

345. WHAT IS THE ANCA-ASSOCIATED VASCULITIS COMMUNITY DISCUSSING ONLINE? A SOCIAL MEDIA ANALYSIS FROM 5 EUROPEAN COUNTRIES

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Background: ANCA-associated vasculitis (AAV) is a severe inflammatory condition with major impacts on patient reported outcomes and experience. When developing new interventions for AAV it is important to understand patient unmet needs and experience but there is little published evidence. This study aimed examined the scope and content of social media conversations in order to understand challenges, unmet needs and patient experience.

Methods: The study collected data using the Radarly platform and specific AAV search terms from online forums, social media channels, websites, media pages and blogs. Data was collected from 1/10/2016 until 30/9/2018 in local language from France, Germany, Portugal, Spain and UK. Qualitative analysis was performed of 257 specific comments.

Results: There were geographical differences in volume of posts mentioning AAV (1952 in UK vs under 320 in other countries) and estimated reach to users exposed to the post (1,570,000 in UK vs under 255,000 in other countries). Patient led conversations contributed most to the high UK volume whereas it was healthcare professional (HCP) and other contributor dominated elsewhere. There were differences in the use of various social media platforms. In UK Instagram is a key platform for patients sharing experience of their daily lives and awareness of AAV. Online forums were important for patient discussions in Germany and France but in Spain online patient discussion was rare. Detailed analysis of individual posts examined conversations with a framework including challenges/unmet needs, symptoms/side effects and treatments, presented in table (% of each

challenge/symptom out of total mentions in category). Ear, nose and throat problems dominated patient symptom conversation (56%), followed by joint pain and impact on daily life (both 28%). HCPs/others focused on long term organ damage (70%). Patients and HCPs/others concentrated on different topics when discussing challenges/unmet needs (61% vs 14%), symptoms (64% vs 32%) and treatments (39% vs 70%).

Conclusion: The AAV community are active on social media although there is variation in volume, originator and content between countries. This analysis has demonstrated the areas of particular unmet need (time to diagnosis, impact and information) for AAV patients that are discussed on online.

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ABSTRACT 345 TABLE 1:

Challenges/ unmet needs		Symptoms	
Time to diagnosis:	33%	ENT/ upper respiratory tract infection:	55%
Impact of AAV on everyday life :	28%	Long term organ damage :	37%
Lack of information about AAV:	26%	Joint pain:	24%
Impact on mental health:	19%	Impact on daily life :	19%
Side effects of treatments:	18%	Fatigue/ tiredness:	21%
Impact on work:	14%	Functional ability :	17%
Relapse :	13%	Weight loss :	11%
Communication:	13%	Night sweats:	7%
Maintenance of remission:	12%	Appetite loss:	5%
Support network:	7%	Drug toxicity:	2%
Treatment toxicity:	6%		
Financial support:	6%		