

episodes of generalized tonic clonic seizures. On examination, she had pallor, edema, oral ulcers and alopecia. She had distinct atypical targetoid lesions, diffuse erythematous rashes with denuded skin all over the face, trunk and extremities (involving >65% body surface area). There were bullae with positive Nikolsky sign. Deep tendon reflexes were brisk. Rest of the systemic examination was unremarkable.

Hemogram showed severe anemia, thrombocytopenia, lymphopenia and high erythrocyte sedimentation rate. Liver and kidney function tests were normal. Urinalysis showed subnephrotic range proteinuria. Antiphospholipid antibody workup (anti-cardiolipin IgG and IgM, 2 Glycoprotein I IgG and IgM, and lupus anticoagulant) was negative. Direct Coombs test was positive. Antinuclear antibody test by immunofluorescence was positive (4+homogeneous with rim enhancement). Anti-DsDNA antibodies tested positive by both enzyme linked immunosorbent assay as well as by immunofluorescence.

Skin biopsy showed full thickness epidermal necrosis. Magnetic resonance imaging (MRI) brain revealed presence of cerebral atrophy with multiple small infarcts suggestive of vasculitic changes. On the basis of clinical and laboratory findings, a diagnosis of SJS/TEN in context of childhood onset lupus was proffered. She was treated with intravenous immunoglobulin, pulse methylprednisolone, antimicrobials and anticonvulsants along with supportive care. The child, however, succumbed to her illness.

**Conclusions** SJS/TEN may, at times, be the presenting feature of childhood lupus. The etiology of SJS/TEN in this patient is conjectural but is unlikely to be drug induced given the time course of events.

**Funding Source(s):** NIL

160

#### FEELING THE BENEFIT: LUPUS AND THE WORLD OF WELFARE

<sup>1</sup>Sara Booth\*, <sup>2</sup>Elizabeth Price, <sup>3</sup>Elizabeth Walker. <sup>1</sup>University of Cambridge; <sup>2</sup>Hull York Medical School; <sup>3</sup>Faculty of Medical Sciences

10.1136/lupus-2019-lsm.160

**Background** This study explores peoples experiences of living and working with SLE whilst simultaneously navigating the contemporary UK welfare system. It is established that SLE is associated with high levels of workplace disability and early retirement from employment, requiring financial support. There is little literature about the experience of claiming benefits whilst living with a fluctuating, invisible medical condition, particularly in young people. Lupus is an exemplar of conditions which affect people in their most productive working years, treatable but not curable, which has profound effects on both educational and employment opportunities.

**Methods** A cross sectional online qualitative study was carried out of people aged 18 and over who were resident in the UK, with a self-reported diagnosis of lupus, through the LUPUS UK website. Participants responded to questions focusing on their experience of working and/or claiming benefits. Employment data is presented elsewhere. Participants were asked to quantify (with numerical rating scales) (i) psychological distress associated with income loss resulting from lupus, (ii) the proportion of income lost (iii) any fear experienced of being unable to sustain future employment (iv) levels of anxiety generated by engaging with the benefits system. There was space to describe these experiences and for additional information of the participants choice.

**Results** A cross sectional online qualitative study was carried out of people aged 18 and over who were resident in the UK, with a self-reported diagnosis of lupus, through the LUPUS UK website. Participants responded to questions focusing on their experience of working and/or claiming benefits. Employment data is presented elsewhere. Participants were asked to quantify (with numerical rating scales) (i) psychological distress associated with income loss resulting from lupus, (ii) the proportion of income lost (iii) any fear experienced of being unable to sustain future employment (iv) levels of anxiety generated by engaging with the benefits system. There was space to describe these experiences and for additional information of the participants choice.

**Conclusions** The experience of people with lupus claiming state support has been inadequately defined and explored so that it is variously, and inconsistently, understood, both by those requiring welfare and those administering it. We argue for a concerted focus on these issues in order to articulate more effectively this aspect of the experience of living with a chronic illness. The legislative and policy-driven processes, apparently designed to enable people with illness to live the most active working life possible, are not informed by scientific data, more is needed. The experiences of people with lupus are likely to be relevant to those with other similar illnesses where individuals may require long-term financial support with/out work.

**Funding Source(s):** No external funding required

161

#### LOW HAPTOGLOBIN LEVEL IN LUPUS WITHOUT HEMOLYSIS

Homa Timlin. *Johns Hopkins*

10.1136/lupus-2019-lsm.161

**Background** Low haptoglobin indicates hemolysis in lupus patients. We present a lupus patient who was found to have low haptoglobin levels in the absence of other evidence of hemolysis.

**Methods** Chart review.

**Results** A 44-year-old Caucasian woman was diagnosed with lupus about 11 years ago, characterized by positive ANA, anti-dsDNA, anticardiolipin antibodies, anti-beta-2 glycoprotein, Direct Coombs, hypocomplementemia, alopecia, arthralgia, arthritis, photosensitive skin rash, serositis, mucosal ulcer, and livedo. She was treated with hydroxychloroquine, steroids, and Imuran. During her first visit in our center, she was found to have mild alopecia and subtle synovitis of 2 small joints. She was taking hydroxychloroquine 400 mg. The hematocrit was 34 (up from 30–31, 3 months prior to the visit and 3 months after the visit), haptoglobin 41 mg/dL (normal 43–212 mg/dL), absolute reticulocyte count of 73 000/mm<sup>3</sup> (normal 20000–80000), negative Direct Coombs, low positive anti-dsDNA of 15 (negative <4 IU/ml), low C3 of 72 mg/dL (normal 90–180), normal C4 of 17 mg/dL (normal 16–47), platelet counts of 147000 (140000–400000/uL), normal WBC (3 months prior to the visit and 3 months after the visit), normal urine protein creatinine ratio of 99 mg/g creatinine (normal 21–161), normal liver function test (one month prior and 3 months after the visit), and CRP was normal (<0.1 mg/dl).

**Conclusions** Further research is needed to detect anti-haptoglobin antibodies in lupus patients and elucidate the mechanism underlying these findings.

**Funding Source(s):** Non.