

Healthcare and Research Priorities of Adolescents and Young Adults with Systemic Lupus Erythematosus: A Mixed-methods Study

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ABSTRACT. Objective. Managing juvenile-onset systemic lupus erythematosus (SLE) is particularly challenging.

The disease may be severe, adolescent patients have complex medical and psychosocial needs, and patients must navigate the transition to adult services. To inform patient-centered care, we aimed to identify the healthcare and research priorities of young patients with SLE and describe the reasons underpinning their priorities.

Methods. Face-to-face, semistructured interviews and focus groups were conducted with patients with SLE, aged from 14 to 26 years, from 5 centers in Australia. For each of the 5 allocation exercises, participants allocated 10 votes to (1) research topics; research questions on (2) medical management, (3) prevention and diagnosis, (4) lifestyle and psychosocial; and (5) healthcare specialties, and discussed the reasons for their choices. Descriptive statistics were calculated for votes and qualitative data were analyzed thematically.

Results. The 26 participants prioritized research that alleviated the psychological burden of SLE. They allocated their votes toward medical and mental health specialties in the management of SLE, while fewer votes were given to physiotherapy/occupational therapy and dietetics. The following 7 themes underpinned the participants' priorities: improving service shortfalls, strengthening well-being, ensuring cost efficiency, minimizing family/community burden, severity of comorbidity or complications, reducing lifestyle disruption, and fulfilling future goals.

Conclusion. Young patients with SLE value comprehensive care with greater coordination among specialties. They prioritized research focused on alleviating poor psychological outcomes. The healthcare and research agenda for patients with SLE should include everyone involved, to ensure that the agenda aligns with patient priorities, needs, and values. (First Release March 1 2017; J Rheumatol 2017;44:444–51; doi:10.3899/jrheum.160720)

Key Indexing Terms:

HEALTH PRIORITIES
ADOLESCENT

PATIENTS

SYSTEMIC LUPUS ERYTHEMATOSUS
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Healthcare and research aim to improve patient outcomes, but priorities for service delivery and research are typically

driven by health professionals, which may not align with what patients regard as important^{1,2,3}. Patients want

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integrated care, rather than to navigate silos of specialty medical care⁴. They prefer nonpharmaceutical approaches to treatment, yet drug trials dominate the clinical research landscape¹.

The inclusion of patient preferences in research is advocated to make practice and policy more relevant to patient needs and thus to reduce research waste^{2,3,5,6,7}. In rheumatology, patients have been involved in research and outcome priority-setting through initiatives such as the James Lind Alliance⁸ and the Outcome Measures in Rheumatology⁹. Priority-setting partnerships in joint pain¹⁰ and osteoarthritis (OA)^{8,11} led to the awareness that patients desire research focused on lifestyle and self-management. However, the views of adolescents on priorities for research and healthcare remain limited. Juvenile-onset systemic lupus erythematosus (SLE) is more severe than in adults^{12,13}, and adolescents and young adults with SLE must navigate a complex and fragmented healthcare system during a critical phase of their life. Specifically, juvenile-onset SLE has been reported to impair school attendance, academic achievement, employment, and establishing independence^{14,15}. This can impinge on treatment adherence and clinical outcomes^{16,17}.

Our study aims to identify the healthcare and research priorities of adolescents and young adults with SLE and to describe the reasons underpinning their priorities. Mixed methods research was conducted to quantify the healthcare and research priorities of young patients with SLE and provide an in-depth understanding of reasons underlying their prioritization^{18,19}. This understanding may inform the delivery of patient-centered healthcare and research, leading to improved outcomes in this population.

MATERIALS AND METHODS

Participant selection and setting. We purposively sampled patients aged 14 to 30 years who were diagnosed with SLE before age 18 to obtain a range of demographic and clinical characteristics from 5 hospitals in New South Wales, Australia: The Children's Hospital at Westmead, Sydney Children's Hospital, John Hunter Children's Hospital, Liverpool Hospital, and Westmead Hospital. Ethical approval was obtained from the Sydney Children's Hospital Network Human Research Ethics Committee (12/SCHN/443). Site-specific approval was obtained from all sites. The primary physician identified potential participants for this study and contacted the patient and their parents (if patients were aged less than 18 years) and obtained permission for DJT to invite them to participate. Recruiting clinicians did not explicitly use the Systemic Lupus International Collaborating Clinics (SLICC) or the SLICC/American College of Rheumatology (ACR) classification criteria. Patients were excluded if they were unable to give informed consent, non-English speaking, or deemed medically unsuitable by their physician.

