

Evaluating Sentiment, Engagement, and Perception of Biologics Among Patients With Psoriasis and Psoriatic Arthritis on Reddit

Nicole Maynard BS,^a Danielle Yee MD,^a Camila Carranza BS,^a Manan Mehta BS,^a Rasika Reddy BA,^b Caterina Zagona-Prizio BS,^c Sabrina Khan BS,^a Samiya Khan BS,^d April W. Armstrong MD MPH^a

^aUniversity of Southern California Keck School of Medicine, Los Angeles, CA

^bUniversity of Texas Southwestern School of Medicine, Dallas, TX

^cUniversity of Colorado School of Medicine, Aurora, CO

^dLong School of Medicine, San Antonio, TX

ABSTRACT

Background: Limited analyses of social media content among psoriasis (PsO) and psoriatic arthritis (PsA) patients exist. These patients may turn to social media to gain insight into treatments such as biologics.

Objectives: This study aims to analyze the content, sentiment, and engagement of social media posts regarding biologics for PsO and PsA.

Methods: Posts and comments discussing biologics were extracted from publicly accessible PsO and PsA Reddit groups. Posts were assigned higher (HOT) and lower order (LOT) themes, sentiments, and engagement scores.

Results: Of 1141 posts extracted, 705 posts were classified under the HOT general/efficacy. Twelve lower order themes (LOTs) were identified: general advice/experience (10.2%), symptoms improved (36.6%), switching biologics (10.5%), and time to results (13.4%). 61.3% of content was of positive sentiment, 24.0% was neutral, and 14.7% was of negative sentiment. The mean sentiment score, defined as the average of all posts' sentiment scores (where negative=-1, neutral=0, and positive=1), was overall positive at 0.47, 95% CI [.41-.52]. Mean sentiment scores between LOTs were significantly different ($P<0.001$). Information regarding biologics on Reddit is mostly positive; however, there remains a significant number of users expressing dissatisfaction with their efficacy or with biologics in general. Many users sought anecdotal advice.

Conclusion: These findings can help guide educational efforts to anticipate concerns and appease hesitancy regarding biologics and their efficacy.

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INTRODUCTION

Social media is becoming increasingly popular as a means for dermatology patients to access health information. In one Swiss study, researchers found that 82.4% of dermatology patients had used the internet or social media to access medical information.¹ The social media platform Reddit is one of the fastest growing social media communities, with 366 million posts in 2021 (an increase of 19% from 2020).² Reddit is a unique platform that focuses on community discussion rather than educational content. Unlike other common platforms such as Facebook and Instagram, Reddit allows users to operate under the guise of a username without being attached to a real name or profile image. Therefore, users may feel more comfortable sharing experiences with more personal matters. The Subreddit feature allows for discussions and questions among individual communities, such as patients with psoriasis (PsO) and psoriatic arthritis (PsA).

Psoriasis is a chronic, immune-mediated disease that affects 125 million people globally.³ An estimated 30% of psoriasis patients also suffer from psoriatic arthritis.⁴ For patients with moderate-to-severe psoriasis, or those with concomitant psoriatic arthritis, systemic medications are typically required.⁵ Among these options are biologics, a newer class of drugs that target specific immune-mediated pathways involving cytokines such as TNF alpha, IL-12, IL-23, and IL-17.⁶ Patients with psoriatic disease may turn to Reddit to seek advice and information regarding this class of medications. However, there is limited information about psoriasis treatment content. It is necessary to characterize this content as it may aid dermatologists in addressing patient concerns when providing clinical guidance. This study sought to analyze the sentiment and content of posts regarding biologics on Reddit within the psoriasis and psoriatic arthritis communities.

