Title: "Lupus means sacrifices" – the perspectives of adolescents and young adults with systemic lupus erythematosus.

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ABSTRACT:

Background: Disease activity, organ damage and treatment burden are often substantial in children and adolescents with systemic lupus erythematous (SLE), and the complex interplay among the developing child, their parents, and their peers makes effective management difficult. We aimed to describe the experiences and perspectives of adolescents and young adults diagnosed with juvenile-onset SLE to inform strategies for improving treatment and health outcomes.

Methods: Focus groups and face-to-face semi-structured interviews were conducted with 26 patients aged 14 to 26 years, from five Australian hospitals in 2013-2014. Focus groups and interview transcripts were thematically analyzed.

Results: Five themes were identified: marring identity (misrepresented self, heightened self-consciousness, sense of isolation); restricting major life decisions (narrowed career options, threat to parenthood); multifaceted confusion and uncertainty (frustration of delayed or misdiagnosis, needing age and culturally appropriate information, ambiguity about cause of symptoms, prognostic uncertainty, confronting transition to adult care); resentment of long-term treatment (restricting ambition, animosity towards medication use); gaining resilience (desire for independence, developing self-reliance, recalibrating perceived disease severity, depending on family, trusting physicians).

Conclusions: Young patients with SLE perceive they have substantially limited physical and social capacities and restricted personal and career goals. Psychosocial and educational interventions targeted at improving confidence, self-efficacy, disease-related knowledge, social support, and resolving insecurities regarding patients' capacity for self-management may alleviate psychosocial distress, improve adherence, and thus optimize health outcomes of adolescents and young adults with SLE.

Significance and Innovations:

- Adolescent and young adults with SLE resent the restrictive impact of disease on career opportunities and parenthood goals.
- They desire autonomy in their healthcare, but are at the same time uncertain about their own capacity to self-manage an unpredictable disease.
- Ongoing and culturally appropriate information regarding treatment and lifestyle management, and active involvement in health decision making may increase confidence and resourcefulness for self-management.

INTRODUCTION:

Systemic lupus erythematosus (SLE) is known to have serious effects on multiple organ systems (1, 2) leading to mortality rates that are 3 times higher than the general population (2, 3). SLE commonly effects young patients, 15-20% of patients have disease onset during childhood and adolescence (4, 5). Compared to adult-onset SLE, juvenile-onset SLE is more aggressive with higher disease activity (4), more severe organ manifestations, and with a higher incidence of renal, cardiovascular and neuropsychiatric SLE (4, 6-8). At present, pediatric and adult management strategies are similar, though the burden of steroid and immunosuppressive therapy is greater among children and adolescents, and care is more complex because they have physical and psychosocial maturation to contend with, and parents and caregivers need also be involved (6, 8).

Adolescence is a phase of life that concerns the transition to adulthood, and the formation of an identity. Life course theory and role theory stipulate that the social context and the behavior expected of adolescents, according to their perceived roles influence their social trajectory, such as education, work and parenthood (9-12). Complex chronic disease such as SLE may compound the challenges during adolescence and impair the capacity of young individuals to fulfill emerging adult roles and responsibilities (13). Specifically, juvenile-onset SLE has been reported to adversely affect school attendance, academic achievement, employment and establishing independence (14-17).

The limited qualitative research into the effect of SLE on adolescents and young adults has highlighted the impact of the disease on self-esteem, stigmatization, and uncertainty of the future (18, 19). Quality of life surveys have shown decrements in scores in the domains of physical health, self-esteem, worry and academic performance in this population (20, 21). The attitudes and perspectives of adolescents and young adults with SLE on the challenges of disease activity, damage and treatment burden on emerging adult responsibilities, and the

development of independence and identity need to be further understood, as they may help inform clinical practice.

Qualitative research may provide in-depth understanding of patient perspectives, concerns, and healthcare needs, which may not always be expressed in the clinical setting. This understanding may help to inform clinical practice, and suggest novel ways to improve health outcomes for patients with juvenile-onset SLE. This study aims to describe the experiences, perspectives, and healthcare needs of adolescents and young adults diagnosed with SLE prior to 18 years of age, to inform the delivery of healthcare services that are responsive to their priorities and concerns, and ultimately improve clinical and quality of life outcomes in this population.