Data collection. We gave participants the option to attend a focus group or a face-to-face semistructured interview, which gave the opportunity for those unable or unwilling to attend focus groups to participate²⁰. We conducted focus groups and interviews from October 2013 to February 2014. We piloted the question guide and allocation exercise with 3 patients to ensure that the questions were clear, comprehensible, and effective in eliciting relevant responses (Supplementary Table 1 is available with the online version of this article). Participants aged under 18 years could choose to have their parents present. All participants were reimbursed with an A\$10 gift card.

Table 1. Participant characteristics (n = 26). Values are n (%).

Characteristics	Values
Male	2 (8)
Female	24 (92)
Age, yrs	
14–18	15 (58)
19–30	11 (42)
Disease duration, yrs	
< 3	10 (38)
4–6	6 (23)
7–9	7 (27)
10–12	3 (12)
Ethnicity	
Asian	16 (62)
White	6 (23)
Other	4 (15)
Clinical manifestations*	
Arthritis	17 (65)
Skin lesions	11 (42)
Hematological disease	9 (35)
Kidney disease	9 (35)
Neurological SLE [†]	4 (15)
Serositis	4 (15)
Education/employment status	
Student	20 (77)
Full-time employment	3 (12)
Part-time employment	1 (4)
Unemployed	2 (8)
Language(s) spoken at home	
English	15 (58)

* Some participants reported more than 1 clinical manifestation.

† Neurological SLE could include self-reported manifestations such as seizures, acute confusional state, optic neuritis, movement disorders, myelitis, psychosis, and peripheral nephropathy. SLE: systemic lupus erythematosus.

We planned to run 3 groups with 6 to 8 participants. Focus groups were held in centrally located meeting rooms external to the hospital and convened by age groups (14–18 yrs, 19–30 yrs) to promote rapport. Three researchers who were not involved in clinical care (DJT, AFR, AT) facilitated focus groups and the cofacilitator recorded field notes. Interviews were conducted by DJT at the participant's home, hospital, local library, or community center, based on the participant's preference.

To maximize engagement and promote discussion, we gave the young participants in our study priority allocation exercises^{21,22} for 5 areas relevant to SLE: (1) general research topics in medical management, prevention and diagnosis, and lifestyle and psychosocial (3 topics), (2) research questions addressing medical management (11 questions), (3) research questions addressing prevention and diagnosis (5 questions), (4) research questions addressing lifestyle and psychosocial care (4 questions), and (5) healthcare specialties (11 specialties). Research topics were based upon standard nomenclature for research classification²³. Specific research questions were developed from a literature review of research gaps in juvenile-onset SLE^{13,24} and discussion among the research team. Selected healthcare specialties were based on the health services young patients are required to access^{12,13,25} (Supplementary Table 2 is available with the online version of this article). For each exercise, 10 tokens (each representing 1 vote) were given to each participant. They were instructed for each exercise to distribute all their tokens to the different research topics, research questions, and healthcare specialties, and to add any questions/specialties they believed were important that were not on the list. Research topics/questions and

Table 2. Some results from the patient focus groups and interviews.

