

Abstract Title	Patient reported symptoms in Giant cell arteritis
Abstract	<p>Objective. The development of dedicated patient reported outcomes (PROs) in vasculitis has received increasing attention. A better understanding of the patients perspectives is pivotal in the development of PROs. We assessed patients perspective of disease amongst cases with newly diagnosed Giant Cell Arteritis (GCA) compared to comparator illnesses mimicking large vessel vasculitis (LVV) included in the Diagnostic and Classification Criteria in Vasculitis Study (DCVAS) database. Methods. Patient Description of Illness (PDI) forms were circulated amongst Centres participating in the DCVAS study. The PDI form records up to 10 free text severity ranked symptoms in descending order of severity, a body map to localise the sites of pain and a free-text short summary of illness description. Free text was reorganized through content and thematic analysis. Results. PDI forms from 89 patients with GCA and 28 comparators (COM) were analysed. There was no difference in age and sex distribution between the two groups (mean age <math>70 \pm 8</math> for GCA and <math>69 \pm 12</math> for COM). The symptoms description and frequency of the first most severe aspect of disease, including the patient's own words, is presented in Table 1. The symptom regarded as the most severe by both groups was headache. While there were no differences in the frequency of sudden visual loss, visual symptoms were reported more commonly as the most severe feature by COM vs GCA (21% vs 8%, <math>p = 0.05</math>). Arthralgia was more frequently reported by COM vs GCA (11% vs 1%, <math>p=0.01</math>). Headache was the most frequently reported symptom in both groups. Patients with GCA reported jaw claudication (37%) as the second most frequently reported symptom, while COM reported arthralgia/ arthritis (32%). Shoulder neck pain was the third most important symptom in GCA (33%), while fatigue was the third most common complaint among COM (21%). Fatigue was reported as the fourth most common feature by 30% of GCA patients. Conclusions. Headache was the most frequent and most severe symptom reported by patients with GCA and comparators. However, the reported frequencies and severities of other symptoms were significantly different between the two groups.</p>

**Table 1. Top 10 most recurrent patient-reported symptoms and correspondent severity rank in giant cell arteritis (GCA) and Comparators (COM)**

Item	Frequency in GCA	Severity in GCA	Frequency in COM	Severity in COM	Examples of patient's own words to describe the symptom
<b>Headache</b>	1	1, 2, 8	1	1, 2, 5	Headaches; Sore head; Thumping headache; Woken by night-time headaches; Stubbing head pain; Pain through temple and eye area; Headache across half of head left side
<b>Jaw claudication</b>	2	3, 6	6	0	Jaw ache; Pain in jaw and swelling in throat; Pain in jaw and teeth; Extreme pain in jaw, difficulty eating;
<b>Shoulder/neck pain</b>	3	3, 4, 5,	0	0	Pain at back of neck and left shoulder; Intense pain on left Shoulder and/or neck pain; Shoulder upper arm pain
<b>Fatigue</b>	4	5, 6, 10	3	3, 6, 7	Tiredness; Severe tiredness; Low energy level; Fatigue; No energy and exhausted; Tiredness and lethargy
<b>Myalgia or muscle weakness</b>	5	5, 7, 10	4	3	Aching muscles; Heavy arms; Achey limbs; Leg and arm pain; Heavy legs; Loss of strength in arms and legs; Weakness in legs and arms; General muscle aches
<b>Blurred vision</b>	6	10	5	4, 8	Blurred vision; Blurred vision left eye
<b>Scalp tenderness</b>	7	8	0	4	Pain and tenderness right side neck and scalp; Irritation to the scalp; Tender scalp; Very sensitive scalp; Hypersensitive scalp
<b>Loss of appetite</b>	8		0	0	Loss of appetite; Lack of appetite
<b>Flu-like symptoms</b>	9	9	0	0	General ill feeling; Flu-like symptoms; Unwell; Sickness, Not very well
<b>Arthralgia or arthritis</b>	10	9	2	3	Pain in shoulder, arms, knee; Hip, knee more on right side; Pains in arms and legs (joints); Pain in back of neck, ankles, wrists, and chest
<b>Other ENT</b>	0	0	7	4	Severe sinusitis; sore inside gums
<b>Sudden visual loss</b>	0	0	8		Loss of eyesight to both eyes; Vision loss in right eye; Lost sight of left eye
<b>Night sweats</b>	0	0	9	4, 8	Night sweats; Night fever sweats
<b>Painful eyes</b>	0	9	10	0	Shooting pain left eye problems, pain worse on concentrating; Pain right eye

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