MATERIALS AND METHODS

Reddit was chosen as the social media platform of interest given its increase in popularity and limited data surrounding its content on the subject of psoriasis and psoriatic arthritis. The data was collected from a publicly accessible forum, so this study was exempt from institutional review board approval.⁷

Publicly accessible posts and comments uploaded between March 1, 2021, and July 31, 2021, within two subreddits (r/psoriasis and r/psoriaticarthritis) were reviewed, and posts in English pertaining to PsO or PsA and biologics were manually extracted. The following search terms were utilized: “biologic,” “biologics,” “Humira,” “Tremfya,” “Cosentyx,” “Taltz,” “Skyrizi,” “Remicade,” “Stelara,” “Enbrel,” “Cimzia,” and “Ilumya.” All posts were de-identified before collection. The text of the post, as well as the total engagement (the sum of upvotes and reply comments), was recorded. Posts were assigned a sentiment corresponding to a numerical value (positive=1, negative=-1,

neutral=0) and then classified into a first-order and second-order theme. Reviewers delineated the themes as posts were identified.

Five first-order themes (FOTs) were identified: general comments (*general*), access to medication (*access*), efficacy (*efficacy*), safety/side effects (*safety*), and how the medication is used (*use*). In this paper, we focus on the themes of *general* and *efficacy*. Within these two FOTs, 15 second-order themes (SOTs) were identified (Table 1).

Statistical analysis was performed using STATA 15.0 (StataCorp LP, College Station, TX). Frequencies, mean engagement scores, and mean sentiment scores were calculated for each FOT and SOT. One-way analysis of variance (ANOVA) tests were used to determine differences in the mean engagement scores and mean sentiment scores between themes. Chi-squared tests were utilized to determine significant differences between sentiment and engagement within the themes. Level of significance was set to $P < 0.05$.

RESULTS

A total of 1141 posts were extracted from Reddit. Among these, 708 (61.8%) were identified under the FOTs of *general* and *efficacy*. 532 posts were classified under the theme of *efficacy*, and 176 posts were identified within the *general* theme. The frequencies of each second-order theme, as well as sentiment, are described in Table 1. Among posts regarding *efficacy*, 68.0%

TABLE 1.**Frequency of Sentiments Across 1,141 Reddit Posts**

Sentiment	General n (%)	Efficiency n (%)	Total
Positive	73 (41.5%)	366 (68.0%)	439 (61.5%)
Neutral	84 (47.7%)	87 (16.2%)	171 (23.9%)
Negative	19 (10.8%)	85 (15.8%)	104 (14.6%)

TABLE 2.**Frequency of Lower Order Themes and Sample Posts**

	Frequency (n, %)	Sample Posts
Second Order Theme	<i>General</i> Advice/experience (72, 10.2%)	“I’ve heard that Humira really does clear up almost everything majority of the time[...]. There are serious risks though. Has anyone experienced any? How long did it take for you to see results if not? Does it help for scalp psoriasis + dandruff as well?”
	Better options (2, 0.3%)	“The thing that knocked out my guttate and kept it away was UVB treatment. Saw improvement after about 4 treatments and after about 6 months of them it was gone. I do a maintenance treatment about once a month. It’s a pain going to the clinic that regularly but a lot less invasive than biologics.”
	General hesitation to use (12, 1.7%)	“that’s what i got put on for the first real strong drug for this stuff and i’m 18... i am BEGGING for the headaches from it to stop because i don’t want to go on a biological just yet because i have some pretty bad health anxiety w medication and side effects...”
	Hoping they work (50, 7.1%)	“I’m hopefully starting Tremfya soon. I’m waiting for the blood work to come back and the dermatologist to argue with insurance. I’m in the Philly suburbs and my dermatologist has been fantastic. Im glad it’s starting to work for you!”
	Unspecified/other (38, 5.4%)	“I hated what otezla did to my GI and switched to biologics after two weeks”
	Worth a try (2, 0.3%)	“I would suggest to try the biologic. If it works, your good. If it doesn’t, it’s back to the drawing board.”
	<i>Efficacy</i>	
	Benefits > Risks (3, 0.4%)	“It’s more important that the medication works and you are getting clearer over time. Don’t get hung up or stressed on any negative side effects of the medication. If you can afford it in the long run and if it makes you happier, just stick with it.”
	Changing Biologics (74, 10.5%)	“Just had my week 0 and week 4 shots of Tremfya, coming off Taltz because it was not working on the PsA, no issues so far but too early to see if it is working”
	Mask the Problem (7, 1.0%)	“Humira doesn’t cure psoriasis, just masks the problem temporarily, look at your lifestyle and diet if you truly want to beat psoriasis.”
	Stop Working (35, 4.9%)	“I’ve about the 1.5 year mark and I feel it’s definitely stopped which it’s very upsetting...”
	Stubborn Areas (19, 2.7%)	“Been on Cosentyx going on 3 years with about 100% skin clearance. However, my nails are started to get worse. Pitted like they were before Cosentyx[...].”
	Symptoms Improved (259, 36.6%)	“Glad to hear it. I could relate, took a different drug but am almost 100% clear. Also had some joint pain, that has lessened as well. Feels great, I didnt understand what a toll this took on my mental health until it started going away.”
	Symptoms not improved/worsened (40, 5.7%)	“There has been no improvement to my joint pain and swelling. I walk like a 100yo. Usually after loading I see at least a bit of relief.”
	Time to results (95, 13.4%)	“My rheumatologist won’t give up on a biologic for about 4-5 months. It would be great if they worked faster.”