METHODS:

Participant selection and setting

Participants were recruited through five hospitals in New South Wales, Australia. Participants were purposively sampled using patient databases to obtain a wide range of demographic and clinical characteristics. Patients were eligible if they were English-speaking, aged from 14 to 30 years old and diagnosed with SLE before 18 years of age. Patients with intellectual disability and unable to give informed consent, or deemed medically unsuitable by their primary physician were excluded. After ethical approval was obtained from all sites, the primary physician of the patient contacted participants as well as their parents (if patients were aged <18 years) and obtained permission for DJT to invite them to participate in the study.

Data collection

Participants had the option to attend a focus group or a face-to-face semi-structured interview. Using multiple methods for data collection can enable more comprehensive data to be collected (methodological triangulation) (22), and provides opportunity for those unable to attend focus groups to be involved in the study (23). Participants aged below 18 years old could choose to have their parents present. All participants were given a reimbursement for their time in the form of a $10 gift card. Focus groups and interviews were conducted from October 2013 to February 2014.

The question guide for the focus groups and semi-structured interviews were developed based on a recent systematic review and thematic synthesis of experiences and perspectives of people living with SLE (24), qualitative studies (18, 19), and discussion among the authors (Supplementary file table S1 & S2). The question guide was piloted on several respondents at study commencement to ensure that the questions were clear, comprehensible, and effective in eliciting responses to relevant research questions.

Focus groups were held in centrally located meeting rooms external to the hospital and convened by age groups (14-18 years, 19-30 years) to promote rapport among participants. We planned to run three groups of 6-8 participants for each age group. The focus groups were conducted by one researcher (DJT) and a second researcher (either AFR or AT) was present to take field notes to record the group dynamics and non-verbal communication. The semi-structured interviews were conducted by DJT at the participant's home, hospital, local library or community center, based on the participant's preference.

Recruitment ceased when we reached theoretical saturation, defined as when little to no new concepts were emerging in subsequent data collection. All focus groups and interviews were digitally audio-recorded and transcribed verbatim.

Analysis

Data analysis was based on the principles of grounded theory and thematic analysis (25), to inductively identify themes and theories about the experiences and perspectives of living with SLE that were grounded in the data collected. The focus group and interview transcripts were entered into HyperRESEARCH (Research Ware Inc. United States Version 3.5.2). DJT read the transcripts line-by-line, and coded the transcripts into concepts identified inductively. 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 DJT, DSG, JC, AT (investigator triangulation) to ensure that it captured and reflected the full range and breadth of data collected (26). An analytical framework was developed through a process of analysis and comparisons of concepts.

RESULTS:

Recruitment and participant characteristics

Twenty-six (59%) of the 44 patients contacted participated in the study. Reasons for non-participation included competing priorities, and parent refusal. Of the 26 participants, eight (31%) participated in one of the three focus groups, and 18 (69%) participated in semi-structured interviews. The participant's characteristics are provided in Table 1. The participants were aged between 14 to 26 years (mean 18 years); 92% were females and 62% identified as being of Asian ethnicity. The median (standard deviation) disease duration for participants was 6 years (± 3.7 years); and participants reported a range of SLE manifestations including arthritis (65%), skin lesions (42%) and kidney disease (35%).

Themes

Five themes were identified: marring identity (misrepresented self, heightened self-consciousness, sense of isolation); restricting major life decisions (narrowed career options, threat to parenthood); multifaceted confusion and uncertainty (frustration of delayed or misdiagnosis, needing age and culturally appropriate information, ambiguity about cause of symptoms, prognostic uncertainty, confronting transition to adult care); resentment of long-term treatment (restricting ambition, animosity towards medication use); and gaining resilience and coping capacities (desire for independence, developing self-reliance, recalibrating perceived disease severity, depending on family, trusting physicians). Illustrative quotations are provided in Table 2, simple count of themes (27) provided in the supplementary file (Table S3), and the conceptual patterns and relationships among all themes are shown in Figure 1.

