

Exploring Canadian Patient Experiences of Living With Lupus Nephritis

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Introduction



- Lupus nephritis (LN) is one of the most severe manifestations of systemic lupus erythematosus (SLE) and as many as 60% of adult patients with SLE develop LN^{1,2}
- Patients with LN can be asymptomatic or can present with a variety of manifestations
- The experiences and perspectives of patients with LN remain understudied

Objective

This research investigates patient experiences and perspectives of 1) LN diagnosis; 2) living with LN; and 3) LN healthcare and treatment

Methods

- Patients fulfilling inclusion criteria were purposefully recruited from a Canadian lupus cohort
- Conducted semi-structured in-depth interviews virtually (via Zoom) or by telephone
- Interviews were transcribed verbatim for subsequent thematic analysis
- Inductively and deductively coded using NVivo Qualitative Data Analysis Software

Key inclusion criteria

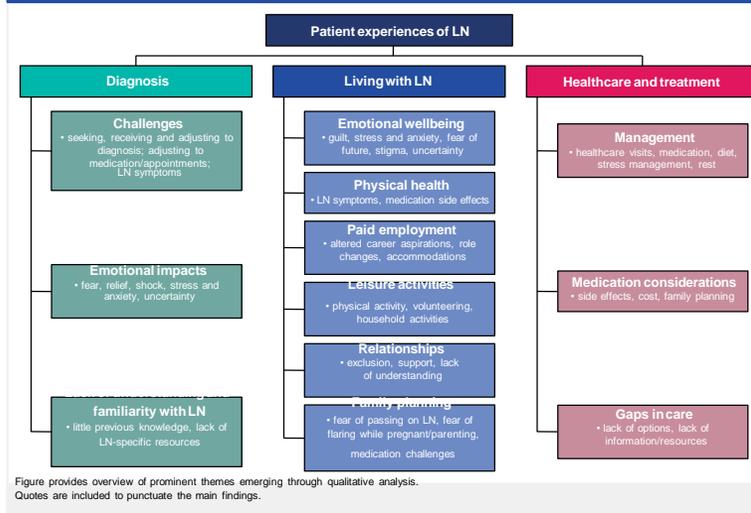
- 18 years of age or older at time of interview
- Fulfill American College of Rheumatology 1997 or Systemic Lupus International Collaborating Clinics 2012 Classification Criteria for SLE
- Biopsy-proven pure or mixed International Society of Nephrology/Renal Pathology Society Class III, IV, or V LN
- Fulfill one of the following **5 categories**:
 - LN diagnosed within the past year and currently receiving treatment for LN
 - LN diagnosed 1–5 years prior and currently receiving treatment for LN
 - LN diagnosed >5 years prior and currently receiving treatment for LN
 - LN diagnosed >5 years prior and no longer receiving treatment for LN
 - Women who have been pregnant or are currently pregnant and received treatment for LN during pregnancy

Results

Table 2. Patient LN characteristics (N=30)

Characteristic	
Medications (ever), %	
Hydroxychloroquine	100.0
Immunosuppressants/biologics	
Azathioprine	40.0
Belimumab Cyclophosphamide	20.0
Mycophenolate mofetil/mycophenolic acid	26.7
Rituximab	93.3
Tacrolimus	20.0
LN classification, %	
Class III	29.6
Class IV	25.9
Class V	18.5
Mixed	23.3
Dialysis (ever), %	25.9
Renal transplant, %	10.0
LN in past year, on therapy, %	43.3
LN 1–5 years prior, on therapy, %	13.3
LN >5 years prior, on therapy, %	43.3
LN >5 years prior, off therapy, %	33.3
LN during pregnancy, %	3.3
	6.7

Figure 1. Thematic overview



*"I felt like my life was just put on pause and I just had to follow this schedule."
"I was in this big transitional period of my life, and the doctors didn't know how I was going to react to my medication... one doctor told me 'I suggest you don't go to university'... that was really hard."
"I even asked them if I am going to die soon... I have children and they're still, I'm still young."
"I didn't even know there was a lupus nephritis..."*

*"I feel like I didn't have enough to give to people, just the energy that it took... your motherly guilt starts kicking in."
"You're feeling really tired and sick but you look fine... maybe for some people they think I'm just having drama..."
"There's some days where I can't walk, which makes it really hard to act normal in the house around your kids, your husband, and I don't like feeling like a burden."
"I always wanted to be a nurse... but after going through everything I was like okay, I'm just going to find the easy route."
"I think about adopting because I don't want to have a kid and watch him suffer like I have to go through."*

*"The side effects and the switching between medications... it's like doing a dance..."
"The main thing that's off-putting about lupus nephritis is medication, right? So normally it's pretty harsh medication, and when we were faced with that, it was woaah, what is this?"
"Most of the time I just deal with the pain... there's not a lot of other options for me."
"My daughter got breast cancer... I couldn't believe the amount of support she had. It was incredible. You can go here for wigs, you can go here for makeup, you can go to this doctor, I mean it was incredible. So now I'm saying the same thing but really, I know there is a Lupus Society, I do belong. But lupus nephritis, I don't know where you go, internet?"*

Conclusions

- A lack of understanding of LN coupled with the uncertainties of diagnosis/living with LN create a substantial psychosocial burden as patients negotiate acceptable risk in the face of uncertainty
- Patients emphasized the burden associated with the experience and management of their illness
- Results emphasize the need for wider LN awareness and will inform the development of LN-specific patient resources
- This study is limited by the inclusion of patients from a single cohort and may not be fully reflective of the broader population of individuals with LN
- Eliciting perspectives of a broader range of patients is an important next step

Disclosures

SG and AB are employees of GSK, and AB holds stocks and shares in the company. MRWB has received consulting fees from AbbVie, AstraZeneca, Janssen, GSK, and Sanofi-Genzyme. KC has received consulting fees from Novartis, and speaker/honoraria from Alexion. AEC has received grant/research support from GSK, and consulting fees from AstraZeneca, BMS, and GSK. FSC and SJE have nothing to disclose.

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