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ORIGINAL ARTICLE

YouTube® in Spanish as an information source for patients with autoimmune hepatitis



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KEYWORDS

Autoimmune hepatitis; Social media; Patient education as a topic

Abstract

Introduction and aim: A large number of patients with autoimmune hepatitis (AH) seek information about their disease on the Internet. The reliability, comprehensiveness, and quality of said information in Spanish has not been studied. Our aim was to describe the characteristics of the information about AH on YouTube®.

Methods: An analytic observational study evaluated videos in Spanish about AH available on YouTube[®], describing their general characteristics, viewer engagement, and information sources. Standardized tools were utilized to analyze reliability (DISCERN), comprehensiveness, and overall quality (Global Quality Score [GQS]).

Results: One hundred videos were included, 93% of which provided information from health-care professionals (group 1), and 7% of which reflected patient opinions (group 2). There were differences in the median reliability (DISCERN 4 vs 2, $p \le 0.05$) and comprehensiveness (4 vs 2, $p \le 0.05$) scores between groups, but equal overall quality (GQS 3 vs 2, p = 0.2). Reliability (DISCERN 4; RIC 3-4) and comprehensiveness (4.5; IQR 3-5) were higher in videos by professional organizations, compared with those by independent users, healthcare information websites, and for-profit organizations (DISCERN 3; IQR 2.5-3.5) (p < 0.001). Reliability (DISCERN 2; IQR 1.5-3), comprehensiveness (2; IQR 1.5-2.5), and quality (GQS 2.5; IQR 1.5-3.5) were lower for videos made by for-profit organizations.

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Conclusion: The majority of videos about AH in Spanish on YouTube® have good reliability, comprehensiveness, and quality. Videos created by academic organizations had higher scores, thus their collaboration, with respect to patient opinion videos, is suggested.

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PALABRAS CLAVE

Hepatitis autoinmune; Medios de comunicación sociales; Educación del paciente como asunto

YouTube® en español como fuente de información para pacientes con hepatitis autoinmune

Resumen

Introducción: Gran parte de los pacientes con hepatitis autoinmune (HA) buscan información de su enfermedad en internet. La confiabilidad, exhaustividad y calidad de esta información en español no ha sido estudiada.

Objetivo: Describir las características de la información sobre HA en Youtube®.

Métodos: Estudio observacional analítico que incluyó videos en español sobre HA disponibles en YouTube[®]. Se describen características generales, interacción, y fuentes generadoras. Se utilizaron herramientas estandarizadas para la evaluación de confiabilidad (DISCERN), exhaustividad y calidad global (Global Quality Score, GQS).

Resultados: Cien videos fueron incluidos. 93% representaban información proveniente de profesionales en salud (grupo 1) y 7% opiniones de pacientes (grupo 2). Hubo diferencias en la mediana del puntaje de confiabilidad (DISCERN 4 vs 2, $p \le 0.05$), exhaustividad (4 vs 2, $p \le 0.05$) entre grupos, aunque igual calidad global (GQS 3 vs 2, p = 0.2). La confiabilidad (DISCERN 4; RIC 3–4) y exhaustividad (4,5; RIC 3–5) fueron mayores en videos realizados por organizaciones profesionales comparados con los usuarios independientes, páginas de información en salud y agencias con ánimo de lucro (DISCERN 3; RIC 2,5–3,5) (p < 0.001). La confiabilidad (DISCERN 2; RIC 1,5 – 3), exhaustividad (2; RIC 1,5 – 2,5) y calidad (GQS 2,5; RIC 1,5 – 3,5) fueron menores para videos por agencias con ánimo de lucro.

Conclusión: La mayoría de los videos sobre HA en YouTube® en español tienen buena confiabilidad, exhaustividad y calidad. Se obtuvieron mayores puntajes en videos realizados por organizaciones académicas. Se sugiere aumentar la colaboración con videos que representen opinión de pacientes.