Theme	Illustrative Quotations
Improving service shortfalls	<p>“Talking to someone would have helped. I only had my friends and I’m one of those people that don’t open up easily, ever since being bullied. I never spoke to the doctor because my mum was usually there and there are things I don’t want to say in front of her.” – 20-year-old F, interview</p> <p>“The process of diagnosis can be very difficult. It took so long and I guess sometimes that can’t be helped. My mental health suffered during this because I felt like, am I just imagining things?” – 15-year-old F, interview</p> <p>“They need to work as a team. I have been to combined clinics when I was younger; they need more of them in my opinion, as my health improved drastically since attending that clinic.” – 19-year-old M, interview</p> <p>“In the country, no one really knows what lupus is, even the general practitioner. I guess if you’ve just been diagnosed, you don’t really know much about it. You need to know how it’s going to affect you, if your symptoms were normal.” – 21-year-old F, interview</p> <p>“Information needs priority, it needs to be simple, no matter how old you are, or what language you speak. There was no information, which my parents could read and understand, in their own language. I couldn’t talk to them.” – 26-year-old F, focus group</p>
Strengthening well-being	<p>“I just feel like that if you are depressed and suffering from stress, it will cause your body to shut down. Your psychological health is half the battle. It is hard enough to deal with lupus, but when you aren’t mentally well, it becomes more difficult, you lose control of your life.” – 15-year-old F, interview</p> <p>“Not enough people are aware of lupus, so I think that more funding should be going into information and education, so people can know about it and patients are treated better in their communities.” – 23-year-old M, interview</p> <p>“Lupus will impact on patient’s relationships, and because at our age we need parents to take care of us and take us to appointments, so it’s crucial for our health.” – 15-year-old F, focus group</p> <p>“I know with the steroids it makes you gain a lot of weight and I had that experience. Dealing with all the other stuff as a teenager, your mental health suffers, so tackling the weight gain issue would also improve patients’ mental health, it allows us to fit in.” – 17-year-old F, interview</p>
Ensuring cost efficiency	<p>“To be honest, all these people (healthcare workers) are important, they are all equal; they need to work as a team. We can use the tokens on all of them to ensure the best care for patients with SLE, meaning fewer hospital visits.” – 14-year-old F, interview</p> <p>“I don’t think you need to see a dietician; they can combine that advice with your time with specialists. All these doctors cost something, my parent’s money; I don’t want to waste resources.” – 19-year-old M, interview</p> <p>“If my rheumatologist doesn’t see me, I see a nurse that works with my rheumatologist. I guess I can tell her more personal things [than] my doctor; she keeps it confidential, this is so valuable for my mental state. I think nurses are very knowledgeable when it comes to getting resources about lupus and the medications I require.” – 26-year-old F, focus group</p>
Minimizing family/community burden	<p>“Well, you want to stop it. You don’t [want] any more people to get this disease; we need to prevent it from happening.” – 17-year-old F, interview</p> <p>“The impact is not only on my life, but also [on] my parents, I can see the stress they go through; we need to focus on them also.” – 21-year-old F, interview</p> <p>“The psychological impact of lupus is important, because if people have psychological issues then their interaction with other people is affected, their families and friends and this impacts on their lives also.” – 14-year-old F, interview</p>
Severity of comorbidity or complications	<p>“Kidney disease affects me, and I really don’t want to go onto dialysis.” – 21-year-old F, interview</p> <p>“I think that occupational therapy/physiotherapy and social work specialties don’t really need priority. Other specialists are more important, like cardiologists, I know a lot of lupus patients die because of heart disease.” – 15-year-old F, interview</p> <p>“I have had a lot of problems with depression, anxiety and I still to this day have a lot of problems, I think if I would have seen someone at the start of my illness, my depression probably wouldn’t have been that bad and probably my lupus would be in a better state, as I would have taken better care of myself.” – 18-year-old F, interview</p> <p>“Psychological health. I think it’s important because you don’t realize it until you’ve lived with it for a while, I was like ‘oh god, I’ve never actually experienced this’. There were months when I didn’t want to take my medication, days I wanted to cut myself, hang myself, just end my life.” – 26-year-old F, focus group</p> <p>“Neurologist, they’re important. I hear stories how lupus can affect you neurological-wise. I’ve seen people who change; they’re not themselves anymore because how lupus affects them.” – 26-year-old F, focus group</p>
Reducing lifestyle disruption	<p>“I spend a lot of money on foundation and concealer, because I feel awkward leaving the house and it’s really red. Lupus is mainly invisible, but the skin rashes are a physical indicator of the disease.” 17-year-old F, interview</p> <p>“Well, SLE is unpredictability. You are never too sure when a flare is going to occur. I think if there were better ways to prevent and treat flares then that would be a great help, so you can live a normal life not in fear.” – 23-year-old M, interview</p> <p>“Actually, the very first time I was in hospital, I was in for six months straight; I was in bed most of the time. I pretty much had to learn how to walk again, it wasn’t easy, I was completely weak and I couldn’t do much for myself. So the physiotherapists definitely helped me get back to a normal life, they do an important job.” – 19-year-old F, interview</p> <p>“I want to be able to just go through the day without feeling tired, because I have issues when I was at university or for an in-service or something at work, I’m just going to fall asleep, I dread it. Sometimes I’m in the movies I’ll fall asleep.” – 26-year-old F, focus group</p> <p>“Well the answer to what causes lupus, because, like, you already have it, it is just knowledge and you can’t change anything, it won’t improve our lives.” – 15-year-old F, focus group</p>

Table 2. Continued.

