



Panorama

Quality and Characteristics of Pediatric Rheumatology Content on Social Media: Toward a New Era of Education for Patients and Caregivers?

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Social media platforms are an extremely common form of online interaction, with more than 4.5 billion users worldwide in 2022. According to Statista.com, there is a significant expectation that this usage will exceed 6 billion by the year 2027. TikTok is a video-sharing social media platform that has become one of the most popular on a global scale, especially among young people, with over 1 billion monthly users worldwide. Interestingly, in 2022, more than half of TikTok users in the United States were between the ages of 18 and 19, representing a cohort of heavy smartphone young users who are perpetually exposed to trending content.

Pediatric rheumatology comprises a wide spectrum of diseases that affect children of all ages (up to 18 years old) and often persist into adulthood. The influence of social media content on patients’ health-related behaviors has been shown to be substantial.¹ The aim of this study was to assess pediatric rheumatology-related content on TikTok, one of the most popular social media platforms among children and adults.

The top 40 most-liked videos from 25 TikTok hashtags on relevant pediatric rheumatology topics were systematically searched between November 15 and 30, 2023. The hashtags were decided by the authors based on the most common pediatric rheumatology-related diseases and topics as well as the popularity of the topics for TikTok users. Videos published in Italian and English were included. Photo sequences, duplicates, and nonrelevant videos were excluded. The videos were assessed by a panel of 2 pediatric rheumatologists and 6 senior residents in pediatric rheumatology. Each video underwent blind analysis by 2 separate authors, followed by a subsequent discussion between them; following their discussion, each variable was defined.

As in similar previous studies, videos were evaluated for the following criteria:

1. Content creator:
 - Healthcare professionals (HCPs): pediatric rheumatologists, pediatricians, rheumatologists, other physicians, nonmedical healthcare providers (eg, physical therapists, nurses), medical students
 - Nonhealth professionals (NHCPs): patients, caregivers, influencers, and sellers

2. Video metrics: views, comments, and other interactions
3. Content purpose: education, patient or caregiver experience, entertainment, or advertising
4. Patient or caregiver sentiment: positive, negative, or neutral
5. Misinformation: minimal (< 30%), significant (> 30%), or absent. Misinformation was assessed by an expert pediatric rheumatologist (LB) affiliated with the Paediatric Rheumatology International Trials Organisation (PRINTO).
6. Quality of information: The Journal of the American Medical Association (JAMA) benchmark criteria were used to assess the overall video quality. The JAMA benchmark criteria is a 4-point rating scale, ranging from a minimum of 0 to a maximum of 4, depending on authorship, attribution, disclosure, and currency.²
7. Understandability and actionability: The Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-A/V) was used, with 2 separate scores to determine the understandability and actionability of educational videos.³ These scales are widely employed in the medical field to assess educational audiovisual content.⁴ Depending on the number of elements considered, the percentage score ranges from 0 to 100%; a higher final score indicates more understandable or actionable audiovisual material.

In summary, a total of 1440 videos were examined, and 847 videos were included and analyzed (the complete source process and database are available as Supplementary Material, available from the authors upon request). Overall, the videos included were viewed approximately 279 million times and had 24.6 million interactions (23 million likes, 0.2 million comments, 1 million saving, and 0.4 million sharing). Considering the top-liked videos included, the 3 most-liked hashtags were “autoimmune-disease” (17.7 million likes), “vasculitis” (2.2 million likes), and “systemic-lupus” (0.8 million likes). We grouped hashtags into 4 categories: (A) autoinflammatory diseases; (B) autoimmune diseases; (C) vasculitis; and (D) other rheumatological diseases/topics (Table 1).

Table 1. Views and metrics for the most-liked videos of 25 pediatric rheumatology-related TikTok hashtags.

