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Real World Experience in ANCA-Associated Vasculitis (AAV) – A Complex Pathway of Patient Referral, Diagnosis, and Management

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Background: AAV is a severe systemic small vessel vasculitis with frequent renal involvement. Diagnosis can be difficult and referral pathways complicated with potentially several different specialists involved. Patient comorbidity is important but poorly reported. This retrospective study aimed to examine referral, diagnosis, and therapy outcomes in AAV patients managed in routine clinical practice.

Methods: A retrospective study was performed on 1197 patients receiving care from 399 physicians in 4 EU countries and 929 incident AAV patients are reported here. Patients were referred between 2014-17 and data collected at baseline and 1, 3, 6 and 12 months following commencement of therapy.

Results: Mean patient age was 56.8 years and 54% were male. 75% of patients were referred by other physicians, 25% direct acute presentations with only 16% referred with ANCA diagnosis. Referral symptoms were general in most cases – fatigue (58%), fever (54%), weight loss (53%), joint pain (47%) – 64% had renal disease. Physicians reported that 16% of patients had had symptoms for over 3 months. Comorbidities were common

(hypertension 45%, diabetes 18%, COPD/asthma 15%, coronary arterial disease 10%, arthritis 9%, osteoporosis 7% and cardiac failure 6%) with only 32% having none. At diagnosis, the median eGFR 35 ml/min, protein excretion median 595 mg/24 hours and 62% had microscopic haematuria; a renal biopsy was performed in 64%. Granulomatosis with polyangiitis was diagnosed in 54% of patients. In only 12% of patients was a formal scale (Birmingham Vasculitis Activity Scale, BVAS) used to assess activity. Clinically, 12% had mild disease, 54% had moderate/systemic disease and 34% had severe/rapidly progressive disease. Resource use at diagnosis and treatment was significant with a mean length of stay of 17 days including 3 intensive care unit days. 83% of patients were managed in collaboration with other specialties (Nephrologist 51%, Rheumatologist 27%, Internal Medicine 18%, Respiratory 16%, ENT 11%).

Conclusions: AAV patients have complex pathways to diagnosis and many have features of renal disease at presentation. Most patients have comorbidities which need to be considered during AAV therapy. BVAS is used rarely in clinical practice and resource utilization at presentation is significant.

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