Marring identity

Misrepresented self: Skin rashes, loss of mobility, weight gain and hair loss changed participants' self-perception from being a young and healthy person to being sick and incapacitated. However, some refused to allow the disease to define them as a sick person. They felt that others, particularly teachers, "stereotyped" them and "made a bigger deal out of it" by treating them differently; or insinuated the need for them to seek psychological services. Some observed that others believed SLE was contagious and that they acted cautiously when in close proximity to them. For these reasons, participants were reluctant to discuss their disease with friends and family.

Heightened self-consciousness: Some participants reported having a poor self-image and felt that their "beauty" was not the same as their peers because of the changes in their physical appearance. Skin changes (acne, striae and flushing) and weight gain from corticosteroids were of particular concern. Younger participants were teased about being a "freak" or looking "weird" in school, for some, this was identified as the most challenging aspect of living with SLE.

Sense of isolation: Feeling ostracized from friends and unable to participate in social activities was expressed by participants. They thought no one understood what they were going through, particularly during times when the disease was "invisible." Those with milder SLE sometimes felt out of place as their disease was less severe compared with what they had read about. Some participants expressed a desire to be understood, to gain a sense of belonging, and to connect with other patients with SLE either in person or online. They wanted greater public awareness about the disease and thought this would eliminate the feeling of abnormality they encounter when trying to explain SLE to others, this stigmatization they believed created barriers to the promotion of awareness of SLE.

Restricting major life decisions

Narrowed career options: The symptoms of SLE and the side-effects of medication meant they had to place boundaries on their future career aspirations. For example, photosensitivity permitted them to work only in indoor environments and one participant explained that this forced them to switch their subject majors during university. Younger participants explained how fatigue limited their capacity to study and said that their parents advised them to choose careers with "fewer hours". Some older participants lost their jobs after disclosing SLE to their employer; or were concerned that disclosure could prevent them from being employed in the future.

Threat to parenthood: Participants were concerned about the effect of medication on fertility and were "upset" about how their ability to have children in the future could be impaired. They were also anxious about genetic transmission of SLE and did not want to "burden" their future children with SLE by passing it on, which caused some to consider surrogacy.

Multifaceted confusion and uncertainty

Frustration at delayed or misdiagnosis: Some harbored resentment regarding the delayed timing of their diagnosis. They felt that if SLE had been detected earlier their disease would not be so severe. The delayed diagnosis made some participants feel dismissed and one participant questioned their own mental state – "I thought I was kind of imagining these things. Like am I doing it for attention? Am I crazy?"

Needing age and culturally appropriate information: Some participants felt bewildered by information they received; which they regarded as too technical for a young person to understand, particularly when unwell. Some stated that information on medications and tests was communicated to their parents rather than being relayed to them directly. This was

particularly perplexing for adolescents with parents of non-English speaking backgrounds. Some did their "own research" on the internet and were left feeling overwhelmed, and some believed that the personal and direct communication from healthcare providers gave them a "peace of mind" and wished they had been told at diagnosis "that it gets better".

Ambiguity about cause of symptoms: Participants were confused regarding the cause of SLE and its symptoms. Some expressed frustration when they perceived that their physician attributed medication side-effects as a symptom of SLE, a number of participants felt blamed by their peers for having symptoms as people did not understand the disease. At times, they believed their parents made them feel "constricted in places" by controlling their lifestyle.

Prognostic uncertainty: Some described anxiety about "not knowing" their prognosis and side-effects of medications. These anxieties were triggered when they read about poor health outcomes and negative personal accounts about SLE on the internet, met someone else with more severe SLE, were at doctors' appointments, or awaiting test results. The unpredictable course of SLE forced one participant to leave work on numerous occasions. Participants with milder disease were concerned about the potential for SLE to become more severe, those in remission questioned how long it would last, those who received a kidney transplant were worried about the disease recurring in the graft.

