

1812 OUTCOME OF CHILDHOOD SYSTEMIC LUPUS ERYTHEMATOSUS (SLE) WITH LUPUS NEPHRITIS (LN)

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A total of 46 patients with SLE-LN were studied (91% females; mean age 13.0 years; mean follow-up duration 5.9 years). Initial renal biopsy showed that out of 46 patients, 2 (4.3%) had Class I, 14 (30.4%) had Class II, 8 (17.4%) had Class III, 20 (43.3%) had Class IV and 2 (4.3%) had Class V lupus nephritis. Based on the renal histopathology and clinical presentation, 23 (50%) patients received intermittent intravenous cyclophosphamide bolus with prednisone and Azathioprine (AZT) or Mycophenolate Mofetil (MMF). The remaining 23 (50%) patients were treated with corticosteroids alone or in combination with AZT or MMF.

Follow up renal biopsies were performed on 21 patients, 4 patients showed no change in histology, 8 patients showed histological improvement of lupus nephropathy, 9 patients showed progression of lupus nephropathy and 7 of these who progressed, were started on intermittent IV CYC bolus.

The clinical follow up revealed that out of 46 patients, 21.7% patients went into complete remission, 58.6% patients remained under control with immunosuppressant medications, 10.8% patients had clinically active disease with normal renal function and 10.8% patients had adverse outcome. The adverse outcome included one patient developed chronic renal insufficiency, three (3) progressed to end stage renal diseases and one died. Five-year kidney survival was 93.5% and patient survival was 97.8%.

Although IV CYC treatment has improved the mortality and morbidity in lupus nephritis but severe adverse effect makes it less than optimal for long term therapy.

1813 SERVICE PROVISION FOR CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS (JIA) IN THE EAST OF ENGLAND (EOE); A COMPARISON WITH NATIONAL CENTRES

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Introduction The EoE has no regional centre or clinical network for paediatric rheumatology. JIA has a prevalence of 1:100 (2), which suggests an estimated 1,200 cases managed in the 17 hospitals of the EoE. What sort of service do these children get, compared with agreed standards, and that provided by national and 'grid training' tertiary centres?

Aim To assess the service provision for children with JIA in the EoE against recommended standards of care as set out by ARMA/BSPAR 2010(1), and compare our results to national data.

Methods A questionnaire was sent to the Paediatric Rheumatology leads of the 17 hospitals in the EoE, focused on the service provision for paediatric rheumatology patients, against BSPAR/ARMA standards. Follow-up phone calls were made where necessary to ensure accuracy. Data from 15 National centres, including all 8 UK grid training centres were used for comparison (3).

Results 16 of 17 hospitals responded in the East of England.

Table 1. Shows the percentage of hospitals achieving each of the audited ARMA/BSPAR standards in EoE, compared with national centres, and grid training tertiary centres data alone. In summary, in grid tertiary centres 17 of 21 standards audited are achieved to a good standard (>85%), whereas in the EoE only 3.

Abstract 1813 Table 1

Standard	EOE (n=16)	National centres (n=15)	Grid Training (n=8)
New patient appointment >45 min	0.0	26.7	62.5
Follow up appointment >20 min	31.3	73.3	75
Paed rheum Nurse specialist	37.5	80.0	100
Paediatric Physiotherapist	87.5	86.7	100
Paediatric Occupational therapist	68.8	53.3	87.5
Access to Psychologist	56.3	80.0	87.5
Access to Ophthalmologist	100.0	100.0	100
Telephone helpline	43.8	73.3	100
Paediatric Anaesthetic list	50.0	73.3	100
Entonox available	37.5	73.3	100
Home Methotrexate training	56.3	66.7	87.5
Access to MTX in <4/52	100.0	93.3	87.5
Prescribe biologics	50.0	100.0	100
Recruit to Biologics registry	50.0	73.3	100
Have audited biologic use	25.0	46.7	75
Part of Clinical network	6.3	80.0	87.5
Recruit to research	25.0	60.0	87.5
Involved in undergraduate teaching	75.0	73.3	87.5
Child friendly clinic setting	81.3	93.3	100
Adolescent clinic	18.8	53.3	75
Referral to a specific adult rheumatologist	75.0	93.3	87.5

Conclusion The EoE hospitals fall seriously short in providing trained, specialist care for the estimated 1,200 children with JIA, suggesting serious inequality of access. Many standards are unachievable without commissioned resource. Our challenge is to improve provision within existing funding.

References

1. Arthritis and Musculoskeletal alliance (ARMA) Standards of Care for children and young people with Juvenile Idiopathic Arthritis 2010.
2. Children's Chronic arthritis association website. HYPERLINK "http://www.ccaa.org.uk" http://www.ccaa.org.uk.
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1814 PSYCHOPATHOLOGICAL PROFILE AND HEALTH RELATED QUALITY OF LIFE IN NARCOLEPSY WITH CATAPLEXY ACROSS CHILDHOOD AND ADOLESCENCE: A CASE-CONTROL STUDY

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Objectives The purpose of our study was to describe the behavioral aspects and quality of life of childhood narcolepsy with cataplexy (NC).

Methods We performed a case-control study based on self-administered questionnaires in 30 NC hypocretin-deficient patients, 39 epilepsy patients, and 39 healthy controls matched for sex and age.

Results Our population of children and adolescents with NC showed an increase in internalizing problems in line with previous reports, typically represented by withdrawal and depression symptoms, and somatic complaints. The two patients groups share higher scores than controls for anxiety disorders, attention, social and oppositional-defiant problems. Psychopathological profile in NC were found to be positively correlated with early NC onset,