Theme	Illustrative Quotations
Fulfilling future goals	<p>“I was depressed and finding it hard to fit back in really. I’d been off school for quite a while. I’d come back looking, well not completely different, but my hair was gone. I didn’t really want to be there.” – 21-year-old F, focus group</p> <p>“My money would be preventing flares, as I am just worried about that like I have been clear for three to four years now. I just hope it stays like that; I need my peace of mind, so I can move forward with my life, my work.” – 23-year-old M, interview</p> <p>“Priority should be given to improving pregnancy outcomes for patients with SLE because I know I want a family and I would hate to think lupus would impact my ability to have a one.” – 20-year-old F, interview</p> <p>“We’ve been told it’s genetic. If I can have kids, then I would like to know if they’d have more chance of having lupus.” – 20-year-old F, focus group</p>

SLE: systemic lupus erythematosus.

healthcare specialties were printed on individual cards and in each exercise the appropriate cards were distributed randomly to each participant to avoid ordering bias. Participants were then asked a series of questions regarding their allocation of votes (Supplementary Table 1 is available with the online version of this article). Participants could change their distribution of votes during the discussion. All sessions were digitally audio-recorded and transcribed verbatim.

Analysis. We calculated the mean and 95% CI based on votes (no. tokens allocated; minimum score 0, maximum score 10) for each research topic, research question, and healthcare specialty.

Qualitative data analysis was based on the principles of grounded theory and thematic analysis^{26,27,28} to inductively identify themes and theories about the priorities of young patients with SLE. Transcripts from focus groups and interviews were entered into HyperRESEARCH (Research Ware Inc., version 3.5.2). DJT read the transcripts line-by-line and inductively coded the transcripts into concepts. HyperRESEARCH was used to generate a report of all the codes with the corresponding text; similar concepts were grouped into themes. The coding framework was discussed among the authors (investigator triangulation) to ensure it identified and reflected the range and breadth of the collected data. We developed an analytical framework and thematic schema through analysis and comparisons of concepts.

RESULTS

Recruitment and participant characteristics. Of the 44 patients contacted, 26 (59%) participated in our study. Eight (31%) participated in 3 focus groups and 18 (69%) participated in interviews. Reasons for nonparticipation included competing priorities, low priority, and parental refusal. Participants were aged from 14 to 26 years (mean 18 yrs, SD 3.15), and 15 (58%) were 18 years old or younger; most were female (n = 24, 92%), of Asian ethnicity (n = 16; 62%), and students (n = 20, 77%). Median disease duration was 6 years (interquartile range 2.3–8); the most common self-reported SLE manifestations were arthritis (n = 17, 65%) and skin lesions (n = 11, 42%; Table 1).

Broad research topics (3 research topics). The research topic “medical management” had a mean of 3.7 votes (95% CI 3.4–4.1) and “prevention and diagnosis” also had a mean of 3.7 votes (95% CI 3.4–4.1). While “lifestyle and psychosocial” research topic had a mean of 2.5 votes (95% CI 2.3–2.9; Supplementary Figure 1 is available with the online version of this article).

Medical management (11 questions). The research question “How can we effectively manage lupus flares?” had the highest mean of 1.3 votes (95% CI 1.1–1.5), and 1 participant (4%) gave 3 votes for this question. Of the 11 research questions, 7 on average received less than 1 vote (Supplementary Figure 2A is available with the online version of this article).

Prevention and diagnosis (5 questions). The research question allocated the most votes with a mean of 2.6 votes (95% CI 2.2–2.9) was “What are the causes of SLE?” Sixteen (62%) participants gave 3 votes or more to this research question. The research question allocated the least votes with a mean of 1.6 votes (95% CI 1.3–1.8) was “Why are certain populations at higher risk?” Two (8%) participants gave 3 votes or more to this question (Supplementary Figure 2B is available with the online version of this article).

Lifestyle and psychosocial care (4 questions). The research question “What is SLE impact on psychological health?” was allocated the most votes with a mean of 2.9 votes (95% CI 2.6–3.1), and 18 participants (69%) allocated 3 or more votes to this question. The research question “What is the impact of SLE on relationships?” received the lowest number of votes, with a mean of 2.0 votes (95% CI 1.7–2.2), and 5 participants (19%) allocated 3 or more votes to this question (Supplementary Figure 2C is available with the online version of this article).

