

Using photovoice to investigate patient experiences of lupus nephritis in Canada

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ABSTRACT

Objective Lupus nephritis (LN) is a major cause of morbidity and mortality, affecting up to 60% of patients with systemic lupus erythematosus (SLE). The perspectives of patients with SLE have been explored; however, little is known of the lived experiences of patients with LN.

Methods Patients aged ≥18 years with biopsy-proven pure or mixed International Society of Nephrology/Renal Pathology Society Class III, IV or V LN were purposefully recruited from a Canadian lupus cohort to participate in a photovoice (visual–narrative participatory research method) exercise. Participants took photos of what LN means to them, impacts on daily life and factors impacting LN management. Photos were shared and discussed in focus groups.

Results 13 individuals with LN participated (92.3% were female; mean (SD) age was 41.7 (14.0) years). The mean (SD) number of photos shared per participant was 4.2 (0.9). Photos (n=54) depicted activities/settings that contribute to well-being (n=15), the participants themselves (n=13), healthcare experiences (n=10), home (n=4), community (n=2), friends (n=2), work (n=2) and other challenges (n=6). All participants described physical and psychosocial impacts of living with LN. Although 12 mentioned activities/settings that contribute to well-being (eg, time in natural environments), participants were consistently reminded of limitations imposed by LN due to physical symptoms, challenges presented by the physical environment and the altered life trajectories experienced. Participants discussed the dual burden of LN and the associated medication journey; side effects and medication-related financial challenges were highlighted by ten and five participants, respectively.

Conclusions Participants reported a substantial psychosocial burden associated with altered life trajectories, the dual burden of LN and the associated medication journey, and the conflicting role of the physical environment. The need for flexibility (ie, from employers, themselves) is an essential component of navigating altered life trajectories.

INTRODUCTION

Although lupus nephritis (LN) is the most common severe manifestation of systemic lupus erythematosus (SLE), affecting 25%–60% of patients,¹ understanding of the lived experiences of patients with LN is limited. A recent interview study of

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Despite being the most common severe manifestation of systemic lupus erythematosus, our understanding of the lived experiences of patients with lupus nephritis (LN) is limited.

WHAT THIS STUDY ADDS

⇒ Through focus groups and photovoice (a visual–narrative participatory research method), this study documents the unique physical, emotional and lifestyle impacts of LN and the associated medication journey. Specifically, the psychosocial health burden of altered life trajectories, the dual burden of LN and the associated medication journey, and the conflicting role of the physical environment are critical components of the LN experience.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Results will inform the development of meaningful and effective interventions that target outcomes most relevant for patients with LN.

Canadian patients with LN found participants reported substantial impacts on daily life from the unpredictability of living with LN, heavy treatment burden and lack of individual patient and societal LN awareness.² Although semistructured interviews provide a valuable approach to explore illness experiences, other qualitative approaches (eg, focus groups) allow participants to share their experiences and build on others' perspectives through group interaction^{3 4}; focus groups can therefore elicit a richer understanding of the broad psychosocial impacts of LN that may not emerge in interviews alone.⁵

Using a social constructionist perspective (an approach that prioritises the subjective experiences of illness⁶), we employed focus groups and an innovative photovoice exercise to explore the experiences and perspectives of individuals with LN. Photovoice is a visual–narrative participatory research method that prioritises patient-lived experiences through photos and related narrative, whereby participants take photographs about

a meaningful issue that can be difficult to articulate with words alone.³ Photovoice centres the participant in the research; this offers participants autonomy and helps elicit the nuanced experiences of those living with a health concern.³ Although photovoice has been used to explore experiences of chronic conditions such as rheumatoid arthritis,⁷ SLE,⁸ diabetes,⁹ food allergy¹⁰ and mental illness,¹¹ to our knowledge, no studies are using this method to explore patient experiences of LN.

METHODS

Patients from the SouThern Alberta Registry for Lupus Erythematosus (STARLET) cohort were recruited to participate in a photovoice exercise and accompanying focus group. Consecutive patients with lupus seen by rheumatologists in Calgary are invited to participate in this observational STARLET cohort (n=426); all patients receive care through a multidisciplinary clinic environment at the University of Calgary Lupus Centre of Excellence, and are also cared for by primary care providers and other specialists in the community. Those ≥ 18 years of age with biopsy-proven International Society of Nephrology/Renal Pathology Society pure Class III, IV or V or mixed Class III/V or IV/V LN¹² and fulfilling the 1997 revised American College of Rheumatology¹³ or 2012 Systemic Lupus International Collaborating Clinics¹⁴ Classification Criteria for SLE, were recruited for this study. To ensure maximum variation, individuals were purposefully sampled with a range of sociodemographic characteristics and various LN-related disease characteristics.