Group	Hashtag	Videos	Duration, sec	Views	Likes	Comments	Saving	Sharing	Interactions
A	#Aicardigoutieressyndrome	33	48 (11-177)	544,611	54,382	2851	3114	2910	63,257
A	#Autoinflammatorydisease	40	25 (5-183)	1,041,783	41,163	1812	2927	1231	47,133
A	#Familialmediterraneanfever	40	33 (5-188)	103,346	3442	599	338	163	4542
A	#Periodicfeversyndrome	37	26 (5-298)	129,886	5496	754	225	276	6751
A	#PFAPA	29	32 (6-344)	2,800,931	56,497	1780	8144	13,763	80,184
A	#Systemicjuvenileidiopathicarthritis	14	15 (7-117)	39,583	1533	89	147	21	1790
B	#Autoimmunedisease	40	21 (5-165)	175,300,000	17,692,600	111,646	687,221	203,730	18,695,197
B	#Juvenilearthritis	40	15 (5-152)	18,120,986	383,204	3822	19,944	3136	410,106
B	#Juveniledermatomyositis	40	19 (5-261)	267,316	11,992	735	694	122	13,543
B	#Juvenileidiopathicarthritis	40	18 (5-180)	1,539,575	83,867	2067	3744	2300	91,978
B	#Juvenilerheumatoidarthritis	40	32 (5-343)	2,032,109	120,784	2133	5078	3413	131,408
B	#Sjogrenssyndrome	40	58 (6-180)	6,420,900	271,603	10,159	18,509	18067	318,338
B	#Systemiclupus	40	11 (5-180)	8,051,979	773,773	11,940	71,435	6212	863,360
B	#Systemicsclerosis	40	15 (5-180)	2,390,788	73,847	1979	2427	937	79,190
C	#Henochschonleinpurpura	40	32 (6-419)	996,355	82,053	2873	2623	6435	93,984
C	#Kawasakidisease	39	52 (7-178)	8,317,800	656,562	14,260	29,026	13,003	712,851
C	#Takayasuarteritis	40	29 (5-173)	2,104,601	89,063	1735	3519	779	95,096
C	#Vasculitis	40	41 (6-466)	41,633,600	2,221,237	39,533	162,527	69,106	2,492,403
D	#Behcet	39	69 (5-576)	1,026,613	26,565	1862	1697	802	30,926
D	#Musculoskeletalultrasound	20	23 (9-94)	134,887	9284	111	281	107	9783
D	#PANDASsyndrome	40	14 (5-310)	540,010	26,875	1054	1395	556	29,880
D	#Pediatricrheumatology	3	59 (15-174)	11,266	212	15	31	18	276
D	#Rheumaticfever	40	69 (10-414)	1,188,496	71,150	2264	3452	1524	78,390
D	#Sydenhamchorea	20	27 (7-291)	3,091,421	155,518	2141	3345	947	161,951
D	#Transientsynovitis	13	36 (4-207)	1,299,149	81,879	998	4114	1298	88,289
-	Overall	847	30 (4-576)	279,127,991	22,994,581	219,212	1,035,957	350,856	24,600,606

Values are expressed in absolute numbers (sum); duration is expressed as a median (range). Videos have been grouped in 4 categories: (A) autoinflammatory disease; (B) autoimmune diseases; (C) vasculitis; and (D) others. PFAPA: periodic fever, aphthous stomatitis, pharyngitis, adenitis; PANDAS: pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections.

Of the 847 videos included, 737 (87%) creators were NHCPs, and 107 (12.6%) were HCPs; 3 were missing (0.4%; Table 2). Among video creators, most of them were patients (439, 51.8%) and caregivers (235, 27.7%), whereas a small percentage consisted of influencers (56, 6.6%) and sellers (7, 0.8%). Interestingly, only a few rheumatologists (7, 0.8%), pediatricians (10, 1.2%), and pediatric rheumatologists (1, 0.1%) contributed as creators; most of the videos by HCPs were by other physicians (51, 6%), nonmedical HCPs (29, 3.4%), and medical students (9, 1.1%). More than half of the videos reported a patient experience (468, 55.3%). Educational videos represented 26% (n = 220), 8.7% reported a caregiver experience (n = 74), and 8.1% had an entertainment purpose (n = 69). Advertisements were only a minority of the sample at 1.8% (n = 15). Of the 674 (79.5%) videos provided by patients or caregivers, 266 (39.5%) reported a neutral emotion; 271 (40.2%) a negative emotion; and 137 (20.3%) a positive emotion. The information was found to be accurate in 719 (84.9%), with minimal misinformation in 97 (11.5%), and significant misinformation in 28 (3.3%) videos (3 unable to assess; 0.3%). No statistically significant differences in misinformation between HCPs and NHCPs were observed ($P = 0.10$). Mean JAMA benchmark score was found to be significantly higher in videos provided by HCPs than NHCPs

that included both educational and noneducational content (2.9 [SD 0.4] vs 2.8 [SD 0.5]; $P = 0.02$).

Significant differences were found among the 4 groups for video duration, views, misinformation, content creator, sentiment, interactions, and mean JAMA benchmark score ($P < 0.001$, Table 2).

