Introduction

AAV-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 group interviews. Inclusion & Exclusion criteria. Patients were over 18 years old, 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

(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 specialties.

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.

(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:

- 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 specialties 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

(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.

- Feeling better
- Going home
- Levels in blood going down
- Feeling more normal
- ‘Return to normal’
- ‘Would like a clear treatment plan’
- ‘Levels in blood going down’
- ‘Would like a clear treatment plan’

Conclusion

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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