Participants were invited to attend an online information session that provided photovoice guidelines and covered ethical considerations of taking photos in the research process.¹⁵ Specifically, participants were asked to take photographs over 2 weeks showing: (1) what LN means to them; (2) how LN impacts their daily life; (3) factors that impact how they manage their LN.

Participants were asked to choose 3–5 photos that were most meaningful to their lived experiences of LN. Participants sent these to the first author (FSC) before the focus groups. Three participants included photos (n=4) captured from the internet to represent their experiences; these visual representations were discussed in the focus groups, thematically analysed^{16,17} and are discussed in the results, but have not been reproduced in the manuscript.

During the focus groups and modelled on a previous photovoice study,¹⁸ participants were asked to describe: (1) what the photo was and where it was taken; (2) why the photo was important to understanding their experience of LN; (3) if they have any suggestions to improve the issue/challenge highlighted in the photo.

After describing each photograph, participants had the opportunity to share reactions, perspectives or experiences related to others' photographs.

All participants provided verbal informed consent to participate in the photovoice exercise and have their photographs and anonymous quotations published. Two

focus groups were conducted: one in March 2023 (n=6 participants) and another in April 2023 (n=7 participants). Focus groups were conducted via Zoom video conferencing. The focus groups were audio and video recorded and lasted 81 and 77 min, respectively. Both were led by FSC, who has extensive experience in qualitative research.

The focus groups were transcribed verbatim for subsequent thematic analysis using NVIVO for Mac. Transcripts were proofed and coded by FSC. Theme codes were developed deductively based on the results of previous semi-structured interviews,² and inductively based on themes emerging during focus group discussions. All photos and transcripts were coded using the theme code set. If uncertainties in coding emerged, FSC met with other members of the research team (SJE and AEC) to ensure discrepancies were addressed before finalising the analysis. The number of photos fulfilling each primary theme and the number of mentions of themes and subthemes by participants are highlighted in the results.

Patients and public involvement

This study was designed alongside a trained patient partner. Participants will be invited to a knowledge-sharing event where we will share results and solicit patient feedback for future research.

RESULTS

Participant summary

13 patients with LN participated; 92.3% were female, mean (SD) age 41.7 (14.0) years, mean (SD) age at LN diagnosis 26.2 (10.1) years, and 30.8%, 7.7% and 61.5% were of Asian, Indigenous and white race and ethnicity, respectively (table 1). All participants had taken an immunosuppressant or biologic during their disease course; four had received cyclophosphamide and eleven had received mycophenolic acid analogues. Three had been on dialysis and two had received a renal transplant. In the parent STARLET cohort from which these patients were recruited, 91.2% were female, mean (SD) age at cohort enrolment was 45.0 (16.1) years, mean age (SD) at SLE diagnosis was 35.0 (15.8) years, and 25.3%, 5.0% 2.2% and 56.3% were of Asian, black, Indigenous and white race and ethnicity, respectively; 56.9% had completed postsecondary education.

Photo overview

Of the 54 photos shared, the mean (SD) number of photos shared per participant was 4.2 (0.9). Images depicted well-being (n=15), the participant themselves (n=13), healthcare experiences (n=10), home (n=4), community (n=2), friends (n=2), work (n=2) and other challenges (n=6) (table 2).

Well-being

15 images, shared by six participants, depicted activities/settings that contribute to well-being. Throughout the focus groups, all participants described physical (eg,

Table 1 Characteristics of participants (all cared for in a multidisciplinary clinic environment)