Although HCPs were less represented than NHCPs (107 vs 737), educational videos (n = 220) were almost equally published by NHCPs and HCPs (124 vs 96). Indeed, 89.7% of HCPs and 16.8% of NHCPs published educational content, respectively. No statistically significant difference was found in educational videos between HCPs and NHCPs in median (range) views (12,300 [388-5,200,000] vs 17,300 [359-13,100,000]; $P = 0.98$), likes (264 [4-343,400] vs 686 [8-1,200,000]; $P = 0.14$), and interactions (340 [4-457,455] vs 772 [8-1,382,474]; $P = 0.16$). In contrast, educational videos published by NHCPs were more often commented on than those provided by HCPs (median [range] 27.5 [0-9047] vs 17.5 [0-2208], $P = 0.03$), whereas the video duration was longer in videos from HCPs than NHCPs (58 [7-414] vs 44 [4-202] seconds; $P = 0.003$).

Among educational videos, the mean (SD) JAMA benchmark score was higher in videos published by HCPs than NHCPs (2.9 [0.4] vs 2.7 [0.5]; $P = 0.001$). Similarly, the mean

Table 2. Comparative group analysis for engagement metrics and quality assessment.

	Group A, n = 193	Group B, n = 320	Group C, n = 159	Group D, n = 175	P	P Comparison*
Duration, sec	30 (5-344)	17 (5-343)	38 (5-466)	47 (4-576)	< 0.001 ^a	A vs B (0.03) A vs C (0.73) A vs D (0.17) B vs C (< 0.001) B vs D (< 0.001) C vs D (> 0.99)
Views	2243 (28-1,500,000)	19,000 (87-15,500,000)	46,300 (695-6,100,000)	5919 (57-1,700,000)	< 0.001 ^a	A vs B (< 0.001) A vs C (< 0.001) A vs D (< 0.001) B vs C (0.01) B vs D (< 0.001) C vs D (< 0.001)
Interactions	96 (7-48,600)	1119 (16-1,529,585)	2416 (57-457,455)	171 (3-115,823)	< 0.001 ^a	A vs B (< 0.001) A vs C (< 0.001) A vs D (0.04) B vs C (0.11) B vs D (< 0.001) C vs D (< 0.001)
Misinformation						
Absent	169 (87.6)	295 (92.2)	92 (57.9)	163 (93.1)	< 0.001 ^b	Absent: A vs C (< 0.001) , B vs C (< 0.001) , C vs D (< 0.001) Minimal: A vs C (< 0.001) , B vs C (< 0.001) , C vs D (< 0.001) Significant: A vs C (0.001) , B vs C (< 0.001)
Minimal	19 (9.8)	19 (5.9)	47 (29.6)	12 (6.9)		
Significant	4 (2.1)	5 (1.6)	19 (11.9)	0 (0.0)		
Missing	1 (0.5)	1 (0.3)	1 (0.6)	0 (0.0)		
Sentiment ^d (n = 674)						
Neutral	104 (60.8)	96 (34.2)	19 (16.0)	47 (45.6)	< 0.001 ^b	Neutral: A vs B (< 0.001) , A vs C (< 0.001) , C vs D (< 0.001) , B vs C (0.001) Negative: A vs B (< 0.001) , A vs C (< 0.001) , B vs C (< 0.001) , C vs D (< 0.001) Positive: NS
Negative	36 (21.1)	122 (43.4)	81 (68.1)	32 (31.1)		
Positive	31 (18.1)	63 (22.4)	19 (16.0)	24 (23.3)		
Video creators						
NHCPs	181 (93.8)	304 (95)	136 (85.6)	116 (66.3)	< 0.001 ^b	NHCPs: A vs D (< 0.001) , B vs C (0.002) , B vs D (< 0.001) , C vs D (< 0.001) HCPs: A vs D (< 0.001) , B vs C (0.002) , B vs D (< 0.001) , C vs D (< 0.001)
HCPs	11 (5.7)	15 (4.7)	22 (13.8)	59 (33.7)		
Missing	1 (0.5)	1 (0.3)	1 (0.6)	0 (0.0)		
JAMA benchmark score, mean (SD)	2.8 (0.5)	2.7 (0.5)	2.9 (0.3)	2.9 (0.4)	< 0.001 ^c	A vs B (0.002) A vs C (0.83) A vs D (0.38) B vs C (< 0.001) B vs D (< 0.001) C vs D (> 0.99)
PEMAT-A/V-U ^e , %, mean (SD) (n = 220)	73.6 (24.1)	73.8 (20.6)	79.7 (18.6)	79.2 (17.1)	0.22 ^c	NA
PEMAT-A/V-A ^e , %, mean (SD) (n = 220)	44.1 (40.6)	42.6 (30.5)	49.4 (22.5)	33.3 (31.6)	0.06 ^c	NA