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Introduction

The use of social media networks (SMNs) is a worldwide phenomenon that has transformed the way we obtain and use information. For the year 2021, 70% of adults used SMNs, with YouTube® standing out (81%), followed by Facebook® (69%) and Instagram® (40%). Likewise, close to 70% of patients with chronic diseases utilize SMNs as a source of information about their medical problems, treatments, and medications. 3

The information patients receive from SMNs is beneficial, helping them understand their disease and empowering them to participate in their care. It facilitates their relationship with healthcare personnel and promotes treatment adherence. However, many healthcare professionals believe the information published online is low-quality and that it does not undergo rigorous peer review. They express concern about using SMNs to share information with their patients, arguing that it could negatively impact their reputations. Such concerns have motivated the perfor-

mance of studies that evaluate the quality and validity of healthcare information about different chronic diseases found on SMNs.^{6,7}

Autoimmune hepatitis (AH) is chronic hepatitis secondary to the loss of tolerance to the patient's own liver antigens. Notwithstanding, its medical treatment improves patient survival. Different studies report a prevalence of AH of 17.3 and 21.2 cases per 100,000 inhabitants, 10-12 affecting persons of all ages. AH also significantly reduces the quality of life of those patients. Regarding other gastrointestinal diseases, up to 75% of patients are reported to seek specific information about their diseases on the Internet. The reliability of information about AH in Spanish on SMNs is unknown.

The aim of the present study was to describe the characteristics of the information in videos about AH in Spanish available on YouTube®, evaluating their quality, reliability, and comprehensiveness, utilizing standardized tools, as well as to determine whether there are differences according to the information sources.

Methods

An analytic, observational study was conducted that evaluated videos about AH in Spanish available on YouTube®. The videos that had information on epidemiology, risk factors, symptoms, diagnosis, treatment, and other AH-related information were included. Duplicate videos were excluded.

Data collection method

A YouTube® account was created exclusively for the present study and a search strategy on the Google Chrome browser was carried out, in incognito mode, to minimize the risk for bias with previous searches. The search was performed on September 13, 2022, utilizing the term 'autoimmune hepatitis', and was filtered, according to the number of visits. The first 100 videos in Spanish were selected, based on a previous study that reported that 90% of users only respond to results that appear on the first three result pages. 16

Two authors independently obtained the information on the most probable target audience of the video (patient or healthcare professional, according to the general presentation, description, and source of the video), the information source of the video, the type of video according to content (personal experience, advertising, patient education, alternative treatments, creation of disease awareness, medical professional education, and others). If the videos were classified differently, the two authors came to an agreement about a single category for them. Information was also collected on the duration of the video, the number of views, subscribers, comments, and likes, the amount of time on the Internet in days (time between video upload and evaluation), and popularity index (defined as the number of likes/time on the Internet in days). The information source of the video was classified as independent users (individuals, from their personal YouTube® accounts), government agencies, professional organizations/academic channels (websites created by healthcare professionals or showing medical congress presentations), healthcare information websites (not associated with professional associations), or for-profit organizations (websites whose aim was to promote medical services or products). For repeated videos, the number of views were added together and the oldest date on which the video was uploaded to the Internet was selected to calculate the amount of time appearing online. For the videos presented in numerous parts, they were combined and analyzed as a single video. One researcher extracted the information and made the group assignment.

Evaluation scores

An initial evaluation generally determined whether the videos presented information that could be considered misleading for the patient. Information was categorized as such, if the video contained inaccurate information that could affect the diagnosis, treatment, or follow-up of patients with AH. Two evaluators had to agree that the video contained inaccurate information, for it to be assessed as "misleading". The reliability, quality, and comprehensiveness evaluations were then carried out, utilizing

standardized tools. All the evaluations were peer-reviewed by specialists in internal medicine. When there were differences in the evaluations, the team reviewed the data and arrived at a consensus. The evaluation tools are described below:

- Reliability was defined as the presentation of scientifically correct information on any aspect of the disease. The modified DISCERN instrument was used, which contains five questions and a score ranging from 0 to 5.¹⁷
- Comprehensiveness was defined as the thoroughness and detail of the information provided on the disease. The instrument utilized by Singh et al.¹⁸ that contains five domains and has a score from 0 to 5 was employed.
- The overall quality of the video was evaluated using the Global Quality Score (GQS). It is a 5-point scale that has been utilized to evaluate educational websites or patients with AH^{19,20} and attempts to determine how useful the information is for a patient.

The present article was structured according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.