Characteristic	Total sample (n=13)
Age, mean (SD), years	41.7 (14.0)
Age at LN diagnosis, mean (SD), years	26.2 (10.1)
Age at SLE diagnosis, mean (SD), years	24.4 (10.5)
Female, %	92.3 (n=12)
Self-reported race and ethnicity, %	
Asian	30.8 (n=4)
Indigenous	7.7 (n=1)
White	61.5 (n=8)
Self-reported post-secondary education,* % (n=11)†	63.6 (n=7)
Medications (ever), %	
Glucocorticoids	100.0 (n=13)
Hydroxychloroquine	100.0 (n=13)
Immunosuppressants/biologics	100.0 (n=13)
Azathioprine	46.2 (n=6)
Belimumab	38.5 (n=5)
Cyclophosphamide	30.8 (n=4)
Mycophenolate mofetil/mycophenolic acid	84.6 (n=11)
Rituximab	23.1 (n=3)
Tacrolimus	23.1 (n=3)
LN classification, % (n=12)‡	
Class III	33.3 (n=4)
Class IV	33.3 (n=4)
Class V	16.7 (n=2)
Mixed (Class III/V or Class IV/V)	16.7 (n=2)
Adjusted mean (SD) SLEDAI-2K Score§	4.9 (3.3)
Dialysis (ever), %	23.1 (n=3)
Renal transplant, %	15.4 (n=2)
Biopsy-proven LN within the past year and currently receiving immunosuppressants/biologic therapy, %	15.4 (n=2)
Biopsy-proven LN 1–5 years prior and currently receiving immunosuppressants/biologic therapy, %	15.4 (n=2)
Biopsy-proven LN >5 years prior and currently receiving immunosuppressants/biologic therapy, %	30.8 (n=4)
Biopsy-proven LN >5 years prior and no longer receiving immunosuppressants/biologic therapy, %	15.4 (n=2)
Women who have been pregnant or are currently pregnant and received immunosuppressants/biologic therapy during pregnancy, %	23.1 (n=3)
*Includes those who have completed a college/university degree or a graduate or professional degree.	
†Two participants did not indicate their level of education.	
‡The LN classification of one participant is unknown.	
§A measurement of lupus disease activity over time determined by the calculation of the area under the curve of Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI-2K) over time by adding the area of each of the blocks of visit interval and then dividing by the length of time for the whole period.	
LN, lupus nephritis; SLE, systemic lupus erythematosus.	

fatigue) and psychosocial (eg, fear, social exclusion, feeling trapped, grief) impacts of living with LN; during

open discussion, 12 participants highlighted activities/behaviours or settings that contribute to well-being and help manage these impacts. For example, photos representing the need for physical activity (n=4), maintaining a healthy diet (n=2), staying hydrated (n=1) and ensuring adequate rest (n=1) were shared. The ‘balancing act’ between activities, such as physical activity and rest, was highlighted:

There’s a balancing act between getting exercise and enough sleep... that’s something I often struggle with. (Participant #4)

Participants also acknowledged both positive and negative contributions of activities (ie, physical activity) to well-being; for some they are a reminder of a ‘previous life’ where LN was not a consideration, and for others they are a reminder that LN does not have to limit them.

I decided I was going to make the most of every single day that I had. Water skiing was my passion prior to getting sick, and it’s... pushed me through. (#12)

Despite physical and emotional benefits, participants described how, even when feeling well, reminders of LN are present during physical activity due to (the possibility of) symptoms (*my hands would cramp up and my knees would be stiff, but I push through* (#5)), or the need for caution while participating (*I am always hearing my doctor’s very sage advice in my ear. Be careful, don’t overdo it* (#3)).

Other activities that positively contribute to emotional well-being were described. Listening to music was identified (n=2 photos) to help manage stress and ‘*get back in a better headspace*’ (#7):


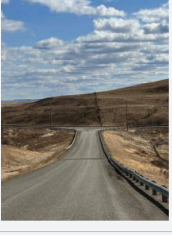
Sometimes even the closest person in your life cannot understand, but when you turn on the music... it helps set the mood. (#6)

The emotional properties of nature-based settings (eg, natural environments) contributing to well-being were also highlighted (n=2 photos; [table 2](#), photo A), as participants described the ‘*sacred place[s] where [they] go to recharge and take in the fresh air*’ (#12). Similarly, plants (n=2 photos) and pets (n=1 photo) were identified; these also acted as a reminder of altered life trajectories. For example, one participant described how their dogs contribute to their well-being, given they ‘*were never able to carry*’ children ([table 3](#), photo A).