Confronting transition to adult care: Young adults depicted the navigation through the adult healthcare system as challenging. They found the system of referrals arduous and were confronted by sharing hospital rooms with older patients. They described that the reliance on their pediatric specialist and parents during adolescences influenced their indecision and delay in deciding crucial components of their healthcare, such as choosing a new specialist. Some participants wanted to be gradually introduced into the adult healthcare system, while some were still seeing their pediatric specialist because of the relationship they had developed and to avoid the "stress" of getting use to a new specialist.

Resentment of long-term treatment

Restricting ambition: SLE was described as a “sacrifice” as participants had to forgo what they wanted to do. The burden of treatment, constant clinical appointments, side-effects of medication use, and symptoms of SLE reduced their capacity to achieve in the workplace and/or their studies. This inhibited the participants’ aspirations for success in their academic and vocational goals. Young adult participants felt constricted in their ability to travel because having to rely on medication could leave them “stuck” somewhere, and because they could not afford the high cost of medication and health insurance overseas.

Animosity towards medication use: Dependency on medication to maintain health was described as “weird” and “sickening” by participants because they felt well and had no “incentive” to take medication. This reliance on medication was paradoxical for some participants who felt well and believed it was not a “big deal” if they refrained from taking their medication. Some participants, however, felt ill after missing medications and became convinced of its necessity. The constant medication and frequent clinical appointments served as reminders of their illness and made them feel abnormal. At times, participants avoided treatment due to the numerous side-effects they experienced while some felt like a “guinea pig” because the constant switching of medications and trialing of dosages that resulted in further side-effects.

Gaining resilience and coping capacities

Desire for independence: Some participants, including young adults, felt that their parents were over involved in their healthcare and therefore lacked confidence about self-management. Participants wanted autonomy and did not want to worry their parents unless they were “really; really sick”.

Developing self-reliance: Participants strived to maintain a positive attitude by viewing SLE as a challenge that they would overcome. Living with SLE made them more confident because they realized their high tolerance for pain and their own strength of character. They learned to cope or problem-solve to deal with side-effects. Living with SLE for some participants had become easier over time as their experiences had allowed them to handle the challenges that they have faced.

Recalibrating perceived disease severity: Participants appreciated “normal days” when their disease wasn’t active. They compared themselves to other patients with SLE and considered themselves “lucky” when they realized they had a less severe form of SLE. Medications and its side-effects were deemed bearable as this minimized the risk of the disease becoming severe. For participants with lupus nephritis, chronic kidney disease and potential end-stage kidney disease became their dominant concern, taking priority over SLE, and another participant explained that they “forget” about their SLE because of overriding complications of meningitis including hearing loss.

Depending on family and friends: Participants felt indebted to their families as they relied on them for practical support, access to the best available treatment and information regarding SLE. Friends provided emotional support, particularly when they “broke down” at school due to the change in their physical appearance because of skin changes and weight gain from immunosuppression.

Trusting physicians: Having confidence in their healthcare providers allowed participants to “tell anything to them and be honest”. Rather than seeing a local specialist, one participant opted to travel the longer distance to see the specialist whom they trusted to keep their SLE controlled. Some participants felt nervous about seeing other healthcare providers or taking medications that were not prescribed to them by their primary physician. They felt frustrated

by other physicians, particularly general practitioners, who some regarded as having a lack of knowledge in SLE. A few participants sensed they were “judged” by their physicians if their SLE didn’t improve, or if they didn’t take their medication.

DISCUSSION:

For adolescents and young adults with SLE, changes in their appearance and limitations in daily functioning impinge on their sense of normality and confidence. The unpredictability of their short and long term prognosis makes it challenging for patients to plan for future career and personal goals. These uncertainties also disrupt their identity. However, some adolescents and young adults develop resilience, coping strategies and rely on social support to overcome challenges, and to maximize their participation in social, school and work life. There were some apparent differences across age groups and diagnosis. Young adults were particularly anxious about how SLE might limit their ability to work and narrow their career goals; while adolescents voiced frustration about being treated differently by teachers or peers. Female participants had concerns about the impact of medication on fertility, there were no other differences identified between male and female participants. For those with lupus nephritis, their dominant health priority appeared to have shifted from SLE to end-stage kidney disease and they have strong and specific fears about the potential need for dialysis or transplantation.

