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Reality of ANCA associated vasculitis (AAV) remission and relapse, prolonged use of glucorticosteroids and burden of disease – a real world study in the UK

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Background: AAV is a relapsing remitting long term condition and patients are at risk of organ damage from both active AAV and therapy in particular glucocorticoids (GC). The remission maintenance phase of AAV is critical for good long term outcomes and therapeutic aims are to control AAV activity, prevent relapse and reduce cumulative organ damage. This retrospective study aimed to examine the definition of maintenance, therapy used and clinical outcomes in AAV patients managed in routine clinical practice.
Methods: 300 AAV patients managed by 100 UK physicians (40% Rheumatologists) who completed induction therapy for organ or life threatening AAV and then initiated maintenance therapy between 2014-16 were studied. Data were collected retrospectively from the time maintenance was determined to begin by the physician and then at 6, 12, 18 and 36 months following that time.
Results: 56% had granulomatosis with polyangiitis; mean age 55.4 years with 54% male. 61% had incident AAV and 39% were studied from time of a relapse. 79% received cyclophosphamide and 23% received rituximab GC, 68% received GCs (78% of these patients received IV then oral GC). 30% of patients received plasma exchange Physicians defined time of maintenance from remission induction treatment start with mean of 4.5 months on basis of fixed time point 47%, starting new drug for maintenance 27%, reaching full remission 16% and no specific criteria 9%. At this time 45% were in full remission vs 49% in partial and 6% refractory. Various maintenance regimes were used, 11% received rituximab (84% 6 monthly and 16% 12 monthly) at varying planned doses 61% 1g, 19% 500 mg and 16% 375 mg/m2, 4% not recorded. Remission rates varied with many patients having ongoing vasculitis activity. Treatment adverse events (AE) and infections were frequent with prolonged GC use over 36 months being common. There was a modest rise in eGFR over the initial maintenance phase but some patients had worsening eGFR or rising blood pressure. At the most recent clinical review patients had been followed for a mean of 49.2 months – 6% had died, 30% had relapsed at least once, and 10% required chronic renal replacement therapy. 62% had no vasculitis activity and were ANCA negative but 14% were still experiencing active disease. 35% were still receiving GCs - 19% of them receiving > 5mg/ day.
Conclusions – Maintenance therapy is variably defined but at approximately 4-5 months from start of remission induction therapy. Achieving full remissions and preventing relapse are still clinical problems and many patients receive ongoing long term GC therapy. Infectious complications and treatment adverse events are a problem with current therapy and there is a significant burden from renal disease.