The participants themselves

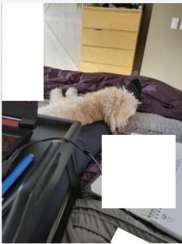

Six participants shared photos (n=13) of themselves. 11 photos displayed images representing physical symptoms, either due to LN (eg, swelling) or side effects of medications (eg, weight gain). Medication side effects were described by 10 participants throughout the focus groups; broad challenges (*[prednisone] changed me, my personality*. (#11); *I wouldn’t wish this medication on my worst enemy*. (#8)), the emotional burden (eg, self-esteem impacts; [table 3](#), photo B) of side effects and bruising (eg, due to

Table 2 Overview of primary and secondary themes emerging from the photovoice focus groups

Photo example	Primary theme presented in photo	Photos (n)	Participants (n)	Secondary themes discussed	Illustrative quote
Photo A 	Well-being	n=15	n=6	Contributing activities/behaviours to well-being Contributing settings to well-being Reminders of LN challenges	Driving up to the mountains and just getting away is kind of like a reset... sometimes just getting away for the weekend really gets the mindset back on track and I usually do just go by myself just so I can be there and take everything in and get my mind and everything else reset. (Participant 7)
Photo B 	The participant themselves	n=13	n=6	LN symptoms Medication side effects Physical environment challenges	Sometimes they'll have a rounded doorknob, and I'm unable to enter, and they don't have the button or anything like that. Because my hands are so stiff, and I'm unable to move them, I can't open the door. One time I locked myself in a bathroom because it was a rounded doorknob. (Participant 5)
Photo C 	Healthcare experiences	n=10	n=7	Medication challenges Individual management behaviours Healthcare challenges	It's a struggle sometimes, because to remember when to take them, and taking everything on time, and making sure you're taking them every day is a lot of work. As you can see there's a lot of medications that you have to take, and each of them all have different side effects. So it's hard managing some of those side effects on a daily basis. (Participant 7)
Photo D 	Home	n=4	n=3	Emotional burden Reminders of LN challenges Reminders of responsibilities (to themselves, to family)	This represents how it feels when you are trapped. I have called it an ice igloo, and looking out I promise myself that as soon as I'm able, I plan on taking off, but it's kind of a relief that right now I don't have to, because I feel terrible. I don't feel well, and so I have an excuse for not moving...now I live with a fairly constant fear of failure. Fear that I'm not going to be able to take off and do what I once did. (Participant 3)
Photo E 	Community	n=2	n=2	Transportation challenges LN symptoms Altered life trajectories	This one is just how I feel everyday living with lupus. You're always at a crossroads, you're always having to make a decision... you have to turn left or right, you can't keep going straight. (Participant 8)
Photo F  <p>Lower part of photo depicts participant on a walk with three friends. They are taking a photo in front of a lake and mountain. Individuals removed from photo to preserve anonymity.</p>	Friendship	n=2	n=2	Therapeutic benefits Reminders of LN	Sometimes you have to go out in the sun, to make fun with your friends. But it's a struggle to go under the sun, and after this... at the end of the day I was feverish, and having symptoms. (Participant 6)

Continued

Table 2 Continued

Photo example	Primary theme presented in photo	Photos (n)	Participants (n)	Secondary themes discussed	Illustrative quote
Photo G 	Work	n=2	n=2	Employment impacts Employment challenges	Attempting to work from home just because it was a bad day, and I couldn't get out of bed. (Participant 1)
Photo H 	Other challenges	n=6	n=4	Financial challenges Challenges of family planning Challenges associated with invisible illness	We were always told it was going to be harder to get pregnant. There's a lot more doctors, and medication, and appointments involved, and there's obviously a high risk of miscarriage. This is from when we had our first miscarriage, we've since had another one. Just the hardships that come with that... I've got kidney disease and it's just one of those additional complexities that you never think of. You don't realize how it's going to impact your life until it does. There's nothing you can really do about it, there's not a lot of information either. (Participant 8)

Potentially identifying components of the images have been removed to ensure participant anonymity is maintained.
LN, lupus nephritis.

injections; *I have to explain bruises... sometimes I lie and say I hit something* (#9); table 3, photo C) were articulated.

While properties of the physical environment (eg, mountains) contributing to well-being were highlighted in both focus groups, other aspects of the physical environment that can exacerbate symptoms were also discussed. Although only one of the 11 photos representing physical symptoms highlighted the possible challenges of the physical environment (eg, rounded doorknobs in public spaces; table 2, photo B), this resonated with other participants and generated discussion around other environmental challenges. For example, participants discussed child safety caps that can prevent them from comfortably opening their medication.