No additional research topics or research questions were suggested by participants.

Healthcare specialties (11 specialties). The number of votes allocated to healthcare specialties is shown in Supplementary Figure 3 (available with the online version of this article). The mean indicated less focus on some allied health specialties, for example, occupational therapy and physiotherapy, 0.5 votes (95% CI 0.3–0.8), and a concentration on medical specialties, for example, rheumatology, 1.6 votes (95% CI 1.3–1.9). No additional healthcare specialties were suggested.

Themes. We identified 7 themes that reflected the reasons underpinning participant priorities: improving service short-

falls, strengthening well-being, ensuring cost efficiency, minimizing family/community burden, severity of comorbidity or complications, reducing lifestyle disruption, and fulfilling future goals. Illustrative quotations are provided in Table 2, the patterns and relationships among all themes are shown in Figure 1.

Improving service shortfalls. Participants based their priorities on addressing service gaps, particularly regarding diagnosis, education, and integrated care. They emphasized the need to improve the SLE diagnostic pathway because delayed diagnosis or misdiagnosis led to worsening symptoms and pain, and forced them to question whether they were “imagining” their symptoms. Participants explained that printed or online educational materials were not always culturally relevant to patients and/or families and often used medical jargon. Thus, patients were unable to discuss SLE with their parents because the educational resources were not translated into their language. The lack of information regarding SLE received at diagnosis left participants frustrated because they did not know whether their “symptoms were normal,” which led to being confused, anxious, and fearful after reading information on the Internet about SLE. They believed general practitioners had an important role in diagnosing SLE because they were the participants’ first point of contact with the healthcare system. Participants wanted clinics to be more multidisciplinary, with input across medical and allied health specialties. They said they felt that receiving care from healthcare providers working in a team would help improve outcomes for patients with SLE.

Strengthening well-being. Participants made decisions based on the expected downstream effect on their mental health that funding a healthcare specialty or research question would achieve. There was a strong emphasis on psychological health; it was described as “half the battle” for improving their SLE because it could affect their motivation and

capacity for self-management. To further improve psychological and emotional outcomes, adolescent participants believed that increasing awareness through education would facilitate empathy toward young patients with SLE and minimize stigma, particularly in schools. They also emphasized the need to understand the effect SLE had on their family relationships because they described being dependent on their parents for access to healthcare. Cosmetic side effects were also of high priority to adolescent participants, for example, improving steroid treatment to reduce associated weight gain, because of its effect on social acceptance.

Ensuring cost efficiency. Participants believed healthcare providers working in combined multidisciplinary clinics across medical and allied health specialties would improve outcomes for patients. Young adult participants expressed awareness of the high costs of healthcare and did not want to waste the resources of their families, who incurred out-of-pocket expenses. Understanding the “backbone of the disease” was expected to negate the need for further resources to be spent on the treatment and psychosocial care; thus, prevention and diagnosis of SLE was often given high priority. Some specialties were deemed less important if it was thought that their advice or treatment could be accessed from another source, such as the Internet, other healthcare providers, or family and friends. For example, participants believed personal trainers could provide a similar service to occupational therapists and physiotherapists. On the other hand, specialties that could not be accessed elsewhere and had a pivotal and specific role in the management of SLE received higher priority. In particular, rheumatologists, nephrologists, and nurses were seen to be primarily responsible for patient survival and quality of life because they provided education and treatment.

Minimizing family/community burden. Participants wanted to alleviate the psychological, emotional, and financial burden SLE imposed on their family and friends. They did not want