Values are expressed as median (range), or n (%) unless indicated otherwise. Values in bold are statistically significant ($P < 0.05$). Group A: autoimmune diseases; Group B: autoimmune diseases; Group C: vasculitis; Group D: other rheumatologic diseases/topics. * To account for multiple comparisons, Bonferroni correction was applied. ^a Kruskal-Wallis test. ^b Chi-square test. ^c 1-way ANOVA. ^d Evaluation of sentiment was limited to videos provided by patients and caregivers. ^e PEMAT-A/V was applicable only for educational videos. HCP: healthcare professional; JAMA: Journal of the American Medical Association; PEMAT-A/V-A: Patient Education Materials Assessment Tool for Audiovisual Materials for actionability; PEMAT-A/V-U: The Patient Education Materials Assessment Tool for Audiovisual Materials for understandability; NA: not applicable; NHCP: nonhealthcare professional; NS: not significant.

(SD) PEMAT-A/V score for understandability was higher in videos published by HCPs than in NHCPs (82.6% [17.1] vs 72.3% [SD 20.6]; $P < 0.001$). The mean PEMAT-A/V score for actionability was higher in videos provided by HCPs than NHCPs (43.4% [SD 31.6] vs 37.4% [SD 32.9]), although it was not statistically significantly different ($P = 0.18$).

In the multivariable linear regression analyses (absolute value difference), educational videos published by HCPs showed a higher mean JAMA benchmark score than those published by NHCPs (0.17, 95% CI 0.05-0.30). Similarly, educational videos provided by HCPs showed higher PEMAT-A/V scores for understandability than those posted by NHCPs (7.33, 95% CI 2.43-12.23). No association was documented between type of content creator and PEMAT-A/V scores for actionability (3.86, 95% CI -4.93 to 12.66).

Misinformation was statistically related to the video's content creator type in educational videos ($P = 0.007$). HCPs provided higher percentages of educational videos without misinformation than NHCPs (89 [92.7%] vs 103 [83.1%]). In the category of minimal misinformation, there was a lower percentage found in educational videos from HCPs than NHCPs (3 [3.1%] vs 19 [15.3%]). Significant misinformation was documented in 2 (1.6%) and 4 (4.2%) educational videos provided by NHCPs and HCPs, respectively.

Because pediatric rheumatologic disorders are rare and not widely known to the general public, this lack of knowledge may lead patients and their families to share their experiences on social media. They may seek out others with similar conditions to humanize the experience or simply to gain a deeper understanding of these "mysterious" diseases. Telemedicine was recently proposed as a current and useful tool for pediatric rheumatology, highlighting the opportunity for HCPs to educate patients and caregivers through online channels (TeleEducation).⁵ The medical community is still beginning to use social media for educational scoping, and specific medical intervention strategies using social media for young populations have resulted in effective outcomes.

To the best of our knowledge, this is the first study evaluating social media content on pediatric rheumatology. There is an enormous amount of pediatric rheumatology-related content available on social media. Although fewer than 3% of content creators were pediatric rheumatologists, pediatricians, or rheuma-

tologists, educational videos made up a considerable percentage of the sample, suggesting there is great interest in understanding and discussing pediatric rheumatology content. Most videos had no misinformation, and high-quality content was documented. Videos regarding other rheumatologic diseases/topics were the most common ones from HCPs. Videos provided by patients and caregivers most often had the purpose of sharing personal experience and were usually accompanied by neutral or negative sentiment. HCPs shared videos with a longer duration and better understandability and quality. Similarly, actionability was higher in videos from HCPs, but with no statistical significance. Also, HCPs produced educational videos with less misinformation than NHCPs.

In conclusion, pediatric rheumatology is a topic of particular interest to a large audience on social media. HCPs, especially pediatric rheumatologists and related medical organizations active in this field, should increase their efforts to provide broader, more exhaustive, and more accurate educational pediatric rheumatology-related content on social media platforms.

DATA AVAILABILITY

Data collected during the realization of this paper are available upon reasonable request to the authors.

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