like I said, I mean I cried...my parents they basically told me, you know, look at the positive side...Them being there calmed me down a lot, like it made me like—okay, this is gonna be okay.
Importance of social workers and guidance counselors	
Q13	[There are] places where they assign like case workers to people who kinda check in with them and [make] sure that they're taking their meds, making sure they're going to their appointments, and if they need anything, helping provide them with those resources...Having someone that's checking in with you not only like as far as your medical care, but like even just as a person I feel like that can be really helpful.
Q14	Like a guidance counselor...I would like to try to gain a mentor—not only to help get in, like get the insurance stuff, but also like keep up with me like talk to me, ask me how I'm feeling, not necessarily about my lupus but [...] someone [who] will talk to me and keep my mind on the right track.

Abbreviations: cSLE, childhood-onset systemic lupus erythematosus; Q, quote.

(T5Q8). Patients noted empathy to be particularly important in scenarios wherein physician demographics differed from patient demographics, as empathy can help build trust despite dissimilarities in background (T5Q9). Young adults noted that strong support networks within their personal lives were influential in providing stability and strength during changing times (T5Q10, T5Q11, T5Q12). Social workers and guidance counselors were often recounted as empowering self-efficacy by connecting

patients to resources and facilitating insurance uptake and use, increasing PA and inquiring about general well-being (T5Q13, T5Q14).

Health care team members' recommendations for improved transition outcomes (Table 6) included early preparation of transition logistics for patients (T6Q1), encouraging use of phone reminders (T6Q2), phone call follow-up for no-shows among transitioning patients (T6Q3, T6Q4), and overlap

Table 6. Health care teams members' suggestions to improve cSLE transition

Category for improvement	Team member suggestion
Early preparation Q1	If you start coming up with your [transition] plan early, then that is huge...for example, are you thinking about going to college in the middle of nowhere? Are you sure that they're going to have a rheumatologist somewhere in the middle of nowhere? [...] Can you give yourself your own injections?
Phone reminders Q2	All the kids have phones. They're on their phones when they're in our appointment...People say 'oh, I can't remember to take my meds.' Well, set a phone reminder.
Follow-up contact Q3	[In pediatrics, patients] do get flagged for social work as well if they're chronically no-showing because that way we can ask them, is there something—is it transportation? We can help with that. Is it because Tuesdays don't work anymore for your child for appointments? Then we can reschedule them for a different day.
Q4	I think this is something that, in our side [within adult rheumatology], we need to change, you know, because you are dealing with an 18-year-old, maybe they might need the reminder. You know, they might need [somebody to contact them]: 'Why didn't you show up?'
Simultaneous pediatric/adult visits Q5	[We] make overlap visits so they'll see the new provider and then come back and see us one last time, so that way, we can make sure you saw this provider, you like this provider, the provider took your insurance...We don't want them to have a lapse in care.
HL concerns with online portals Q6	[The existence of online portals] clearly benefits a certain subsegment who will be able to understand and utilize that system and then it doesn't benefit people that are not as capable of navigating that type of system.
Effect of lupus camp Q7	The patients that I've had that have come back from [lupus] camp seem to have a better understanding, they feel, you know, a little more accepted, they have met some people that have lupus too. They don't feel like they're the only ones...
Respecting linguistic preferences Q8	If I see that the patient is very resistant to [speaking] Spanish, then at the end, when we're done, if we were talking in English, then I'll speak in Spanish to the parent and just give them a summary...If [the patient] came with a parent, it's because they want them involved.
Early engagement of social workers Q9	As far as trying to figure out insurance for people that are going to lose insurance [...], maybe we could engage with a social worker earlier to make sure that they understand their options [...] and to be realistic about how they're going to obtain [coverage].
Adult rheumatology resource limits Q10	We do not have great access to social work. We just don't...We can help in terms of understanding the disease and the medications and all of that, but just some of the other community resources that you might need access to—maybe you don't know how to get transportation to an appointment. Maybe you don't know that Medicaid [...] can provide you transportation [...] and you don't know how to fill out the form or you don't know who to call. I wish we did better with that, but I feel like it'd be awesome to have some other staff members who can help with some of those other resources.
Q11	The adult rheumatology team is more limited in terms of resources. We don't have a social worker. We don't have physical therapies. We don't have a psychologist or other things that I know that they have available [in pediatrics].