Our results reflect similar themes identified in the qualitative studies of adults with SLE, for example stigmatization, as patients feel socially ostracized from family, friends and clinicians due to a lack of understanding and empathy. Patients symptoms were often trivialized because of their invisible nature, creating conflict in relationships and in the work place (24). Similar themes have been identified in the few qualitative studies that have been conducted with adolescents and young adults with SLE (18, 19). For example, worries about future parenthood and career options. However, our findings add to the existing literature by detailing the challenges of transition to adult care and their desire for autonomy in healthcare despite doubts about their ability to self-manage. Our results also draw attention to how patients recalibrate the severity of SLE, based upon their interaction with fellow patients, or their overriding concerns of comorbidities, particularly end-stage kidney disease.

Patients with juvenile-onset SLE have reported lower quality of life compared with healthy children and children with arthritis (18, 21), particularly in the domains of physical health, worry, self-esteem (6, 20) and school (6, 17). The themes identified in our study may help to explain these findings. For example, we found that patients perceived SLE disease manifestations of kidney disease, neurological SLE and hematological disease to be severe and the lower scores in the domain of worry may be due to fears about life-threatening complications including risk of cardiovascular disease or end-stage kidney disease. The relatively lower scores in self-esteem could be because patients have a heightened self-consciousness due to changes in skin appearance associated with SLE and weight gain due to medications; which in turn can lead to being bullied at school and account for the reduced scores for the school domain.

In our study, we used both focus groups and face-to-face semi-structured interviews, which were both effective in eliciting in-depth data from an under-studied population. However, we acknowledge a number of potential limitations. Despite offering flexible times for focus groups, the response and attendance rates were low; however the semi-structured interviews provided an alternative for patients to share their perspectives. The majority of our study population were female and Asian, which reflects the gender and ethnicity distribution of patients with juvenile-onset SLE in Australia and internationally (28-30). While the exclusion of Non-English speaking patients may limit the transferability of these findings, other qualitative studies conducted with patients with juvenile-onset SLE have reported similar themes, which suggests that the findings may be relevant to other settings (18, 19).

Juvenile-onset SLE can lessen the capacity of adolescents to achieve various developmental milestones including academic achievement, employment, independence and parenthood (14-16). It is well recognized that interventions to improve their ability to achieve these goals, and address patients' concerns are needed. Such interventions may be

in the form of multi-disciplinary care transition clinics (31-33) and low-cost social support networks such as internet-based communication, which are increasingly being used by patients with various health conditions including SLE (34, 35).

SLE before 18 years of age is complicated by numerous factors that make the transition to adult care challenging (31). The need for transition clinics with multidisciplinary care is widely advocated (31, 32). Transition clinics are dedicated clinics which involve both pediatric and adult healthcare teams that help facilitate the handover of patient management and have been reported to improve the health outcomes in rheumatic diseases (36, 37). However, there is limited data on transition in the context of SLE. One strength of our study is the inclusion of both adolescents and young adults, as it identified many of the concerns raised during the transition period. Concerns which transition clinics for SLE may help to alleviate, as they provide the opportunity for adolescents to achieve independence, develop rapport with the new specialist, establish support networks outside the family, and receive relevant education that address specific health concerns, e.g. risk of developing osteoporosis at an early stage in life, concerns about sexual health, reduced fertility, parenthood capacity, and career options (31, 32).

Our findings confirm a critical clinical practice gap – the provision of social support networks to improve optimism and empowerment in adolescents and young adults with SLE (38-40). Studies have demonstrated that poor social support is associated with higher SLE activity, and impaired quality of life (41).Moderated online public or private bulletin board post forums have the potential to improve patient self-empowerment and change patient lifestyle behavior (42, 43), although their effects on health outcomes are still unclear (44, 45). They help alleviate stigmatization as they allow patients with SLE to find supportive relationships, seek health information, receive emotional support and provide an opportunity to contribute (34, 35).

