ORIGINAL RESEARCH

Content Analysis of Idiopathic Pulmonary Fibrosis–related Information on Twitter

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ABSTRACT

Background: Information regarding idiopathic pulmonary fibrosis (IPF) on the internet is often outdated, inaccurate, and potentially harmful. Twitter is a social media platform that allows users to post content in the form of "tweets".

Objective: We sought to assess the prevalence of inaccurate information regarding IPF on Twitter. We hypothesized that foundations and medical organizations would be the least likely to post inaccurate information and that inaccurate tweets would have higher user engagement.

Methods: All tweets posted between 2011 and 2019 were gathered using "snscrape" on Python 3.8 while searching for the phrase "idiopathic pulmonary fibrosis". Quantitative analysis was performed to describe trends in IPF-related tweet frequency over time. A subset of tweets made between 2018 and 2019 was screened for verifiable medical statements, which were then analyzed for accuracy compared with contemporary clinical practice guidelines, with descriptive statistics reported. Logistic regression was used to compare tweet accuracy and recommendation of nonindicated therapies across sources, with adjustment for tweet age and character count. Wilcoxon rank-sum tests were used to determine if user engagement (favorites, retweets, and replies) differed between accurate and inaccurate tweets.

Results: A total of 16,787 tweets were identified between 2011 and 2019. Between 2018 and 2019, 4,861 tweets were included, of which 1,612 (33%) contained verifiable

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medical statements. Tweets from sources other than foundations or medical organizations were more likely to contain inaccurate information and to recommend nonindicated therapies in both unadjusted and adjusted analyses. News and media sources had the highest odds of communicating potentially harmful information in both adjusted (odds ratio [OR], 12.00; 95% confidence interval [CI], 5.87–27.16) and unadjusted (OR, 11.62; 95% CI, 5.70–26.21) analyses when compared with foundations and medical organizations. Tweets containing inaccurate information had significantly lower numbers of favorites and retweets ($P < 0.001$ for both).

Conclusion: Misinformation regarding IPF is present on Twitter and is more often presented by news and media sources. Medically inaccurate tweets displayed less user engagement than accurate tweets. This differs from findings on IPF-related information on YouTube and Facebook, which may reflect differences in both author and consumer qualities across social media platforms.

Keywords:
lung diseases; interstitial; social media; communication; antifibrotic agents

Idiopathic pulmonary fibrosis (IPF) is a chronic, progressive lung disease with limited treatment options. It is characterized by declining lung function associated with dyspnea, exercise limitation, cough, and progressive respiratory failure (1, 2).

Recommended management strategies for patients with IPF include supportive measures aimed at improving quality of life, reducing the risk of concurrent illness, and attenuating a decline in lung function with the use of antifibrotic medications (1).

The treatment paradigm for patients with IPF changed significantly with the PANTHER- IPF (Prednisone, Azathioprine, and *N*-Acetylcysteine: A Study that Evaluates Response in Idiopathic Pulmonary Fibrosis) trial in 2012, in which it was found that triple therapy with corticosteroids, azathioprine, and *N*-acetylcysteine was associated with increased mortality (3). This change in treatment philosophies underscores the importance of the judicious use of interventions for these patients. Further to this, advising patients against therapies with no known benefit, or potential harm, has become an important part of care for patients with IPF.

Current diagnostic and treatment guidelines for IPF reflect this philosophy (1, 2, 4). Namely, recommendations have been made against therapies such as *N*-acetylcysteine, azathioprine, prednisone,

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and ambrisentan, citing a lack of benefit and potential for adverse effects. At the same time, therapies with known benefits are recommended, with the goals of maintaining lung function as well as improving quality of life. These therapies include antacid medications for those with concurrent gastroesophageal reflux, pulmonary rehabilitation, supplemental oxygen, lung transplantation, and antifibrotic medications. These guidelines aim to improve care for patients with IPF by informing clinicians about reasonable, evidence-based interventions.

Information regarding IPF on the internet is often outdated, inaccurate, and potentially harmful, as was demonstrated in a review of internet website searches for IPF on Google, Yahoo, and Bing (5). On the social media platforms Facebook and YouTube, user engagement in the form of views and likes was higher in content containing potentially harmful information (6, 7). This propagation of medical misinformation on social media platforms is present in a variety of healthcare topics outside of IPF (8–11). Importantly, information on social media platforms can influence patient decisions and is often used by patients to supplement recommendations by healthcare providers (8, 12). These insights underscore the importance of understanding the quality of information available on social media, as patient exposure to these platforms is widespread, with more than half of the world now using at least one type of social media (13).