Two other photos of the participants themselves were shared; one depicted a tattoo of a wolf, acquired to represent the *'destructive but beautiful part of me that has taught me a lot'* (#9). The final photo was of a participant travelling, as a reminder that *'we need to find things that are fun'* (#1).

Healthcare experiences

10 photos, shared by seven participants, displayed experiences of the LN healthcare journey. Six highlighted daily medication challenges; of these, four depicted a medication collection, drawer or cabinet (table 2, photo C). Participants discussed the cost, side effects, logistical challenges required to manage the medication burden:








I'm getting my meds from 3 different pharmacies. Everything's filled at different intervals. (#9)

The fifth photo displayed a warm compress and eye drops (table 3, photo D), highlighting the individual management behaviours that participants employ to *'take control over lupus'* (#2). The sixth was of a low-molecular-weight heparin injection, shared to highlight their illness, medication and family planning experiences.

Three photos highlighted other healthcare-related challenges, depicting experiences of medication infusions (eg, belimumab, rituximab). Broad infusion-related challenges were shared; one participant identified through their photo that they had to step away from belimumab infusions due to cost, and medication-related financial challenges were shared during the focus groups by five participants. The other two photos highlighted additional infusion-related challenges including discomfort, frequency of appointments, time requirements, geographical distance to appointments and impacts on daily life (eg, missed employment) (table 3, photo E).


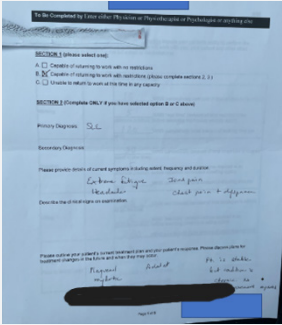
Other healthcare system-related concerns emerged in open discussion, including the need to improve wait times and appointment flexibility, care coordination between providers and pharmacies, and communication with healthcare providers (*[my pain] is not really acknowledged by my medical staff... it's like, 'well, everybody has pain*

Table 3 Additional photos and corresponding quotes representing primary photovoice themes

Theme	Other representative photos	Corresponding quotes
Well-being	<p>Photo A</p> 	<p>My husband and I had envisioned we'd be playing with grandchildren... but I was never able to carry... [The dogs] are affectionate, loyal, and they need us... they are sort of the light. (Participant 3)</p>
The participant themselves	<p>Photo B</p> 	<p>This is me taking prednisone, and this has been a struggle for years, no matter what I do. Nothing helps, this picture I think would be the most frustrating for me of all the pictures that I sent... it has its own side effects and it affects everybody differently. For me, all the weight is around my stomach, so it's a challenge because for my self-esteem, you know it makes you feel like crap sometimes, and you want to wear certain clothes and it's hard to find stuff. That's one of the biggest challenges I've had being on a medication that causes changes to your body. (Participant 7)</p>
	<p>Photo C</p> 	<p>You can take warfarin, but you can also continue to inject with tinzaparin. You can't take any other oral anticoagulant because in clinical trials people like us have strokes, and so I take tinzaparin, I refuse to take warfarin... I've gotten better at my tinzaparin injections. I go slow, try to avoid blood vessels and apply pressure after. Bruises take a long time to heal, stain the skin, and aren't always avoidable, and after a year after and a half of injecting, 540 plus injections later, I still bruise, and I refuse to damage my front abdomen skin. But love handles are never pretty, anyway. (Participant 9)</p>
Healthcare experiences	<p>Photo D</p> 	<p>I've been on the same medication for over 5 years, and one of my biggest fears right now is the side effects... I know it's really bad for the eyes and I have been warned by my optometrist... that I should keep the eyes as healthy as possible. One of the ways that I've been doing this is I do a warm compress regularly, and then eye drops because I stare at the computer all the time and there's no way for me to cut down on the medication. (Participant 2)</p>
	<p>Photo E</p> 	<p>A lot of people just don't understand the medication and appointment component that we deal with, you have to take a whole day off work, it's an 8h infusion, and you're stuck there, and it's its own beast in itself that you need to deal with... it depends on how often you have these infusions, maybe you have multiple different medications that require infusions. (Participant 1)</p>
Home	<p>Photo F</p> 	<p>It is very much an invisible illness. So my peers or my colleagues at work, people don't know that I'm sick unless I say so. And it does impact what I'm able to do every day, so I do share that information. I found it's helped me in my career being transparent with that... but I don't know what my day is going to look like, or how my lupus is going to impact me... there's still days where I get run down, even though I'm in remission where I can't do a day to day task that a normal person can do so, the mountains to me kind of reflect this, you know, every single mountain is different and unique and has its own beauty with it. (Participant 8)</p>
	<p>Photo G</p> 	<p>This one is symbolic to me. Believe it or not, this moose came through my yard last year... I was thinking that lupus is actually a lot like the moose, because it can do a lot of destruction but it can also hide really well. So that was the piece that really tied it together for me, you know it's this big thing that we're dealing with that can be very scary, and it can be very sudden if it comes up out of nowhere and can do a lot of damage, but it also can teach us a lot. (Participant 12)</p>