Statistical analysis

The qualitative variables were described through absolute and relative frequencies. The quantitative variables were reported as median and interguartile range (IQR), if they had non-normal distribution. The normality supposition was evaluated using the Kolmogorov-Smirnov test, with a 5% significance level (p < 0.05). The comparison of the categorical variables between groups was carried out using the chisquare test. The video characteristics, according to opinion group (healthcare professional vs patients), were compared using the Mann-Whitney U test The scores of the scales utilized to evaluate quality, comprehensiveness, and reliability were dichotomized into "good" (a score of 3-5) and "poor" (a score of 0-2). Evaluation agreement was assessed with the dichotomized variable, through Cohen's kappa coefficient. The comparison of the video characteristics was made utilizing the Kruskal-Wallis test. The statistical analysis was carried out using the STATA (Stata Statistical Software: Release 16. College Station, TX: StataCorp LLC) program.

Ethical considerations

Because the present study is considered a low-risk analysis, signed statements of informed consent were not required. The study was approved by the institutional ethics and research committee of the *Hospital Universitario San Ignacio* and the *Pontificia Universidad Javeriana* (Act number FM-CIE-0301-22).

Results

The search for the first 100 videos was carried out; it included nine videos that were not related to AH, and so the next nine videos on the reproduction list were entered in their place. The final 100 videos included in

Number of videos, <i>n</i> (%)	Total	Group 1: Healthcare professional opinion	Group 2: Patient opinion	р
	n = 100 (100)	n = 93 (100)	n=7 (100)	
Video characteristics				
Autoimmune hepatitis video, n (%)	55 (55)	50 (53.8)	5 (71.4)	0.22
Autoimmune hepatitis video on overlap syndrome, n (%)	21 (21)	19 (20.4)	2 (28.6)	
Chronic liver disease video, n (%)	12 (12)	12 (12.9)	0 (0)	
Review of other autoimmune diseases, n (%)	9 (9)	9 (9.7)	0 (0)	
Other types of videos, n (%)	3 (3)	3 (3.2)	0 (0)	
Patient as target audience, n (%)	28 (28)	21 (22.6)	7 (100)	<0.05
Health professional as target audience, n (%)	72 (72)	72 (77.4)	0 (0)	<0.05
Video with inaccurate information, n (%) Country of origin, n (%)	12 (12)	8 (8.6)	4 (57.1)	<0.05
Mexico	30 (30)	29 (31.2)	1 (14.3)	0.75
Colombia	17 (17)	14 (15.1)	3 (42.9)	
Spain	15 (15)	15 (16.1)	0 (0)	
Argentina	15 (15)	14 (15.1)	1 (14.3)	
Peru	8 (8)	8 (8.6)	0 (0)	
Chile	7 (7)	6 (6.5)	1 (14.3)	
Remaining countries	8 (8)	7 (7.5)	1 (14.3)	
Type of video				
Personal experience, n (%)	4 (4)	1 (1.1)	3 (42.9)	<0.05
Advertising, n (%)	3 (3)	1 (1.1)	2 (28.6)	
Patient education, n (%)	13 (13)	13 (14.0)	0 (0)	
Alternative treatments, n (%)	7 (7)	6 (6.5)	1 (14.3)	
Create disease awareness, n (%)	3 (3)	3 (3.2)	0 (0)	
Medical professional education, n (%)	69 (69)	69 (74.2)	0 (0)	
Others, n (%)	1 (1)	0 (0)	1 (14.3)	
Viewer engagement parameters				
Views, median (IQR)	813 (279.5-4296)	734.5 (245.2–4757.2)	2195 (1539-3290)	0.09
Duration in seconds, median (IQR)	1231 (468-3247)	1367 (522.7–3367.5)	254 (78–361)	<0.05
Time on Internet in days,	760	730.5	2186	<0.05
median (IQR) No. of subscribers, median	(439–1599.5) 2830	(245.2–4767.2) 3930 (594–18375)	(710–3358) 585 (78–8040)	0.16
(IQR) No. of comments, median	(537–18200) 0 (0–4.5)	0 (0-4)	2 (0-25)	0.15
(IQR) No. of likes, median (IQR)	12	11.5 (3-67)	19 (15-67)	0.18
Popularity index median	(3-65.5)	0.016	0.0139	0.82
Popularity index, median (IQR) Information source	0.01651 (0.00381–0.05427)		(0.00447-0.094)	0.82