Provision of health information about SLE, treatments and the services available to patients has been shown to improve confidence for self-management, partnerships with healthcare workers and ability to engage in social, school and work activities (46, 47). Research has shown that healthcare worker led health-information interventions have the potential to improve patients self-efficacy, self-care, leading to increased healthcare utilization, improve quality of life and better health outcomes in both adolescents and adults with SLE (48-51). It has been suggested that specialist nurses play a vital role in providing care and education to patients with rheumatic conditions including SLE (52, 53). Further qualitative studies exploring the health information seeking behaviors of adolescents and young adults with SLE and studies identifying the barriers to accessing health-information interventions in these populations are suggested.

Most of the quality of life scales used in SLE are not specifically developed for young patients (54). Of note, the Simple Measure of the Impact of Lupus Erythematosus in Youngsters (SMILEY) is a validated pediatric quality of life scale specific for SLE and measures four domains: effect on self, limitations, social, and burden of SLE; which has been used in clinical care (55). These domains are based on qualitative research (18) and encapsulate some of the themes identified in our study including marring identity and restriction of major life decisions. Based on our findings, it may also be relevant to include items relating to knowledge of SLE, confidence in accessing healthcare, and perceived capacity for self-management.

Young patients with SLE perceive they have limited physical and social capacities and restricted personal and career goals. Psychosocial and educational interventions targeted at improving confidence, self-efficacy, disease-related knowledge, social support, and resolving insecurities regarding patients' capacity for self-management alleviate poor treatment and health outcomes of adolescent and young adults with SLE.

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Table 1: Participant characteristics (n=26)

Characteristics	n	%
Gender		
Male	2	8
Female	24	92
Age (years)		
14-18	14	54
18-30	12	46
Disease duration (years)		
0-3	10	38
4-6	6	23
7-9	7	27
10-12	3	12
Ethnicity		
Asian	16	62
Caucasian	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	3	12
Not working	2	8
Part time	1	4
Language/s spoken at home		
English	15	60