Continued

Table 3 Continued

Theme	Other representative photos	Corresponding quotes
	<p>Photo H</p> 	<p>The bird has been freed from the igloo. I have to, it's just the responsibility to get moving... I do not have the abilities I once did, so I hold off on doing those activities that I love. Each year I hope I will have the chance to get back at it, each year will be better... I have to get back out for all the people and friends, and sister who donated a kidney to me, I have a responsibility... it's not only for me, but for all those who have been there to help me. (Participant 3)</p>
Other challenges	<p>Photo I</p> 	<p>This is from the insurance. Sometimes they approve it, sometimes they deny it. I don't know what they want to see, they deny the claims. It's stressful, too. (Participant 6)</p>

Potentially identifying components of the images have been removed to ensure participant anonymity is maintained.

that has lupus' (#12)). Despite challenges, five individuals expressed that they were thankful for their healthcare providers. This was emphasised in the final photo related to healthcare experiences; it included the names of the participant's healthcare providers, highlighting how '99% of my doctors have helped me along the way' (#11).

Home

Three participants used photos of home (n=4) to describe their LN experiences. The emotional burden of LN was highlighted in this set of photos, as they symbolised the invisible, destructive and unpredictable nature of LN. For example, the invisibility of LN was highlighted in an image of the mountains taken from the participant's home (table 3, photo F):

It's very much an invisible illness... the mountains to me kind of reflect this, every mountain is different and unique and has its own beauty. (#8)

The destructive nature of LN was symbolised through a photo of a moose in the participant's backyard (table 3, photo G):

Lupus is actually a lot like the moose, because it can do a lot of destruction. (#12)

One participant also shared an image of their home that represented the challenges and responsibilities that accompany LN. The photo (table 2, photo D) of a plastic crow covered in ice, signifying 'how it feels when you are trapped' (#3). A second photo (table 3, photo H) of 'the same railing' symbolises the 'responsibility to get moving... to get back out for all the people and friends, and sister who donated

a kidney to me, I have a responsibility... it's not only for me, but for all those who have been there to help' (#3).

Community

Two participants shared photos depicting elements of their communities. The first highlighted public transportation. When sharing this photo, the participant described the confusion they experienced while taking the train, complicated further by their fear of driving when experiencing a flare:

I struggle a lot with brain fog... I'm scared to drive, there's hazards on the road. What if I'm driving and I'm like 'where am I going?' (#5)

The second photo (table 2, photo E) depicted an intersection in the participant's community, symbolising 'how [they] feel everyday living with lupus.' (#8). The altered life trajectories represented in this photo were likened by the participant to balancing their fertility journey with other aspects of life; they described navigating complex family planning decisions, medications, trying to avoid a flare, maintaining their career, home and relationship.

Friendship

Two photos depicting the therapeutic properties of friendship were shared by two participants; one photo included a friend's child, representing how spending time with friends can 'help me get out of my head and focus on other people and beautiful things' (#12). The second photo (table 2, photo F) included the participant and friends on a walk. While the value of friendship was emphasised, both participants indicated that activities enjoyed with friends

(eg, physical activity) can serve as reminders of their LN and the altered life trajectories experienced. Despite the therapeutic benefits of friendship highlighted, impacts to social dynamics and social exclusion were discussed by four participants during the focus groups:

I wanted to make friends at this new school... I never joined theatre because I was unable to walk. (#5)

Work

The impacts of LN on employment were depicted in two images by two participants. One participant discussed the flexibility and accommodations provided to them (*'I had to work from bed because I had a bad migraine'* (Participant #1; table 2, photo G), while the other, through an image of their workplace, described the lack of flexibility to work from home and the physical impacts they experience (*this is a struggle... it's physically exhausting* (#6)).