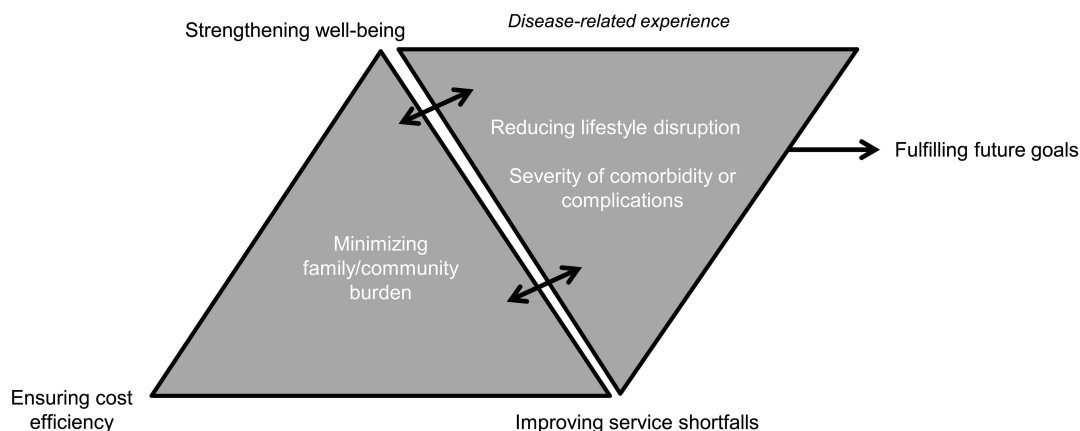


Figure 1. Thematic schema representing the conceptual patterns and relationships of the reasons for healthcare and research prioritization.

other patients or the community to experience the disease burden they had to endure. Participants considered a focus on improving mental health services, and research into the effect of SLE on psychological health, would help all patients with SLE improve relationships with their family and friends and gain social acceptance. Participants stated the need for a comprehensive approach to healthcare and research for the broad benefit of the patient population with SLE. They prioritized highly, in some instances, healthcare services and research not directly relevant to their individual experience. For example, they considered improving treatment for lupus nephritis (LN) important because dialysis would reduce the quality of life of young patients with SLE.

Severity of comorbidity or complications. The relative importance of complications of SLE was based on whether it would increase their mortality risk. Cardiovascular (CV) health was indicated to be important by participants who were aware of the high rates of CV-related deaths in patients with SLE. Additionally, the effect of health complications on quality of life was considered. For example, LN was deemed a priority because of the potential need for dialysis, and neurological SLE was considered important because it could make patients “not themselves anymore.” Participants said they believed that impaired psychological well-being could damage their health because of suicidal thoughts or indifference toward treatment adherence, particularly for patients with depression and anxiety.

Reducing lifestyle disruption. Participants considered in their allocations the effect that clinical manifestations and comorbidities of SLE had on their social life. Skin rashes and alopecia made adolescent participants anxious and uncomfortable in social groups because they felt “awkward leaving the house, as skin rashes are a physical indicator of lupus” and as a result avoided school and social gatherings. Participants experienced fatigue and dreaded having to concentrate for extended periods in their school, university, or work. The uncertainty and fears about the relapsing characteristic of SLE and its effect on everyday life were also considered in their allocation choices. Research questions perceived to be “just knowledge” and without improvements in patients’ quality of life were allocated fewer votes. For example, participants deemed that understanding the cause of SLE would have little to no effect on current management and hence their lives.

Fulfilling future goals. Participants wanted research to focus on the prevention of SLE and flares to improve their capacity to achieve vocational and family goals. Female participants desired efforts to improve pregnancy outcomes and research on genetic transmission to understand the risk of “passing on” their disease to their children. Young adult participants struggled with a sense of uncertainty because SLE impinged on their “peace of mind.” They believed SLE could threaten their ability to work and their career aspirations. Therefore, they ranked research questions that would result in disease

quiescence highly, for example, a cure for SLE or improving management of flares.

Conceptual interplay. Patterns and relationships among all themes are shown in Figure 1. The participants’ prioritization was influenced by concerns for themselves as well as their family, other patients, and the wider population. Addressing deficiencies in care, focusing on improving quality of life, and ensuring efficient use of available resources were believed to be important for minimizing the psychological, emotional, and financial stress on the community. The benefit to families and other patients was at times prioritized over the individual needs and goals of young patients with SLE, although improving the SLE-related experiences of young patients could help improve the burden placed upon the community.

DISCUSSION

Adolescent and young adult patients with SLE emphasized the need for an integrated and multidisciplinary approach across medical and allied health specialties. They asserted that healthcare and research should empower them to self-manage their disease, improve quality-of-life outcomes, and address the anxiety associated with the unpredictable characteristics of SLE, either directly or indirectly. Young patients with SLE prioritized the need to address gaps in service provision and to focus resources on research that would help mitigate financial and emotional costs to families. Minimizing this community burden was often prioritized over the personal SLE-related needs of young patients. Those needs included gaining normality in their everyday lives (improving appearance, reducing fatigue) and achieving family and vocational goals.