were positive, 16.2% were neutral, and 15.8% were negative. Within the *general* theme, 41.5% of posts were positive, 47.7% were neutral, and 10% were negative. Compared to the *general* posts, the *efficacy* posts had a significantly higher mean sentiment score (mean sentiment score: 0.52 [0.45-0.59] vs 0.31 [0.21-0.40], $P<0.001$). However, *engagement* did not significantly differ between engagement and *general* groups (mean engagement score: 7.38 [5.56-9.19] vs 7.24 [5.42-9.04], $P=0.461$). The sentiment and engagement scores for each SOT are depicted in Table 3.

Among the two first order themes of *general* and *efficacy*, the most prevalent SOT was that biologics did improve symptoms (36.6% of posts). The next most common theme was the time it takes to see results (13.4%), with some users reporting immediate results and others reassuring that it can take weeks to months for the effects to show. Another category of users expressed hopefulness that biologic medication would help

with their symptoms (7.1%) Other common topics included having to switch biologics (10.5%) and general inquiries of advice or experiences (10.2%). Approximately 5.7% of posts described that symptoms had not improved or worsened on biologics, while another 4.9% reported that the biologics stopped working altogether. Some users argued against the use of biologics, claiming that they only mask the problem rather than treating the underlying cause (1%) (Table 2).

DISCUSSION

This study aims to understand the online perceptions of biologics within the psoriasis and psoriatic arthritis communities, specifically on Reddit. The scope of this paper focuses on posts pertaining to general perceptions of biologics or biologic efficacy. Previous studies have shown that psoriasis patients may have greater satisfaction with biologics than with other treatment modalities.⁸ This matches the majority of sentiment found on Reddit, suggesting that it may be beneficial

TABLE 3.

Mean Sentiment and Mean Engagement Scores of 1,141 Reddit Posts on Biologics for Psoriasis/Psoriatic Arthritis						
Second Order Theme	Mean Sentiment Score	95% CI	P-value	Mean Engagement Score	95% CI	p-value
<i>General</i>						
Advice/experience	0.13	-0.61 – 0.87	$p<0.001$	8.18	-16.66 – 33.02	$p=0.461$
Better options	-1.00	–		2.5	1.08 – 3.92	
General hesitation to use	-0.58	-1.60 – 0.44		7.42	-6.40 – 21.24	
Hoping they work	0.76	-0.10 – 1.62		8.16	-22.46 – 38.78	
Unspecified/other	0.38	-1.34 – 2.10		4.76	-11.84 – 21.36	
Worth a try	1.00	–		3.00	-2.66 – 8.66	
<i>Efficacy</i>						
Benefits > Risks	1.00	–		1.67	0.51 – 2.83	
Changing Biologics	0.37	-0.95 – 1.69		5.31	-6.81 – 17.43	
Mask the Problem	-1.00	–		0.00	-5.48 – 5.48	
Stop Working	-0.29	-1.43 – 0.85		3.66	-2.88 – 10.20	
Stubborn Areas	-0.32	-1.96 – 1.32		8.00	-20.7 – 36.7	
Symptoms Improved	0.94	0.36 – 1.52		7.35	-42.77 – 57.47	
Symptoms not improved/worsened	-0.93	-1.47 – -0.39		17.13	-43.57 – 77.83	
Time to results	0.63	-0.65 – 1.91		6.94	-28.50 – 42.38	

