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A United Kingdom (UK) wide mixed-methods qualitative study and pilot survey

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Introduction

- Despite being one of the most common primary glomerulonephritis, Immunoglobulin A nephropathy (IgAN) loin pain (LP), while experienced by patients,^{1,2} is not included internationally in standard reports of clinical manifestations or management³.
- Limited research pre-1990s has referred to LP in IgAN,⁴⁻⁵ however modern research of pain in rare kidney disease is notably lacking, despite the established link between pain and long-term conditions⁶, including kidney disease.⁷⁻⁹
- Vasilica et al.'s¹⁰ study is the only known modern explicit discussion of LP in IgAN that has been published and peer-reviewed. Referred to as 'kidney pain', it was described in social media posts as pervasive, unwanted, intrusive, unrelenting; linked to infection, stress, dehydration; and dismissed by doctors.

Objectives

To build on this work, and address this gap both in the literature and in practice, this mixed-method research co-developed with PPIE, aims to explore the experience and impact of LP in IgAN through identification of LP description, prevalence, and impact.

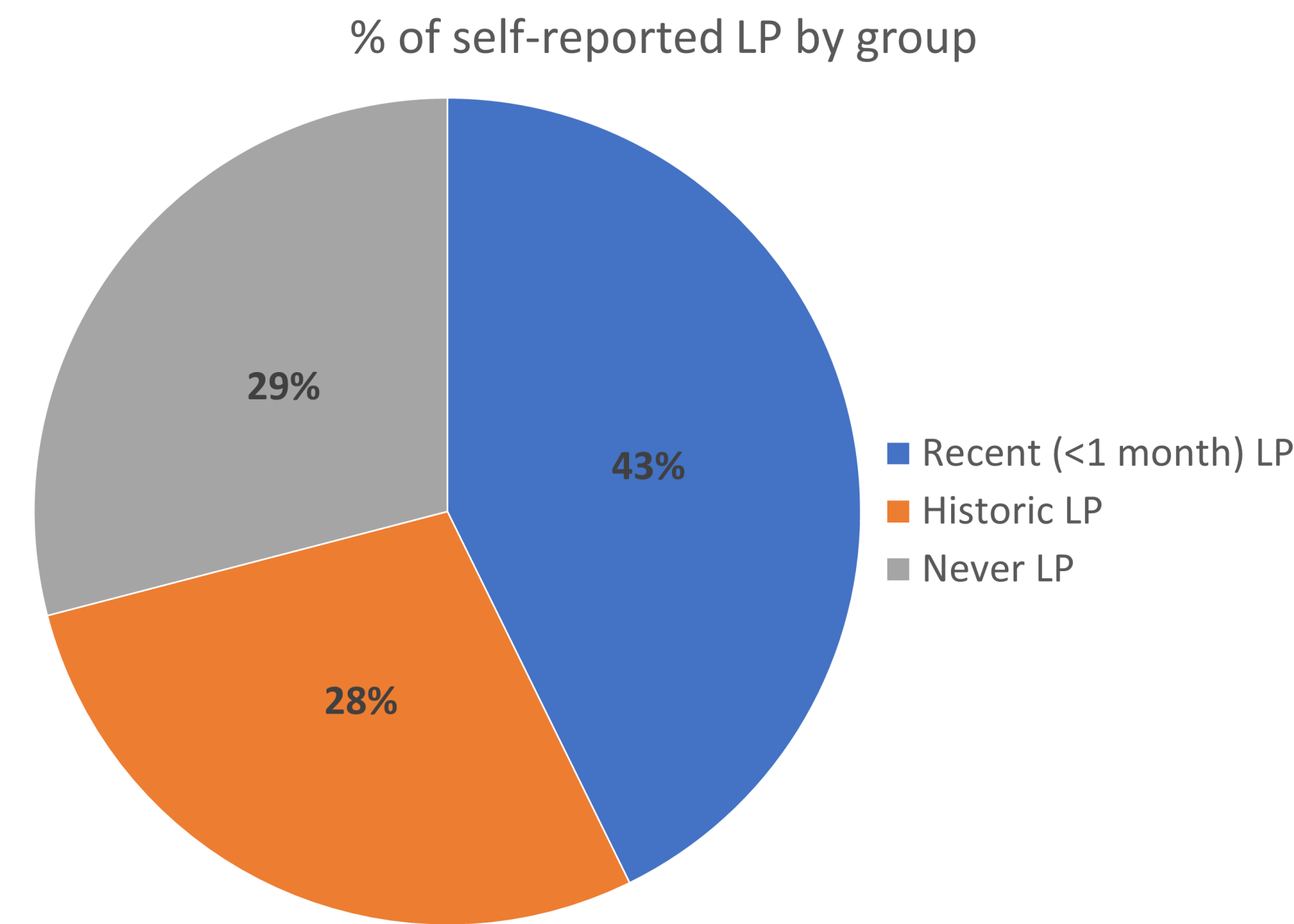
Method

- National online pilot survey in collaboration with RaDaR incorporating validated measures Kidney Symptom Questionnaire¹¹ (KSQ), Short-form McGill Pain Questionnaire 2¹² (SFMPQ2), Pain Self-Efficacy Questionnaire¹³ (PSEQ), and Brief Illness Perception Questionnaire¹⁴ (BIPQ).
- Descriptive statistics and analysis of group variance through T-tests, Chi-squared, and one-way ANOVA were conducted on survey data using SPSS.
- Qualitative semi-structured interviews were conducted with IgAN patients, family members, and healthcare professionals (HCPs). Follow-up focus groups with a sample from each group assessed if findings are representative. Data was thematically analysed¹⁵ using NVivo.

Results