Twitter is a social media platform in which users publish short-form commentary in the form of tweets. Its user population comprises representatives from both scientific and nonscientific communities. Its impact on patients has been evaluated in a variety of settings, including cancer care, vaping, and asthma (9, 10, 12, 14, 15). We aimed to evaluate the quality and sources of information discussed on Twitter regarding IPF. We hypothesized that foundations and medical organizations would be least likely to generate inaccurate information and that inaccurate tweets would have higher user engagement in the form of favorites, retweets, and replies.

METHODS

Search Strategy and Data Extraction

All tweets and their associated user information and engagement metrics posted between 2011 and 2019 were gathered using the application "snscrape" on Python 3.8. The search term "idiopathic pulmonary fibrosis" was applied to the Twitter web application. For each respective tweet, snscrape collected the URL, date of publication, number of favorites, number of retweets, user handle, the name associated with the user handle, tweet text, tweet ID, and user description. Tweet replies were manually counted between the years 2018 and 2019 for analysis. Tweet character count was generated manually from tweet text.

Data Processing

Tweets collected between 2011 and 2019 were included in prospectively specified quantitative analysis. Each individual tweet collected for the years 2018 and 2019 was manually reviewed as a subgroup by two separate physicians (S.O. and J.K.) for inclusion criteria, including being written in the English language, relevant to the topic of interest, and original (as opposed to a retweet). Eligible tweets were processed for descriptive statistics and content analysis. These tweets were assigned to various subject categories, which included opinion;

guidelines, scientific evidence, or clinical information; personal anecdote; news; advertisement or for profit; and other on the basis of the above physicians' analysis of the written content of each tweet. When consensus was not reached, a third physician was involved (G.C.G.) to adjudicate.

The use of a prospectively specified subgroup was done to make content analysis practically feasible. The use of the last 2 years of tweets in the search period rather than a random selection of tweets over the whole period was preferred as recent tweets would be more likely to represent current topics of discussion on Twitter. As well, tweets before the release of more recent guidelines were felt to be a potential source of bias, as they may have been technically medically accurate statements during the time of publication but are currently inaccurate because of updates in care standards (1, 2, 4). Tweets were labeled according to respective sources according to their associated user descriptions, including foundation or medical organization, news or media, industry or for-profit organization, independent medical professional, or independent nonmedical user. Foundations and medical organization sources were defined as groups aimed at supporting patients whose primary motive was nonprofit. Conversely, industry and for-profit sources were considered groups with a primary focus on financial gain and industrial development. Medical user sources were identified on the basis of self-descriptions on user pages and were not limited to physician users but rather healthcare professionals in general. This included, but was not limited to, nurses, physiotherapists, pharmacists, social workers, and occupational therapists.

Subsequently, the 2018 and 2019 subsets of tweets were individually screened by two separate physicians (S.O. and J.K.) for those containing a verifiable medical statement, which was defined as a specific statement that could be verified as accurate or inaccurate on the basis of current knowledge. Tweets with a verifiable medical statement were included in prospectively specified subgroup analysis for accuracy of content in the entirety of the tweet, comparing to published IPF guidelines (1, 2, 4), whether a therapy was mentioned, the name of any mentioned therapies, and whether the tweet had recommended it. Therapy names mentioned by tweets were recorded. Tweets in which there was discordance in accuracy status between two separate physicians were discussed with a consensus agreement made between them. In cases in which a consensus could not be reached, a third physician (G.C.G.) was involved in making a final decision on accuracy status.

Statistical Analysis

All tweets collected between 2011 and 2019 were displayed with quantitative trends in relation to major publications and guidelines in IPF literature (1–4, 16, 17). Descriptive statistics for the subgroup of tweets meeting inclusion criteria collected between 2018 and 2019 were calculated with means and standard deviation reported for normally distributed variables and medians and interquartile range (IQR) reported for nonnormally distributed variables. Logistic regression analysis was used to characterize tweet accuracy and recommendation of nonindicated therapies by source, with adjustment for tweet age and character count. Wilcoxon rank-sum tests were used to determine if user engagement metrics such as favorites, retweets, and

replies differed between accurate and inaccurate tweets.

Statistical analysis was performed using R Statistical Computing Platform (version 4.0.4) with $P < 0.05$ considered statistically significant.

RESULTS

A total of 16,787 tweets were identified via the described search parameters (Figure 1).