Other challenges

The remaining six photos portrayed other challenges of living with LN. Three photos were shared to convey the challenges associated with securing insurance coverage for medication or employment accommodations. In addition to financial implications, the uncertainty of the application process can impact psychosocial health (table 3, photo I). During open discussion, participants also emphasised the need for treatment-related solutions, both through improved medication options and financial resources/programmes to provide funding for those affected; one participant with a renal transplant felt fortunate that *'transplant patients go to the hospital for drugs... free of charge'* (#3), while others shared the need for physicians to advocate for treatment subsidies/programmes.

Although family planning challenges were described in both focus groups, the starkest depiction was presented in a photo of three pregnancy tests, highlighting the participant's experience of pregnancy loss (table 2, photo H). The individual shared that despite knowing the risk of miscarriage and other challenges of pregnancy with LN, their kidney disease is *'one of those additional complexities that you never think of. You don't realise how it's going to impact your life'* (#8). Others shared experiences with family planning when discussing this photo; miscarriage, the emotional burden of conception (*I'm only 8 weeks and it's too soon to tell* (#2)), adoption and for those who did not start a family, spending time with pets, family and friends were described.

Two photos depict abstract illustrations of LN; one (of a glitchy screen) portrays the challenges of brain fog (*this is how I feel daily* (#13)) and the other (of an empty blue space) illustrates the challenges of living with invisible illness.

DISCUSSION

This study used photovoice to explore the experiences and perspectives of individuals with LN. This participatory approach aimed to elicit perspectives that may not

have emerged with interviews alone; while broad themes related to the unpredictability of LN and the heavy treatment burden are consistent with results from previous semistructured interviews,² the use of photographs accompanied by narrative highlights the unique aspects of living with LN. Specifically, the psychosocial health burden of altered life trajectories, the dual burden of LN and the associated medication journey, and the conflicting role of the physical environment emerged as critical components of the LN experience.

Respondents reported a substantial psychosocial health burden associated with the altered life trajectories that can accompany an LN diagnosis. While activities that contribute to well-being were emphasised, the physical, emotional and lifestyle impacts of LN and the associated medication journey serve as frequent reminders of the disease burden, both now and into the future. While quantitative studies demonstrate adverse mental¹⁹ and emotional outcomes^{20 21} in those with active LN, the qualitative literature exploring the emotional burden of living with LN is limited and will be explored in our future work. Participants also shared memories of their lives pre-LN, emphasising the need for flexibility from themselves (eg, understanding lifestyle may differ from original career/family expectations), as well as others (eg, friends, employers) to manage the demands of daily life with LN. The complex nature of relationships with family and friends was highlighted in this context. While the therapeutic benefits of socialising were identified, other emotional impacts were attributed to relationships, including feelings of social exclusion, reminders of family planning challenges (eg, through spending time with family/friends' children) and feeling a responsibility to family/friends to maintain health. Similar tensions (eg, balancing the need for social connection against physical symptoms²²) have been recognised in the SLE,²³ LN² and chronic illness literature,²² as both the therapeutic nature of engaging with social networks²⁴ and the impacts of chronic illness on relationships with peers, partners and family^{2 23 25 26} have been identified.

The dual burden of LN symptoms and the associated medication journey emerged in both focus groups, echoing previous qualitative studies on patient experiences of the medication burden associated with LN² and SLE.^{23 27 28} All participants had taken an immunosuppressant or biologic at some time during their disease course, and while participants acknowledged the need to control their LN through medication, side effects were identified by ten participants as they described medication-related symptoms that impacted both physical and emotional well-being (eg, self-esteem). Medication-related financial challenges were also highlighted by five participants, which has been documented in the qualitative SLE literature²³; the uncertainty of insurance coverage and associated psychosocial burden was described, and one participant reported changing medication due to cost. The physical and psychosocial burden associated with the medication journey highlights the need for improved

accessibility to existing, and additional, medication-related resources and support (eg, insurance plans with higher annual caps, broader public funding of medications) and treatment options that can better meet patient needs. Although all participants were receiving care in a publicly funded healthcare system in Alberta, Canada, some medications used in LN treatment (ie, mycophenolate mofetil, mycophenolic acid, belimumab, rituximab) are not consistently covered by public funding as it varies across provinces and access can therefore be challenging.