358 participants participated in the survey (male $N = 237$; female $N = 121$; 90.3% White British; age range = 19-89 years, $Mean = 53.25$, $SD = 13.71$; BMI range 18-58, $M = 27.56$, $SD = 6.11$; date of diagnosis range 1969-2023 $M = 2007.75$, $SD = 11.91$; eGFR $M = 43.14$, $SD = 23.04$, $N = 25$ on dialysis; $N = 132$ with a functioning transplant.

Of $N = 358$ IgAN patients, 153 report LP within the last month, 101 report historic LP, and 104 report never having LP; 71% having experienced LP overall.



Significant demographic differences

- Participant groups significantly more likely to report LP were female, younger, had higher BMI, diagnosed more recently, on immunosuppressants, used paracetamol and opioids more, had poorer general health or poorer general mental health.
- Both eGFR stage and exact reported number were not significantly different between groups.

Significant differences between three LP groups

- Recent LP consistently significantly reported worse ratings than historic and never LP groups with more significant differences between recent and never LP groups.

| Measure | LP groups | Significant at $p < .001$ | Significant at $p < .05$ |
|---|----------------------------------|---|---|
| KSQF Symptom frequency | All (recent, historic, never LP) | Itching, sleep disturbance, loss of appetite, feeling tired, pain in bones/joints, poor concentration, loss of muscle strength, cramp/muscle stiffness, restless legs, KSQF total score | Shortness of breath, feeling cold, need to urinate more often |
| KSQI Symptom importance | All (recent, historic, never LP) | Sleep disturbance, feeling tired, pain in bones/joints, poor concentration, cramp, restless legs, KSQI total score | Loss of muscle strength, shortness of breath, need to urinate more often |
| SFMPQ2 Pain descriptors | Recent vs historic | Throbbing, stabbing, sharp, gnawing, aching, tender, SFMPQ2 total score | Shooting, cramping, hot/burning, heavy, tiring, sickening, punishing, electric-shock, light touch, tingling, numbness |
| PSEQ Self-efficacy despite pain | Recent vs historic | Cope without medication | Enjoyment, coping, work, hobbies, goals, normal life, active, PSEQ total score |
| BIPQ LP perceptions | Recent vs historic | Consequence, timeline, identity, illness concern, emotional representation, BIPQ total score | Coherence |