Quantitative Analysis of Tweets between 2011 and 2019

All tweets were included in the quantitative analysis summarized in Figure 2. Demonstrating the increasing number of IPF-related tweets over time, our search strategy captured a total of 1,215 IPF-related tweets in 2011 and 788 in 2012, whereas we captured 2,795 tweets in 2018 and 2,322 in 2019. This reflects a 2.9-fold increase in tweets from 2012 to 2019, compared with a 2.3-fold increase in all tweets posted on the platform from 2012 to 2019 (18). There is evidence of increased tweet quantity in relation to guidelines and major publication releases. For example, in the year 2014, when both the ASCEND (Assessment of Pirfenidone to Confirm Efficacy and Safety in Idiopathic Pulmonary Fibrosis) and INPULSIS trials were published, there was approximately a threefold increase in tweet quantity compared with the prior year.

Baseline Characteristics of Tweets between 2018 and 2019

A total of 5,146 tweets had publication dates in the years 2018 and 2019, of which 4,861 met the eligibility criteria for content analysis. The baseline characteristics of these tweets are summarized in Table 1. The most common source of tweets between 2018 and 2019 was nonmedical users, followed by foundations and medical organizations. The most common tweet subject category

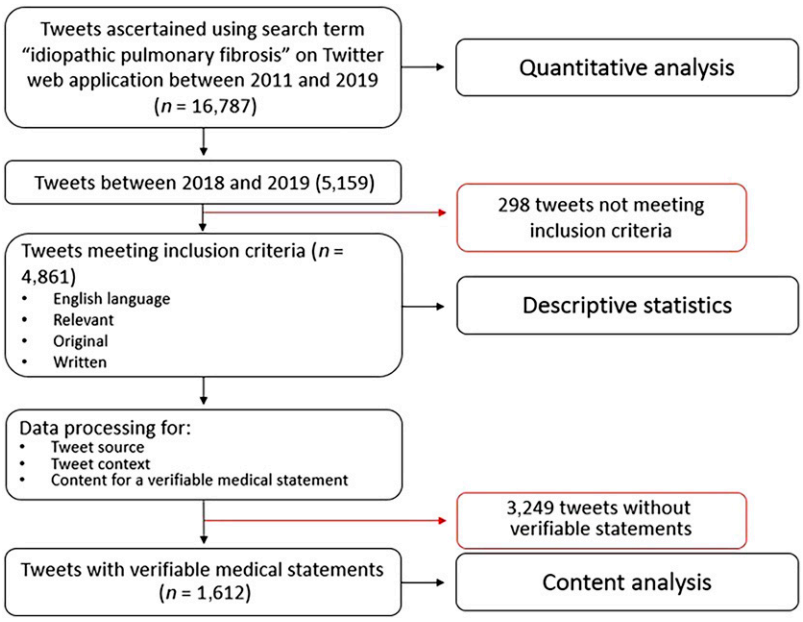

Figure 1. Flowchart describing data processing of tweets identified between 2011 and 2019 for quantitative analysis, descriptive statistics, and content analysis. Quantitative analysis ascertained trends in tweet frequency in relation to major idiopathic pulmonary fibrosis (IPF) publications and guidelines over a 10-year period. Tweets meeting eligibility were included in descriptive statistics to determine baseline characteristics of a subset of tweets between 2018 and 2019. Tweets included in the content analysis contained a verifiable medical statement and were examined in relation to current guideline recommendations.