***** Some participants reported more than one clinical manifestation

Table 2: Illustrative quotations

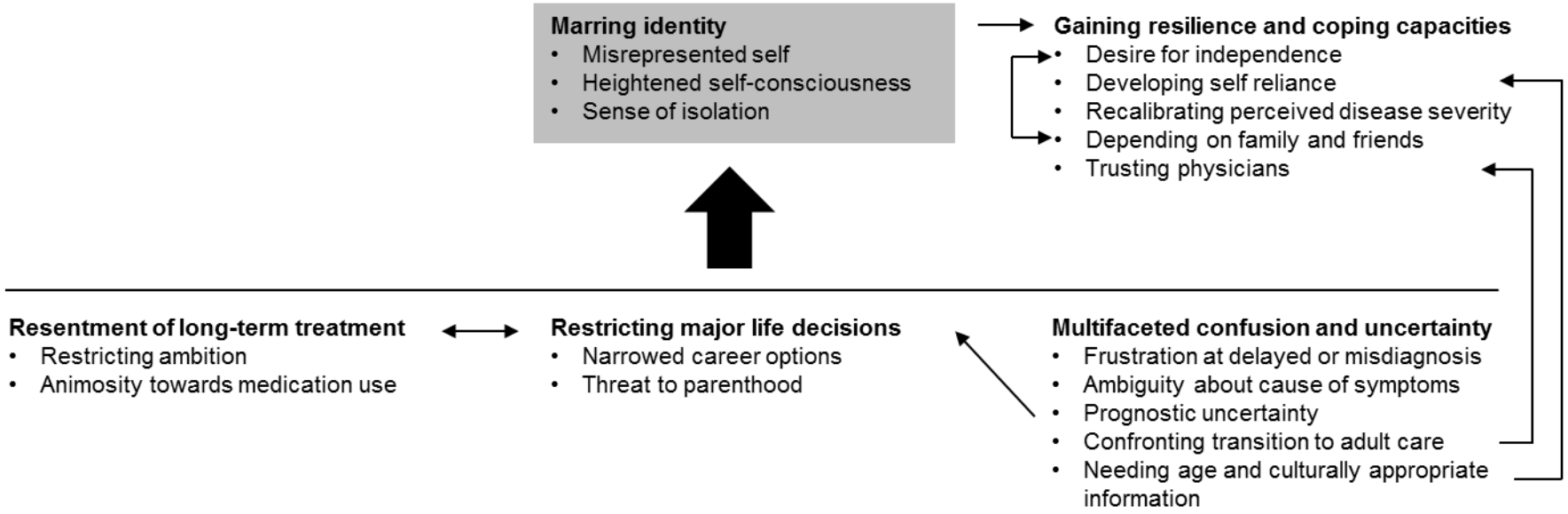
Theme	Illustrative quotations
Marring identity	
Misrepresented self	**"**I don't really disclose it until I have to. I don't want to be treated differently; I am the same as before, I just have to take better care of myself." *19yrM Interview*
	"I don't want to make [lupus] who I am. I really want to promote it and say research needs to be done, but then also I don't want people to think that is who I am, it's not who I am. I want to separate it." *20yrF Interview*
	"I don't want to talk about it all the time, because I don't think my disease should define who I am" *15yrF Interview*
Heightened self-consciousness	**"**It brought a lot of insecurity, since you gain a lot of weight with the prednisone, you get hair loss, they are really nasty a lot of the time" *18yrF Interview*
	"I guess taking so much medications and you're not growing as the same as everyone else. Your beauty is not the same." *16yrF Interview*
	"It was really hard getting to school; I was on prednisone and got pretty fat, so I was getting bullied a lot, it was hard." *20yrF Focus group*
Sense of Isolation	**"**Young people need to know that they are accepted into society by seeing that there are others like them. It is good to bring people together, so they can relate and share stories.*18yrF Interview*
	"I'm even finding this [focus group] quite useful, this is the first time I've ever met anyone else with lupus, and someone who's my age." *21yrF Focus group*
Restricting major life decisions	
Narrowed career options	"My mum thinks I should do something with fewer hours. Full-time, but less hours, or in a more relaxed environment" *17yrF Interview*
	"I know that it [lupus] affected what I was doing at university because I wanted to go into archaeology, I went to one of the seminars for it you have to be in the sun constantly, you have to be 100% healthy, so then I had to change my major." *20yrF Interview*
	"Once you put stuff on the internet, if I ever go for a job like it's a very high chance that they might say no because there's a high chance that you might have an issue with your health. That's just the ugly truth. " *20yrF Interview*
Threat to parenthood	**"**I mostly think about bearing children. I know that they don't know really if lupus is heredity but even if it isn't they could have kidney disease, brain disease all these things from me. So I want to do IVF with a surrogate mother. Even if I don't pass anything on to them, my medications will harm a newborn; it is not something you want burden your children with." *18yrF Interview*
	"If I fall pregnant, I'm on methotrexate that can actually kill my baby, that's what I'm scared of." *26yrF Focus group*
Multifaceted confusion and uncertainty	
Frustration at delayed or misdiagnosis	"I don't understand how he missed it or even suggested that it could be sunburn. I have dark skin and I don't burn that easily. I don't think my blood was ever tested. I think he might have not been a very good GP, I don't see him anymore." *19yrF Interview*
	"I mean GPs do have to understand a lot of different diseases. Perhaps he wasn't a great GP and couldn't put my symptoms together. I was kind of unhappy with that, not being taken seriously. I guess I kind of doubted if I was sick, I thought I was kind of imagining these things. Like am I doing it for attention? Am I crazy?" *15yrF Interview*
Needing age and culturally appropriate information	"When I was younger I could have had someone explain it to me, I could have had like a psychologist explain that it wasn't something that wasn't going to go away." *18yrF Interview*
	"When I first found out I was really eager to know what it was, so I looked everything up on the internet. I told my doctor and he was like "No they only post all the bad things online." I got really scared." *16yrF Interview*
Ambiguity about cause of symptoms	"People go "You may have eaten something wrong", but we don't really know what causes lupus." *17yrF Interview*
	"It's hard when you know that the side effects are from the medication, they try and turn it around and say it's your lupus that really