Number of videos, <i>n</i> (%)	Total	Group 1: Healthcare professional opinion	Group 2: Patient opinion	p
	n = 100 (100)	n = 93 (100)	n = 7 (100)	
Independent users, n (%)	39 (39)	34 (36.6)	5 (71.4)	0.21
Professional	54 (54)	53 (57.0)	1 (14.3)	
organizations/academic				
channels, n (%)				
Healthcare websites, n (%)	3 (3)	3 (3.2)	0 (0)	
Medical	4 (4)	3 (3.2)	1 (14.3)	
advertising/for-profit companies, n (%)				
Evaluation score				
Reliability (DISCERN), median (IQR)	4 (3-4)	4 (3-4)	2 (2-3)	<0.0
Good _γ n (%) ^a	85 (85)	82 (88.2)	3 (42.9)	<0.0
Comprehensiveness, median (IQR)	4 (3-5)	4 (3-5)	2 (1.5–2.5)	<0.0
Good; n (%) ^a	80 (80)	78 (83.9)	2 (28.6)	<0.0
Quality (GQS score), median (IQR)	3 (3-4)	3 (3-4)	2 (2-4)	0.2
Good; n (%) ^a	87 (87)	84 (90.3)	3 (42.9)	0.2

GQS: Global Quality Score; IQR: interquartile range.

the study were assessed by two independent evaluators. The Cohen's kappa coefficient determined that agreement was fair for reliability (kappa = 0.50, confidence interval (CI) 0.24–0.76), substantial for comprehensiveness (kappa = 0.27, CI 0.03–0.50), and moderate for quality (kappa = 0.45, CI 0.17–0.74). Agreement was statistically significant (p < 0.05 for each of the evaluations). No videos produced by government agencies were found.

Twelve videos had some element of inaccurate information that could be considered misleading for the patient. The information in 93 videos was created by healthcare professionals and their perspectives (group 1) and the information in 7 videos was created by patients and their opinions (group 2). Upon comparing the two groups (Table 1), patients were the target audience of all the videos created by patients, but for only 22.6% of the videos created by healthcare professionals (p < 0.05).

The majority of the videos came out of Mexico (30%), followed by Colombia (17%) and Spain and Argentina (15%) (Table 1). The group 2 videos were more frequently focused on personal experience (1.1% vs 42.9%) or advertising (1.1% vs 28.6%), whereas the group 1 videos were more frequently focused on medical professional education (74.2% vs 0%) (p < 0.05).

There were statistically significant differences, regarding the duration of the videos (137 vs 254s, p < 0.05) and the length of time the video was on the Internet (730.5 vs 2186 days, p < 0.05). The rest of the viewer engagement parameters had no statistically significant differences. Lastly, there were differences, with respect to the median reliability (DISCERN: 4 vs 2, p < 0.05) and comprehensiveness (4 vs 2 p < 0.05)

0.05) scores between the two groups, but no differences were found, with respect to the quality of the videos (GQS 3 vs 2, p = 0.20).

Information sources

In the evaluation of the sources of information (Table 2), the healthcare websites (100%) and for-profit organizations (75%) more frequently created videos directed at patients, whereas healthcare personnel were the primary target viewer of the videos created by independent users (51.3%) and professional organizations (94.4%). No statistically significant differences were found, with respect to the audience engagement parameters.

Finally, reliability was greater for the videos created by professional organizations (DISCERN: 4; RIC 4–4), compared with those created by independent users, healthcare information websites, and for-profit organizations (DISCERN: 3, 3, and 2, respectively) (p < 0.05). The comprehensiveness score was also greater for the videos created by professional organizations (DISCERN: 4.5; IQR 3–5), compared with those created by independent users, healthcare information websites, and for-profit organizations (DISCERN: 3, 2, and 2, respectively) (p < 0.05). Finally, the median score of the overall quality evaluation was similar to that of all the sources (p = 0.21). However, the dichotomous evaluation of the quality score revealed ''good'' quality in the videos created by professional organizations and independent users (96.3% and 79.5%, respectively), compared with

^a Goodis defined as a score ≥ 3 on the scale.