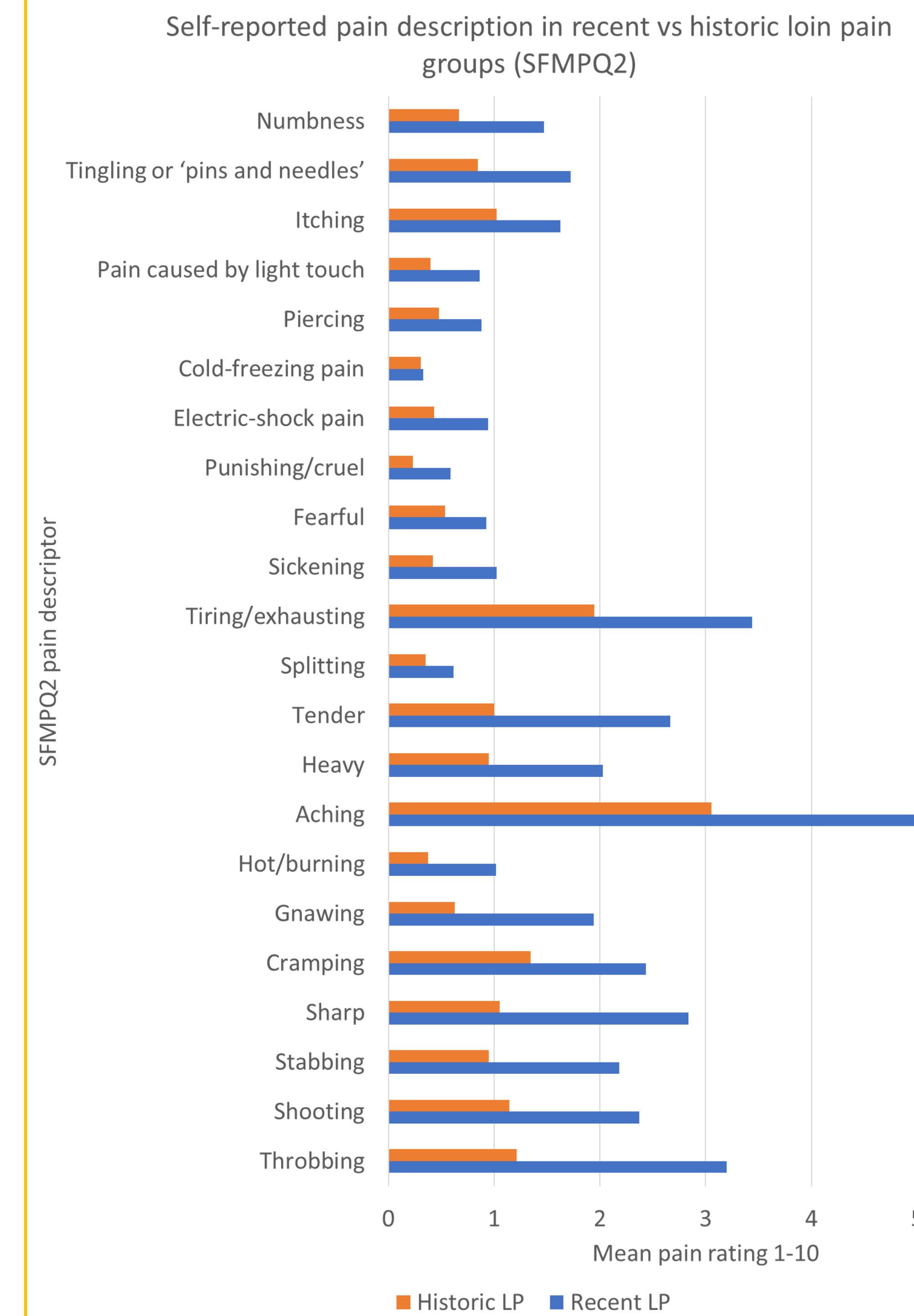
- A one-way ANOVA of KSQ measures across LP groups was significant for all KSQF variables apart from loss of libido and all KSQI variables except itching, loss of appetite, loss of libido, and feeling cold.

Significant differences between recent and historic LP

Independent sample T-tests found significant worse ratings in recent LP in the following:

- All SFMPQ2 variables except splitting, fearful, cold-freezing, piercing, and itching.
- All PSEQ ratings except chores and socialising despite pain.
- All BIPQ ratings except personal and treatment control.

Aching was the most frequent descriptor with the highest mean rating in both LP groups.



Qualitative studies

- 46 participants completed interviews (age range 23-75 years, $Mean = 45.27$, $SD = 12.05$; $N = 13$ male, $N = 33$ female; 70% White British); 21 IgAN patients, 12 carers (9 partners, 3 parents, 1 sibling, 1 adult child), and 13 HCPs.
- Data was thematically analysed to capture detailed LP personal experience and impact, and then mapped on to survey findings for interpretation.

| Factor | Survey | Qualitative |
|-----------------------|---|--|
| Prevalence | 71% have experienced LP | HCPs think LP is rare, patients are dismissed when raising LP. |
| Description | Aching highest rated descriptor. Most pain descriptors rated higher in recent LP (SFMPQ2). Most think LP is related to IgAN. | Aching most common description. Additional sharp pain sometimes present in worse LP. Most think LP is related to IgAN. IgAN related LP is described differently to other comorbid condition pain by descriptor, location, and additional symptoms. |
| Impact | Self-efficacy reduced in most domains in recent LP compared to historic LP (PSEQ). General health and mental health rated lower in recent LP. | Impact dependent on LP severity and personal situation. Can affect both patient and loved ones social life, work, family life, relationships, hobbies, exercise, and mood. |
| Burden | Poorer ratings in recent LP compared to historic LP in most domains (BIPQ). | Frustration main descriptor, anxiety and depression symptoms in some patients and family. Concern about what LP means for IgAN. |
| Other symptoms | Most common kidney symptoms more frequent with LP (KSQ). | Tiredness, viral infections, changes in urine ('frothy' and 'darker') common in moderate-severe LP. |
| Management | Higher paracetamol and weak opioid use in recent LP. Management effectiveness lower in recent LP. | Limited options available for LP management, especially in moderate-severe LP where paracetamol does not work. Most manage with heat and rest. |

Conclusion

LP is a prevalent symptom in IgAN and more recent LP experience had consistently significantly poorer patient reported outcomes. LP was not significantly associated with eGFR, suggesting LP is not a result of kidney function decline. Additionally, this research challenges the assumption that IgAN is a largely asymptomatic disease. Qualitative findings support the survey results, and highlight communication issues and a difference in health beliefs between patients and HCPs as a barrier to LP management. Further research on international descriptors and management of LP in IgAN, and comparison of LP across rare kidney diseases should be a priority.

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