Abbreviations: cSLE, childhood-onset systemic lupus erythematosus; HL, health literacy; Q, quote.

between final pediatric and initial adult rheumatology visits (T6Q5). In concordance with our patient interviews, health care team members valued the utility of an online portal, although they emphasized possible technology access barriers (T6Q6). Lupus camp (T6Q7) and respect for language preference (T6Q8) were also suggested as valuable tools toward improved HL. Health care teams enumerated the importance of involving social workers in the transition process, stressing their expertise in facilitating insurance uptake/use (T6Q9). Adult rheumatologists were routinely frustrated by a lack of funding for

social workers within their practice (T6Q10). To a lesser degree, they also expressed frustration regarding funding deficits for other health care team members, such as psychologists and physical therapists (T6Q11).

DISCUSSION

In this qualitative study, we provide the perspectives of post-transition adult patients with cSLE and health care team members on HL during the transition from pediatric to adult lupus care. Both

patients and health care teams acknowledged various HL components influencing transition success, including baseline education and language fluency (descriptors of Functional HL) and components of Interactive HL such as disease-specific knowledge, ability to navigate within the health care system, and knowledge of one's personal medical history. Our interviews suggest that PA is driven by several factors, including an internalized understanding of the implications of cSLE diagnosis, self-education, introspection, autonomy, and the formation of a trustworthy doctor-patient relationship. Patients frequently applauded the utility of a patient-facing online portal and recommended multimodal educational materials and increased access to social work and counseling services. Health care team members reiterated the importance of early preparation for transition and the use of mobile phone reminders/applications and endorsed interventions such as lupus camp and increased funding for partnership with social workers and psychiatrists.

The Health Literate Care Model hinges, in part, on establishing universal HL precautions and developing health literate, activated patients as a means of attaining improved outcomes, especially engagement in care (25). Smith et al have suggested that Functional HL and PA, although they are weakly correlated to one another, independently predict health outcomes (26). Interestingly, another study by Woodard and affiliates suggests that Functional HL and PA exert a synergistic effect when applied to attaining glycemic control in diabetes, another lifelong multisystem disease (27). Interactive and critical HL have been less researched but are closely correlated with disease management self-efficacy (28,29), including the perceived ability to organize care, interact with health care providers, and perform self-care (30).

Optimizing HL has several potential benefits to patients, care teams, and the health care system (25). For example, among adolescents with irritable bowel disease (IBD), implementation of a Patient Education Program was linked to increased self-management, transition competencies, and QoL (31), suggesting a promising direction for interventions among adolescents/young adults with other chronic diseases, including cSLE. HL status and interventions are understudied in SLE (32). To our knowledge, no studies have evaluated the impact of HL interventions among patients with cSLE transitioning to adult care (33). Our interviews suggest that interventions aimed to increase HL may directly improve patient outcomes during transition. Analysis of transitioning patients with IBD has demonstrated that clinicians vastly overestimate HL transition readiness (13), illustrating the need for a standardized assessment before implementation of targeted HL interventions.

Patients and health care team members in our study emphasized PA as an important component of the transition process. Understanding motivations for patients' behavior—especially when rooted in denial—followed by use of motivational interviewing techniques, establishment of trustworthy doctor-patient relationships, and undertaking practical goal setting may lead to enhanced activation. Importantly, these

techniques can improve perceived patient-doctor communication, which is an independent predictor of Patient Activation Measure (PAM) scores among adult patients with SLE (34) and is related to improved Interactive/Communicative and Critical HL (29).

