Background Parental involvement is a critical pillar in the provision of quality care for preterms, especially given their increased risk of compromised neurodevelopment.¹ However, parental opinions, experiences and preferences regarding neurodevelopmental follow-up of preterms have hardly been studied or considered in healthcare planning.

Objectives

- To understand what parents know about neurodevelopmental outcomes for children born preterm.
- To describe parents' experiences, satisfaction and recommendations for neurodevelopmental follow-up of preterms.

Methods

METHODS **Purposive sampling:** parents of 2- to 3-year-old children who were born preterm.

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Virtual in-depth interviews

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Thematic content analysis²

The South Central – Hampshire B Research Ethics Committee approved the study (REC reference: 19/SC/0474).

Results Emerging themes are shown in table 1 from 17 interviews of parents whose children were born at <32 weeks (n=5), 32 to <34 weeks (n=5) and 34 to <37 weeks' gestation (n=7).

Limitation:

Potential recall bias of past experiences by parents.

Conclusions Parent interviews have emphasised the need for policymakers and the neonatal care team to consider parents' knowledge, experiences, satisfaction and preferences for pre-term neurodevelopmental follow-up.

REFERENCES

1. doi: 10.1016/j.clp.2018.05.001. PMID: 30144844
2. <https://www.bmj.com/content/320/7227/114>

British Society for Rheumatology

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REAL WORLD TREATMENT OF JUVENILE SYSTEMIC LUPUS ERYTHEMATOSUS (JSLE): EVIDENCE FROM THE UK JSLE COHORT STUDY

¹Naomi Egbiwwe, ²Andrea L Jorgensen, ³Michael W Beresford, ³Christian M Hedrich, Eve MD Smith, on behalf of the UK JSLE Study Group³. ¹Institute of Life Course and Medical Sciences, University of Liverpool, UK; Department of Paediatric Rheumatology, Alder Hey Children's NHS Foundation Trust, Liverpool, UK; Liverpool University Hospitals NHS Foundation Trusts, Liverpool, UK; ²Department of Biostatistics, University of Liverpool, UK; ³Institute of Life Course and Medical Sciences, University of Liverpool, UK; Department of Paediatric Rheumatology, Alder Hey Children's NHS Foundation Trust, Liverpool, UK

10.1136/archdischild-2021-rcpch.790

Background Juvenile-onset systemic lupus erythematosus (JSLE) is a chronic autoimmune/inflammatory disorder that affects multiple organs. JSLE has a more severe phenotype when compared to adult-onset SLE that can result in significant, sometimes life-threatening, sequelae. To date, no standardised treatment approaches are available, and clinical practice differs between clinicians and centres. The Single

Hub and Access point for paediatric Rheumatology in Europe (SHARE) recommendations were published in 2017, with the aim of harmonizing treatment and improving outcomes.

Objectives The primary aim was to explore UK JSLE treatment approaches, utilising longitudinal data from the UK JSLE Cohort Study. The secondary aim was to investigate compliance with SHARE treatment recommendations.

Methods Data from the UK JSLE Cohort Study collected between 01/2010 and 05/2020 were accessed. Patients fulfilled 4 or more American College of Rheumatology (ACR) criteria for SLE and were diagnosed at <18 years. At each visit, paediatric British Isles Lupus Assessment Grade 2004 (pBILAG-2004) scores were calculated. Data on the sequence of the immunosuppressants used was extracted. To explore how different clinical manifestations of JSLE may guide treatment choice, pBILAG organ domain scores (active/moderate involvement = A or B) were considered. Logistic regression was used to determine if treatment choice was associated with specific organ domain involvement(s). Given the data collected by the UK JSLE Cohort Study, we were able to assess for compliance with 11/25 SHARE JSLE treatment recommendations.

Results First-, second- and third-line immunosuppressant treatments described are in addition to hydroxychloroquine and corticosteroids. The most commonly used first-line immunosuppressant treatment was mycophenolate mofetil (MMF) (72/197, 37%), followed by azathioprine (56/197, 28%), and methotrexate (43/197, 22%). MMF was also the most common second-line treatment (40/197, 20%), followed by rituximab (23/197, 12%). Cyclophosphamide, azathioprine and methotrexate were also used as a second-line treatments in few patients. Rituximab was the most commonly chosen third-line treatment (15/197, 8%).

Considering different organ domain involvements, MMF was the most commonly used treatment across the majority of organ domains with the exception of the gastrointestinal domain (azathioprine; Odds ratio (OR) 3.10; 95% confidence interval (CI): 1.59–6.04; p=0.004). Patients with renal involvement were 1.99 (95% CI: 1.65–2.41; p=0.004) times more likely to receive MMF (p<0.01) than any other organ domain. Patients with neuropsychiatric (OR 3.10, 95% CI: 1.80–5.33), renal (OR 1.61 95% CI: 1.16–2.23), cardiorespiratory (OR 5.05 95% CI: 2.82–9.04), haematological (OR 2.82 95% CI: 1.92–4.16) and mucutaneous (OR 1.95 95% CI: 1.39–2.74) involvements are significantly more likely to receive cyclophosphamide as compared to other organ domain involvement (p-values <0.01). Patients with MSK involvement were more likely to receive methotrexate (OR 2.55, 95% CI: 1.87–3.48; p<0.01). The use of ciclosporin was very sparse. High levels of compliance were demonstrated within the UK JSLE Cohort Study for 9/11 SHARE recommendations.

Conclusions Commonly used first-line JSLE immunosuppressants in the UK include MMF, followed by azathioprine and MTX. RTX is the most commonly used second- and third-line agent. Across UK JSLE Cohort Study centres, treatment is largely in accordance with SHARE recommendations assessed.