	annoys me." *20yrF Focus group*
Prognostic uncertainty	"Not knowing. When the next flare –it could move to another organ or if it gets worse or if it will get better you don't know." *18F Interview*
	"Yeah I'm worried about the kidney, it's my dad's kidney so I'm worried that in 30 or 40 years what's going to happen" *16F Interview*
	"Sometimes I get worried, sometimes I do get sick at work, and my doctors will chase after me if my bloods are bad, it just ruins me, I just break down in tears. It's happened a few times, but it actually does worry me because it's unpredictable." *26yrF Focus group*
Confronting transition to adult care:	"One thing the doctor could have if they could break it [the transition] up, just getting used to it. It was kind of hard going from children's straight into adults, sleeping with adults was very weird." *19yrM Interview*
	"I think that has been something that's been difficult for me, the transition and to start making my own decisions, because they [parents] have been so heavily involved. Like I need to start figuring out what adult doctor I'm going to see." *20yrF Interview*
Resentment of long-term treatment	
Restricting ambitions	"For me lupus means sacrifices. I can't actually do what I want to." *16yrF Interview*
	"Well if I want to live overseas or something, or do backpacking, I can't do it because if I run out of medication that's it, it's the end of the world for me." *26yrF Focus group*
Animosity towards medication use	"I thought that there was nothing wrong with me, so why am I taking this for?" *23yrM Interview*
	"The main thing I have trouble with is getting used to taking medication and understanding that if I don't I will be sick and it's weird knowing that you are dependent on medication in order to live healthy" *15yrF Interview*
	"I hate it when they use me as a guinea pig, try other treatments and stuff. They just try me on different immunosuppressant drugs; I really suffer a lot with side effects." *26yrF Focus group*
Gaining resilience and coping capacities	
Desire for independence	"I still do a lot of things myself, but my parents still help me out. So I don't think that's as independent as I want to be" *15yrF Interview*
	"But I mean I know that I want to travel and do all these sorts of things and I don't know if I'll be able to do that by myself." *20yrF Interview*
	"You don't actually need support unless you are really; really sick and you can't do it on your own." *15yrF Focus group*
Developing self-reliance	"I sort of grew, I became a bit stronger, more independent , because my parents, come from a non-English speaking background, it was hard for them to understand what it was, so basically since I started doing everything myself." *26yrF Focus group*
	"I just took it every day at a time and that's how I got through it." *23yrF Focus group*
Recalibrating perceived disease severity	"I think because they don't often show the different degrees of how you can be affected, like I've probably been lucky." *20yrF Interview*
	"Well it made me feel like I had this disease but that's not really what I am experiencing. Then you realize there are different levels of it." *15yrF Interview*
	"I'm really worried about the kidney disease, I almost forget about the lupus because I don't want to go onto dialysis." *23yrF Focus group*
Depending on family and friends	"I was quite young when I first got diagnosed, and basically when I am sick, I really can't speak for myself and make decisions for myself, so my parents have been very influential in the decisions around my health" *20yrF Interview*
	"What helped me the most; I had a really big group of friends and they didn't really care what I looked like." *21yrF Interview*
	"My mum is very interested in it now; she reads a lot about the studies and things. She always pass on the information" *15yrF Interview*
Trusting physicians	"I don't really mind travelling all the way to the city if you've got a really good specialist and they know what they're doing and nothing goes whacky." *21yrF Interview*
	"Mostly around doctors you don't feel comfortable but I feel comfortable, like I am not afraid to say anything to him and be honest with him." *15yrF Interview*
	"I just want their opinion before I do things just because I get nervous. I don't really want anything to go wrong" *17yrF Interview*

* M= male, F= female

Figure legends

Figure 1: Thematic schema representing the conceptual patterns and relationships among all the perspectives and experiences of adolescent and young adults living with systemic lupus erythematosus.



Resentment about the restrictive impact of SLE and its treatment on life decisions and goals, and the uncertainties about their long-term health and day-to-day health status contributed to a profound sense of a marred identity. The unpredictability of their prognosis meant they felt unable to define career and family goals. To overcome these challenges, participants developed resilience and coping strategies