

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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INTRODUCTION

ANCA-associated vasculitis (AAV) leads to an acute illness of variable but often significant clinical severity. Current induction therapy regimes 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 thematic analysis.

PARTICIPANTS. 33 AAV patients from France (n=6), Germany (n = 8), Italy (n = 9) and UK (n = 19) 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).

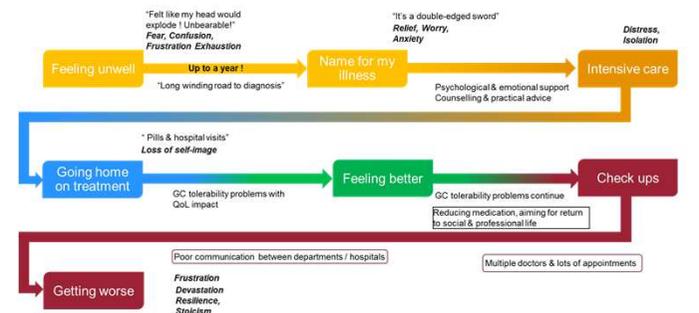
INCLUSION & EXCLUSION CRITERIA. Patients were over 18 years, had a confirmed diagnosis of AAV for at least 12 months and had received at least one course of induction therapy to achieve remission.

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.



RESULTS

(1) Suboptimal referral. Patients raised major concerns over their individual clinical pathways to diagnosis and described the impact on clinical outcomes but more particularly adverse psychological and emotional impact. They describe the journey as;

Long – patients experienced symptoms for months or years **AND**

Winding – the diagnosis was made after they had seen 3-4 different specialities

Patients expressed feelings of being invisible and those without close caregivers expressed stronger emotional problems and the lack of counselling or psychological support was a challenge.

(2) Recognition. Patients appreciate recognition of AAV although the information can lead to emotional challenges. The emotional burden was seen to be underrecognised and not supported by health care professionals and patients described the feeling of;

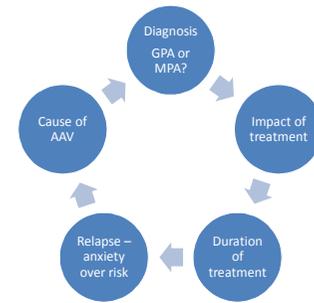
Being "invisible or tortured" - leading to mistrust, anger and isolation

Being a "lucky survivor or saved" – leading to a strong bond and gratitude to the diagnosing physician.

The features of the early part of the AAV patient journey had a strong and lasting effect on patients emotions.

| Strong negative long lasting impact | Moderate negative temporary impact |
|--|---|
| "Delayed diagnosis" – numerous referrals, erroneous diagnoses | Rapid diagnosis – quick referral to a specialist who recognises diagnosis |
| Complex care – patients with multiple visits to various physician specialities who all continue to be involved | Single team – patient is under the clinical management of a single AAV team from the start |
| Rapid AAV progression – patients present acutely to hospital | Slow AAV disease progression – diagnosis is picked up "by chance" as part of investigations |

(3) Knowledge gaps. At various points through their journey patients had knowledge gaps which they would prefer to fill. They wished to understand more about the specific issues below:



(4) Measuring response. Patients have a low awareness of how their response is assessed clinically but expressed views on their own measures of response and their experience with care.



RESULTS

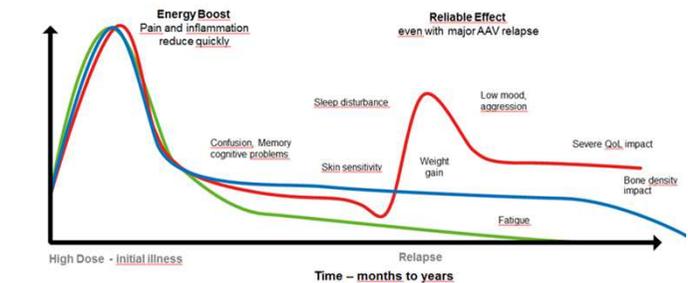
(5) Decision making. Treatment decision making was a major concern for patients and they felt they were not as involved in benefit risk assessments as they would like to be.

| Period in patient journey | Major goal for patients | Risks and concerns |
|-------------------------------|--|---|
| Initial induction therapy | Getting out of danger | Fear of death Impact of hospitalisation |
| Choice of immunosuppressant | Side effect management | Understanding the side effect risks and memory of previous treatments |
| Maintenance therapy | Avoid relapse – symptoms return and induction therapy required again | Prevention of relapse and improvement in AAV symptoms |
| Long term therapy (> 5 years) | Successful management of persistent/recurrent disease | Relief from the burden of immunosuppression |

(6) Unmet needs – the impact of glucocorticoids. Patients expressed strong emotions regarding glucocorticoids and is clearly an area of unmet need.

Patient views changed over time but were repeated as patients experienced a relapse requiring additional high dose treatment.

Initially patients reported an energy boost but this phase was short (typically weeks). Patients associate many adverse events to glucocorticoids in particular weight gain, body image changes, mental health changes (negative mood and sleep disturbance) and impaired cognition. While each patient expressed an individual journey a summary is presented below.



CONCLUSIONS

AAV patients experience many challenges before and after the diagnosis is made and the emotional impact can be long lasting.

There is an evolution of patient experience over time but challenges over recognition of their views, information gaps and involvement in decision making are recurrent and important themes. The fear of relapse and the repeat of need for induction therapy is a particular concern.

Physicians needs to consider AAV patients needs at diagnosis, when assessing response to treatment and when considering therapy changes.

Glucocorticoids are a particular problem for patients – they appreciate the early benefits in terms of AAV control but have concerns over the impact of adverse events in short and long term.

There is a need for new therapies in AAV which control the vasculitis activity but also reduce the significant treatment burden experienced by patients.

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