PA can be optimized through proven interventions. When Alegria et al implemented an intervention to improve PA among predominantly (>60%) publicly or non-insured patients with mental health diagnoses, incidence of follow-up appointment within 6 months more than tripled (35). In a qualitative study focused on IBD providers, transitioning pediatric patients' abilities to take ownership over their care (as assessed by their health care team) was considered a positive determinant of transition outcomes (36). Similarly, interviews with SLE health care team members found that patients with strong problem-solving skills and ability to demonstrate proactive engagement were thought to experience the best transition outcomes (37). Whether interventions focused on increasing PA improve transition outcomes for patients with cSLE is unknown.

Our patients and health care teams routinely viewed insurance acquisition and use as a confusing subject area impeding care continuity. In our sample, both patients and care teams valued consultation with social workers to help navigate the highly complex process of determining qualification for, and eventual enrollment within, public insurance plans. Our interview findings align with data on new enrollment in Medicaid/Marketplace insurance programs following health care coverage expansion under the 2014 Affordable Care Act, wherein the strongest predictor of application completion was receipt of enrollment help from a "navigator" or application assister (38). Deserving of future study is the question of whether increased access to social workers, particularly in adult clinics where these resources are often lacking, benefits the HL of young adults with cSLE.

Patients reported varying ability to recount relevant personal medical history upon their initial adult rheumatology visit; however, care teams iterated specific expectations of what knowledge they routinely seek from transitioning patients. An online portal used in both the pediatric and adult rheumatology practices of this study was highly regarded by both groups for its ability to overcome limited knowledge of personal medical history. Use of online portals has shown promise in increasing PA (as assessed by PAM-13 score) in acute care settings (39). The effect of online portals upon HL, especially among patients with limited knowledge of personal medical history, is deserving of further study. These technologies could exacerbate health disparities if patients who most need educational support are expected to obtain this knowledge on their own yet are unable to access because of technical and/or use barriers. This concern is illustrated by the finding that differences in age, HL, numeracy, and graph literacy each independently contributed toward differences in task performance between the lowest- and highest-performing adults in using an online portal (40).

Several interventions to improve transition outcomes were proposed by participants of this study. Our patients believed they would benefit from personal mentors and from increased attention to their mental health needs, which could be accomplished by long-term formal partnership between rheumatology and psychiatry and through shorter-term community-building initiatives, such as lupus camp, whereby patients with SLE could meet older role models with their disease. Among children with IBD, attendance at an all-IBD adventure-based summer camp was associated with increased health-related QoL (41) and increased disease-specific knowledge (42), and thus should be considered for adaptation and formal evaluation in cSLE.

Limitations of this study include interviews with patients and health care team members from a single geographic setting and lack of male patients with cSLE. Although patient age and geographic location were similar among the participants interviewed and those who were invited but did not participate, it is possible that these samples differ in ways that could bias the aforementioned results. Additionally, our interviews were restricted to English-speaking participants and therefore do not fully capture the challenges experienced amongst non-English-speaking patients. HL and PA were prominent themes that emerged from our interview analyses, rather than predetermined topics for exploration. For this reason, HL and PA were not quantitatively measured at interview onset. Most of our young adult participants possessed either public or no insurance (85%); therefore, our results are not necessarily transferrable to a privately insured cSLE population. However, the concordance of our data to that of Harry et al supports the existence of overlap between the challenges faced by our patients and those faced by a Midwestern US cSLE demographic with lower utilization of public insurance (2).

In this qualitative study, we had a unique opportunity to interview young adults with cSLE who transitioned to adult care, along with health care team members caring for patients with cSLE. Our interviews yielded a deeper understanding of the roles of HL and PA during the transition to adult care. Further research is warranted to evaluate which interventions are most appropriate to increase HL and to determine whether these interventions improve the cSLE transition process, such as by improving QoL, medication adherence, appointment-keeping, and/or disease activity measures.

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All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Bitencourt had full access to all of the data in

the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Makris, Kramer, Bitencourt.

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