

# Patient Experience in ANCA-Associated Vasculitis Evolves over Time from Diagnosis and Both Benefits and Adverse Impacts Are Felt with Current Therapy

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## SESSION INFORMATION

Date: Tuesday, October 23, 2018

Session Type: ACR Poster Session C

Session Title: Vasculitis – ANCA-Associated Poster II

Session Time: 9:00AM-11:00AM

**Background/Purpose:** ANCA-associated vasculitis (AAV) leads to both acute illness and a long-term condition in which the disease remits and relapses. Therapy is often complex and associated with toxicity in its own right. Relatively little is known about the patient experience in AAV and how that evolves over time, but it is important when considering new therapeutic options. This study aimed to examine patient experiences and views around AAV and its treatment.

**Methods:** Qualitative research was performed using one-on-one interviews with 33 AAV patients (11 male) from 4 European countries. 20 patients had granulomatosis with polyangiitis, 12 had microscopic polyangiitis, and 1 had eosinophilic granulomatosis with polyangiitis. AAV duration (median 3.5 years, range 1-32) and patient age (3 under 40 years old, 25 aged 40-80 years, and 5 over 70 years) allowed rich insight into the patient journey from diagnosis through follow up.

**Results:** Thematic analysis of the interview transcripts by a single experienced researcher was performed to examine issues along the patient journey from diagnosis to treatment. Key findings were: (1) Suboptimal referral – patients report a long journey to diagnosis leading to long lasting psychological damage, worsened with treatment burden following diagnosis. (2) Recognition – patient experience is worse with sudden onset or misdiagnosis. Patients express concern over low empathy and understanding of their needs by professionals. (3) Knowledge gaps – patients want to understand their future, duration of therapy, and when they can expect to return to normality. (4) Measuring response – patients have a low awareness of how their response is assessed clinically and categories of response or scales used by clinicians. Patients refer to “feeling better” and going home as being important to them. (5) Decision making – they had a low involvement in treatment decisions particularly over glucocorticoids (GCs) and immunosuppression. (6) Unmet needs – while they are grateful for the efficiency of GCs, they feel major side effects which impair their quality of life, satisfaction and functional status with evolving symptomatic problems over their journey as GC dose changes. These findings were consistent across the 4 countries with only minor differences driven by variations in healthcare system and organization.

**Conclusion:** Patient experience in AAV is challenging both before and after diagnosis, and once treatment begins with evolution over time. Physicians need to consider AAV patients’ needs at

diagnosis, when assessing response to treatment, and when changing treatment. GCs are a particular problem for patients and there is a need for new therapies which reduce the significant treatment burden.

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**Disclosure:** P. Rutherford, Vifor Pharma, 3; D. Goette, Vifor Pharma, 3; J. O`Donoghue, Elma Research, 3; X. Liu, Elma Research, 3.

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