Number of videos, n (%)	Total n=93 (100)	Independent users (individuals, from their personal YouTube® accounts) n = 39 (100)	Professional organizations Academic channels (congresses) n = 54 (100)	Healthcare information websites (not associated with professional associations that impart information on medical topics)	For-profit organizations (whose websites promote the acquisition of medical services or products)	p
				n = 3 (100)	n = 4 (100)	
Video characteristics						
Autoimmune hepatitis video, n (%)	50 (53.8)	18 (46.2)	31 (57.4)	3 (100)	3 (75)	0.24
Autoimmune hepatitis video on overlap syndrome, n (%)	19 (20.4)	7 (17.9)	14 (25.9)	0 (0)	0 (0)	
Chronic liver disease video, n (%)	12 (12.9)	10 (25.6)	2 (3.7)	0 (0)	0 (0)	
Review of other autoimmune diseases, n (%)	9 (9.7)	3 (7.7)	5 (9.3)	0 (0)	1 (25)	
Other types of videos, n (%)	3 (3.2)	1 (2.6)	2 (3.7)	0 (0)	0 (0)	
Video with inaccurate information, n (%)	8 (8.6)	8 (20.5)	1 81.9)	1 (33.3)	0 (0)	
Patient as target viewer, n (%)	21 (22.6)	19 (48.7)	3 (5.6)	3 (100)	3 (75)	<0.0
Health professional as target viewer, n	72 (77.4)	20 (51.3)	51 (94.4)	0 (0)	1 (25)	0.0
(%)	(,	20 (0.10)	J. (7)	5 (5)	. (23)	
Type of video						
Personal experience, n (%)	1 (1.1)	3 (7.7)	1 (1.9)	0 (0)	0 (0)	< 0.0
Advertising, n (%)	1 (1.1)	2 (5.1)	0 (9)	0 (0)	1 (25)	
Patient education, n (%)	13 (14.0)	7 (17.9)	3 85.6)	2 (66.7)	1 (25)	
Alternative treatments, n (%)	6 (6.5)	6 (15.4)	0 (0)	0 (0)	1 (259	
Create disease awareness, n (%)	3 (3.2)	1 (2.6)	1 (1.9)	1 (33.3)	0 (0)	
Healthcare professional education, n (%)	69 (74.2)	19 (48.6)	49 (90.7)	0 (0)	1 (25)	
Others, n (%)	0 (0)	1 (2.6)	0 (0)	0 (0)	0 (0)	
Viewer engagement parameters	. (*)	(,				
Views, median (IQR)	813 (279.5–4296)	1241 (507.5–5743.5)	546.5 (231–2114)	1205 (800–8071)	4653 (1716–24336)	0.10
Duration in seconds, median (IQR)	1231 (468-3247)	664 (381.5–2510.5)	1486 (724-3327)	244 (241-2116.0)	804 (139.5-2696)	0.20
Time on Internet in days, median (IQR)	760 (439–1599.5)	810 (555–211.5)	666 (301–1433)	1398 (1123–2410)	1017 (883–1525.5)	0.10
Popularity index, median (IQR)	0.016	0.01425	0.017	0.006 (0.003-0.006)	0.027 (0.008-0.789)	0.27
, , , , , , , , , , , , , , , , , , , ,	(0.004-0.054)	(0.005-0.103)	(0.002-0.040)	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	(,	
No. of subscribers, median (IQR)	2830 (537–18200)	1440 (198.5-24900)	3380 (1600–10400)	19,700 (16650-24350)	10,990 (3282.5-33200)	0.22
No. of comments, median (IQR)	0 (0-4.5)	0 (0-14.5)	0 (0-3)	1 (0.5–1.5)	2 (1-63)	0.61
No. of likes, median (IQR)	12 (3-65.5)	17 (4.5–171.5)	10.5 (1–31)	5 (2.5-7.5)	45.5 (9–715)	0.11
Evaluation score	,	,	,	,	,	
Reliability (DISCERN), median (IQR)	4 (3-4)	4 (3-4)	3 (3-3.5)	4 (4-4)	3 (2-3)	<0.0!
Good; n (%) ^a	82 (88.2)	82 (88.2)	30 (76.9)	52 (96.3)	2 (66.7)	<0.0
Comprehensiveness, median (IQR)	4 (3-5)	4 (3-4.5)	3 (3-4.5)	4.5 (3-5)	2 (1.5-3)	<0.0
Good; n (%) ^a	78 (83.9)	78 (83.9)	30 (76.9)	48 (88.9)	1 (33.3)	<0.0
Quality (GQS score), median (IQR)	3 (3-4)	3 (3-4)	3 (3-4)	3 (3-4)	3 (2.5–3.5)	0.28
Good; n (%) ^a	84 (90.3)	84 (90.3)	31 (79.5)	52 (96.3)	2 (67.7)	<0.0

GQS: Global Quality Score; IQR: interquartile range. a Goodis defined as a score ≥ 3 on the scale.

those created by healthcare information websites and forprofit organizations (67.7% and 50%, respectively) (p < 0.05).

