

12 microscopic polyangiitis, and 1 had eosinophilic granulomatosis with polyangiitis. AAV duration (median 3.5 years, range 1-32) and patient age (3 < 40 years, 25 aged 40-80 years and 25 > 70 years) allowed rich insight from diagnosis through follow up.

**Results:** Thematic analysis of the interviews identified issues along the patient journey. Key findings were: (1) Suboptimal referral – long delays in diagnosis lead to long lasting psychological damage, worsened with treatment; (2) Recognition - sudden onset and misdiagnosis impairs patient experience. Patients are concerned over low empathy and understanding of their needs by healthcare professionals; (3) Knowledge gaps – patients want to know when they will return to normal and the duration of therapy and its impact; (4) Measuring response – patients have a low awareness of how their response is assessed clinically with scales/scores; instead they refer to the importance of “feeling better” and going home; (5) Decision making – patients report a low involvement in treatment decisions particularly over glucocorticoids (GCs) and immunosuppression; and (6) Unmet needs – patients have high regard for the efficiency of GCs in the acute phase but report major side effects which impair quality of life and functional status as GC dose changes. Findings were consistent across the 4 countries; differences reflected variations in healthcare system and organization.

**Conclusions:** Patients are challenged before and after diagnosis and once treatment begins with evolving experience over time. Physicians need to be aware of AAV patients concerns and needs from first interaction, when assessing response, and if treatment changes are needed. GCs pose a particular problem for patients and new therapies which reduce the significant treatment burden of AAV would be beneficial.

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##### **Patient Experience in ANCA-Associated Vasculitis - Challenges from Diagnosis and Need for New Approaches**

Peter A. Rutherford,<sup>1</sup> Dieter K. Goette,<sup>1</sup> James E. O'Donoghue,<sup>2</sup> Xierong Liu.<sup>2</sup>  
<sup>1</sup>Vifor Pharma, Zurich, Switzerland; <sup>2</sup>Elma Research, London, United Kingdom.

**Background:** ANCA-associated vasculitis (AAV) brings challenges to patients in terms of acute illness and then a long term remitting relapsing condition. Therapy is complex and associated with significant acute toxicity as well as cumulative damage. Relatively little is known about the patient experience and how it evolves over time.

**Methods:** Qualitative research was performed using 1 on 1 interviews with 33 AAV patients (11 male) from 4 EU countries. 20 patients had granulomatosis with polyangiitis,