for potential patients to refer to the platform for insight into experiences with biologic treatment. We found that a majority of patients felt positive about the efficacy of biologics as an anti-psoriatic medication, with the most frequent theme being that biologics work well for the management of psoriasis signs and symptoms. Other users reported that they were hoping to get on a biologic and/or hopeful that they would improve symptoms. Some responses praised the speed at which they saw their skin and joint pain improve. Positive sentiment can be attributed in part to efficacy but also convenience, ease of dosing, and manageable side effects.

Some users had discussed biologics with their dermatologist and were looking for more advice or anecdotal experiences with the medication. If patients express hesitation when counseled on biologics, their dermatologists may find that referring them to other patient anecdotes may help them feel more comfortable with starting these medications. Additionally, the volume of users seeking anecdotal advice or experiences may indicate that general counseling might not be sufficient for some patients.

While the mean sentiment score was overall positive, there were still a notable number of posts expressing dissatisfaction with biologics. This included claims that they did not work, stopped working, or simply masked the problem. Some users expressed dissatisfaction with having to switch biologics multiple times, although others tried to instill hope by ensuring that there are multiple options available should one need them. Some posts expressed frustration with delayed time to efficacy, and others complained of stubborn areas, such as the scalp or palms and soles. Because residual psoriasis while on a biologic is not uncommon, patient expectations should be managed appropriately so they understand that complete clearance might not be immediately achievable. Providers can reassure them, however, that a trial of multiple biologics, or adding a topical medication, may help target any stubborn areas.⁹

Previous research has shown that online support groups for psoriasis patients can improve patient empowerment and provide valuable support and advice.¹⁰ By accessing these forums, patients can share advice, provide hope, and connect with others who are experiencing similar struggles. As such, patients should not be discouraged from seeking health information on Reddit in particular. However, while subreddit forums for psoriasis and psoriatic arthritis can provide ample benefits, they also carry risks. For instance, they are not moderated nor fact-checked, and as a result, users may interact with misinformation or opinions stated as fact.¹¹

A limitation of this study is that the population of Reddit users may not be representative of the greater psoriasis and psoriatic arthritis patient population. Additionally, the accuracy of the information conveyed on these platforms may be variable.

For physicians, it is important to recognize the benefits of social media for patients while also educating them on the potential downsides. This study aims to better understand the content of discussions on Reddit so that providers can anticipate common concerns regarding biologics and their efficacy. Physicians should understand what information individuals are seeking on these forums, but they should also caution that some of the provided information may be based on the individual experience and does not necessarily apply to all patients with psoriatic disease. In addition to more in-depth counseling during patient visits, providers can encourage patients to seek additional information from reputable sources such as the National Psoriasis Foundation. Providers must remain aware of content on these online forums to anticipate common patient concerns and understand how patients use social media for dermatologic advice.

DISCLOSURES

AWA has served as a research investigator and/or scientific advisor to AbbVie, Almirall, Arcutis, ASLAN, BI, BMS, EPI, Incyte, Leo, UCB, Janssen, Lilly, Nimbus, Novartis, Ortho Dermatologics, Sun, Dermavant, Dermira, Sanofi, Regeneron, Pfizer, and Modmed.

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AUTHOR CORRESPONDENCE

April W. Armstrong MD MPH

E-mail: armstrongpublication@gmail.com