Most (n=12) participants discussed activities that contribute to well-being, and the role of the physical (eg, natural, built) environment was highlighted. Characteristics of the natural environment that contribute to well-being were discussed, particularly related to the physical and emotional healing properties of spending time in nature. This is consistent with results from the only other photovoice study of patients with SLE (though not necessarily LN); participants in this study (available in abstract form) described aspects of their urban neighbourhoods and the importance of greenspace when sharing their lupus experiences.⁸ Further, while not specific to LN or SLE, there is a growing literature on the therapeutic benefits of exposure to natural environments^{29–32} and how they can positively contribute to physical activity participation and reduce disease burden^{31–33} for those impacted by chronic illness. Alongside clinical treatment protocols, other non-clinical nature, social or cultural-based interventions (eg, that use natural assets such as forests³⁴ to deliver health and social support³²) should be considered to improve physical and psychosocial health for those with LN.

Conversely, participants also identified challenges presented by the built environment in both a photograph and open discussion (eg, rounded doorknobs in public spaces), emphasising the conflicting role of physical spaces for individuals with LN. Although an extensive body of work exists on the relationships between the built environment and health,^{35–38} with the exception of osteoarthritis³⁹ there has been limited work on how those with rheumatological diseases experience the built environment; while we know that neighbourhoods (eg, poverty,⁴⁰ socioeconomic status⁴¹) can impact health and well-being outcomes in SLE, to our knowledge LN or SLE patient *experiences* of the built environment have not been explored in previous qualitative studies, emphasising the value of pairing photographs with narrative in this work. Considering the needs of those with chronic illnesses such as LN is critical when planning future policy changes that influence how public spaces are shaped to improve accessibility.

This research has significant implications that could improve care and well-being for those with LN. For example, better use of shared decision-making approaches by clinicians may help address the medication-related challenges expressed by participants. Other initiatives such as improved access to insurance guidance, employment accommodations

and mental health and other social supports could help improve patient well-being. While these supports cannot fully address the identified challenges expressed here, lupus community stakeholders (eg, healthcare providers, lupus advocacy organisations) can play a critical role in advocating for both the development of new supports and better access to existing initiatives that can improve the well-being of individuals with LN.

This study has limitations. First, results may not fully reflect the experiences of individuals with LN as we recruited from a lupus specialty clinic in one geographical region of Canada, and many are comanaged in a multidisciplinary setting with rheumatology and nephrology. While we aimed to include participants with diverse LN experiences and demographic backgrounds, our sample included primarily those of Asian or white race and ethnicity and individuals who had completed post-secondary education. However, we included patients with varying severities of LN, as 23.1% had required dialysis and 15.4% had received a renal transplant. Next, while data generated from two focus groups are not generalisable, our aim was to provide an in-depth exploration of the LN experience. Further, some of the experiences that participants attributed to LN may have been due to extrarenal manifestations (eg, photo B (table 2) depicts SLE-associated Jaccoud's arthropathy), comorbidities or medication side effects and not LN per se, emphasising the unique and complex experiences and management challenges of patients with LN. Finally, ensuring that photographs and narratives are presented in a way that accurately portrays the participants' experiences⁴² is challenging; to ensure consistency and credibility in interpretation of themes, the research team met throughout the analysis to discuss findings.

Alongside evidence from semistructured in-depth interviews with those with LN,² results of this study not only draw attention to the unique physical, emotional and lifestyle impacts of LN and the associated medication journey, but will inform the development of meaningful and effective strategies that target the outcomes most relevant for patients with LN.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants and was approved by the University of Calgary Conjoint Health Research Ethics Board and the University of Waterloo Office of Research Ethics. The study protocol was designed alongside a trained patient partner prior to recruitment to ensure patient perspectives were adequately captured. Upon study completion, the results will be disseminated to all interested participants in a lay document for their feedback. Participants gave informed consent to participate in the study before taking part.

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Data availability statement All data relevant to the study are included in the article or uploaded as online supplemental information. All data relevant to the study are included in the article. Due to the qualitative nature of the study and protection of personal identifiable information, data other than those included in the manuscript are not available to readers.

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