ANCA-associated vasculitis (AAV) leads to an acute illness of variable but often significant clinical severity. Current induction therapy regimens have led to AAV becoming a long term condition in which the disease remits and relapses. Therapy is often complex and patients follow an individual clinical course following diagnosis. In addition patients frequently experience adverse events in the acute setting e.g. infections or with long term organ damage e.g. corticosteroid induced complications. Relatively little is known about the patient experience in AAV and how that evolves over time although it is known that health related quality of life is reduced in AAV patients with fatigue being a major problem. This study aimed to understand patient experience and its evolution from diagnosis in AAV.

METHODS

STUDY DESIGN. Qualitative research methodology using in depth 1 on 1 interviews followed by

PARTICIPANTS. 33 AAV patients from France (n=6), Germany (n = 8), Italy (n = 9) and UK (n = 10) were invited to participate and gave their informed consent. Twenty patients reported their AAV diagnosis as GPA, 12 as MPA and 1 as EGPA. Median time from AAV diagnosis was 3.5 years (range 1 to 32) and age ranges were under 40 (n=3), 40-60 years (n=16), 60-79 years (n = 13) and 80 years or over (n=1). 21 patients had urban residence and AAV diagnosis was made by rheumatologists (n = 12), nephrologists (n = 13) and other (n = 8).

INCLUSION & EXCLUSION CRITERIA. Patients were over 18 years, had a confirmed diagnosis of AAV for at least 12 months and had received at least one course of induction therapy to achieve remission.

DATA COLLECTION. Interviews were facilitated by a single researcher with open ended questions and predetermined probes during these semi-structured interviews. Probes and questions were based on – Current wellbeing, overall impact of different aspects of life, patient experience at different phases of the AAV journey, impact and role of stakeholders and current unmet needs and expectations.

DATA ANALYSIS. Transcripts were analysed using content analysis, emergent themes were identified and linked to create an overall patient orientated view of AAV and its treatment.

RESULTS

Overall AAV patient journey. Overall view of the patient journey with AAV from initial illness, diagnosis, treatment and follow up including relapse. Key patients emotions are presented alongside patient views of services delivered to them. The overall patient views were very consistent across countries and age groups. Six key themes were then identified along this journey and are described in detail.

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