Discussion

The present study is the first to evaluate videos available on YouTube® in Spanish, as a source of information for patients with AH. Our results suggest that the majority of videos have good reliability, comprehensiveness, and quality. With respect to information sources, information directed at patients was more frequently created by healthcare information websites and for-profit organizations, whereas information directed at healthcare professionals was produced by academic organizations. Our data also suggest that the reliability and comprehensiveness of the information was superior, when it came from videos created by academic organizations. The videos reflecting patient opinion and those created by for-profit organizations had the lowest scores.

In the present study, the majority of AH videos on YouTube® had good reliability, comprehensiveness, and overall quality. Thus, YouTube® can be a useful source of information for patients. Different studies have shown similar results for other diseases, such as inflammatory bowel disease, 21 osteoporosis, 22 gout, 23 lupus, 24,25 rheumatoid arthritis, 18 Sjögren's syndrome, 26 and spondylolisthesis. 27

Patients with AH were the target audience in less than half the AH videos. There is a high demand, by patients with other gastrointestinal diseases, for information regarding their diseases, 15 therefore videos targeting patients with AH could help empower them, with respect to their disease, improve their relationship with healthcare personnel. and promote treatment adherence.^{4,5} The main source of videos for patients with AH are independent users and the fact that the information has good reliability, comprehensiveness, and quality, should signal academic and professional organizations to see the interaction with SMNs as an opportunity to educate and empower patients through peer-reviewed information. Therefore, we recommend that the medical community work together with independent users and patients to meet this demand for information by patients with AH.

The lower reliability and comprehensiveness in the patient opinion videos could be associated with the presence of inaccurate information in a little over half of those videos, which in turn, is most likely related to the advertising related to nonmedical consultations. Said consultations encourage the patient to stop taking his/her medications, through inaccurate information, and recommend the use of alternative treatments for managing AH. Importantly, the classification of "patient opinion" was contingent on the self-described identification of the person appearing in the video as the patient, something we could not corroborate. Thus, we reiterate our suggestion that academic organizations work together with AH patients or AH patient associations, to produce videos with reliable academic peerreviewed data that meet the information needs of the patients with AH.

Lastly, we found differences in reliability and comprehensiveness, when comparing the video information sources. Videos created by professional organizations were more reli-

able and comprehensive than those of the other sources, findings that were similar to results from other studies. 22,24,26 Nevertheless, the quality of the videos from the different information sources was similar. The lowest reliability, comprehensiveness, and quality scores were found in the videos produced by for-profit organizations. Notably, the majority of those videos were directed at patients and half of them focused mainly on advertising and alternative treatments. Even though for-profit organizations were not found to have higher information inaccuracy, the information could have been presented with bias, given that those videos focus on the sale of nonmedical care services and alternative treatments, resulting in lower evaluation scores. We believe the physician should keep abreast of the information presented by for-profit organizations on SMNs because the recommendations contained therein could conflict with the treatment of AH.²⁸

One of the limitations of our study was the fact that, despite using standardized evaluation tools, there was a subjective component in the assessment of the different videos. That effect was controlled by the peer review of the videos, as well as by the search for agreement between the different evaluators. Understanding that the evaluation of healthcare information reported on SMNs is a growing field of research,²⁹ future optimization and development of better tools for assessing the reliability, comprehensiveness, and quality of the information is expected. Another limitation was the fact that only the information available on YouTube® was evaluated, and so possibly our results cannot be extrapolated to other SMNs.³⁰

In conclusion, the majority of videos about AH on YouTube® in Spanish have good quality, reliability, and comprehensiveness. The videos produced by professional organizations are superior to the other sources. As physicians, we should keep up with the information presented as patient opinion and that coming from for-profit organizations. We also suggest that academic societies work together with patient organizations to create audiovisual content that resolves the educational needs of patients with AH.

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Conflict of interest

The authors declare that there is no conflict of interest.

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