Differences between age groups were apparent. Young adults considered the financial and personal cost of health services, and their priorities were driven by career goals. For adolescent patients, peer acceptance was important and they wanted to minimize stigma and improve body image. Their healthcare priorities were influenced by dependence on their parents for access to healthcare.

Clinical practice guidelines for the management of SLE recommend coordinated multidisciplinary care^{29,30}. Models of care with a comprehensive and integrated approach are used in the management of adult patients with SLE^{31,32}, but less so in adolescent patients with SLE^{17,24}. The transition from pediatric to adult care presents a challenge in SLE because transitioning patients are at increased risk of poor symptom control, hospitalization, and mortality^{16,33}. SLE may also compound challenges associated with adolescence and impair young individuals’ capacity to meet emerging adult responsibilities^{34,35} and achieve educational and vocational goals^{14,36}. While transition clinics with comprehensive education programs have been shown to improve outcomes in other diseases³⁷, there are limited data on transition and SLE. Multidisciplinary clinics with psycho-

logical services may help address the unmet needs of adolescent and young adult patients with SLE^{35,38,39}. Further, transition clinics closely integrated with research may help address the knowledge gap of the timing of transitioning and identify the specific healthcare processes important to improve health and quality-of-life outcomes of young patients with SLE³⁹.

Our study demonstrates that young patients with SLE place a high priority on research that would indirectly improve psychological outcomes. Research to assess the direct effect of SLE on psychological health was important, but more broadly, they wanted research to address deficiencies in diagnosis, the reduction of flares, and cosmetic side effects, because these were perceived to cause anxiety and depression. Despite this, there is a paucity of mental health research in juvenile-onset SLE. Most research has been conducted to answer questions of etiology, understand disease mechanisms, and evaluate the effectiveness of pharmacological interventions^{40,41}. Given this mismatch, we suggest a research priority-setting partnership involving all stakeholders, including clinicians, researchers, patients, and caregivers as recommended by the James Lind Alliance⁴², to be conducted to further inform a patient-focused research agenda.

Our findings share similarities with previous studies on patient priorities in rheumatology. Research priority-setting on joint pain and hip and knee replacement for OA^{8,10,43} found that patients focused on lifestyle and self-management, and prioritized research that would improve outcomes such as pain and physical functioning. Our results share some similarities with 2 studies that elicited patient perspectives on healthcare service delivery in adult outpatient clinics⁴⁴ and in juvenile idiopathic arthritis⁴⁵. Patients also voiced the need to minimize delays in diagnosis and to help patients achieve vocational goals. We identified that young patients with SLE prioritize research aimed to alleviate fears of flaring disease, depression, and anxiety³⁸, and resolve experiences of debilitating pain, fatigue, and prognostic uncertainty^{35,46}.

In our study, methodological triangulation was used through semistructured interviews, focus groups, and allocation exercises. The use of this mixed-methods design allows for comprehensive and rich data to be obtained^{18,19} and provides a unique perspective on the priorities of young patients with SLE. However, there are potential limitations of our study. The quantitative exercise generated descriptive data because of a small sample size. The exercise was used to prompt discussion about the reasons for participants' priorities. Despite the low attendance rates of focus groups, we were able to capitalize on group dynamics to ascertain reasons for similarities and differences of opinion. We acknowledge that the group setting may inhibit responses, but this was not apparent^{19,47}. There were also limitations in our study recruitment. Although clinicians were asked to recruit patients diagnosed with SLE, we cannot ascertain whether patients were classified according to the ACR or

SLICC/ACR criteria. Non-English-speaking patients were excluded. The majority of participants were female and Asian, which reflected the sex and ethnicity distribution of patients with juvenile-onset SLE in Australia and internationally^{48,49,50}. Our study was conducted in a single region and differences may be evident across other research and healthcare structures. For example, the healthcare specialties presented in allocation exercises may not reflect all services accessed by young patients with SLE in other countries.

Young patients with SLE value comprehensive and coordinated care. They prioritize research that alleviates anxiety associated with a remitting-relapsing disease and improves patients' social acceptance among their peers. Decisions about resource allocation should be guided by a healthcare and research agenda developed through a priority-setting partnership that includes patients, which may improve treatment satisfaction, health, and quality-of-life outcomes.

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ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

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