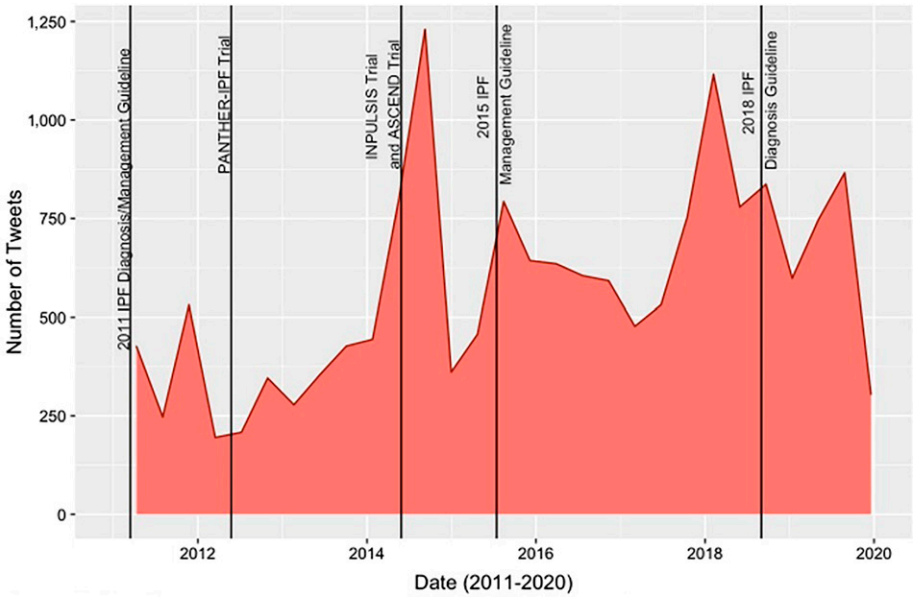

Figure 2. Number of idiopathic pulmonary fibrosis (IPF)-related tweets over time in relation to landmark IPF-related trials and guidelines between 2011 and 2020. ASCEND = Assessment of Pirfenidone to Confirm Efficacy and Safety in Idiopathic Pulmonary Fibrosis; PANTHER-IPF = Prednisone, Azathioprine, and *N*-Acetylcysteine: A Study that Evaluates Response in Idiopathic Pulmonary Fibrosis.

was related to guidelines, scientific resources, or clinical information (43%), followed by news (26%), other (11%), personal anecdote (8%), opinion (7%), and advertisement or for-profit (5%), respectively. Subjectively, most tweets that were classified as being within the subject category of guidelines, scientific resources, or clinical information presented information or links to recent studies or guidelines.

Content Analysis of Tweets between 2018 and 2019

Verifiable medical statements were identified in 1,612 (33%) tweets collected in 2018 and 2019. Foundations and/or medical organizations and independent medical professionals had the highest frequency of verifiable tweets (35% and 38%, respectively), with news and media, industry or for-profit, and independent nonmedical users each having 32% of tweets containing verifiable claims. Of these, 115 tweets (7%) were found to be inaccurate compared with current IPF guidelines. Of those with verifiable medical claims, 559 tweets (35%) mentioned a specific therapy, with 369 (66%) of those recommending the mentioned therapy. Of the 559 tweets mentioning a specific therapy, 81 (14%) were inaccurate tweets. The source with the highest percentage of inaccurate tweets was news and media sources, followed by nonmedical users (Figure 3A).

Compared with foundations and medical organizations, all other tweet sources had an increased likelihood of containing inaccurate information and recommending nonindicated therapies (Table 2). News and media sources had the highest odds of both containing inaccurate information (odds ratio [OR], 12.0; 95% confidence interval [CI], 5.87–27.16; $P < 0.001$) and recommending nonindicated therapies (OR, 6.29; 95% CI, 3.78–10.68; $P < 0.001$). Medical users were also more likely to provide inaccurate information compared

Table 1. Baseline characteristics of analyzed tweets related to idiopathic pulmonary fibrosis (IPF) that were posted in 2018 and 2019

Tweet Characteristic	
Source, *n* (%)	4,861 (100.0)
Foundation or medical organization	1,426 (29.3)
News or media	622 (12.8)
Industry or for-profit	668 (13.7)
Medical user	466 (9.6)
Nonmedical user	1,679 (34.5)
Subject category, *n* (%)	
Seeking advice or opinion	330 (6.8)
Guidelines, scientific references, or clinical information	2,103 (43.3)
Personal anecdote	388 (8.0)
News	1,278 (26.3)
Advertisement or for-profit	221 (4.5)
Other	528 (10.9)
Favorites, mean (SD)	5.7 (117)
Retweets, mean (SD)	2.0 (27)
Replies, mean (SD)	0.4 (2.5)
Character length, median (IQR)	175 (126–249)
Contains a verifiable claim, *n* (%)	1,612/4,861 (33.2)
Accurate claim, *n* (%)	1,497/1,612 (92.9)
Mentions therapy, *n* (%)	559/1,612 (34.7)
Recommends therapy, *n* (%)	371/1,612 (66.7)

Definition of abbreviations: IQR = interquartile range; SD = standard deviation.

with foundations and medical organizations (OR, 3.37; 95% CI, 1.37–8.53; $P < 0.001$), having a similar likelihood of tweeting inaccurate information as nonmedical users (OR, 5.55; 95% CI, 2.82–12.25; $P < 0.001$).

The most mentioned nonrecommended therapies included preclinical drugs such as BBT-877 and NP-120, as well as medications currently under investigation for potential benefits, such as pamrevlumab and recombinant human pentraxin 2. Many therapies with a lack of benefit or unproven benefit were also mentioned, such as antireflux surgery, thyroid hormone, and Chinese herbal medicines in combination with *N*-acetylcysteine.

Engagement Metrics of Tweets between 2018 and 2019

The median number of favorites per tweet was zero (IQR, 0–3), with a mean favorite

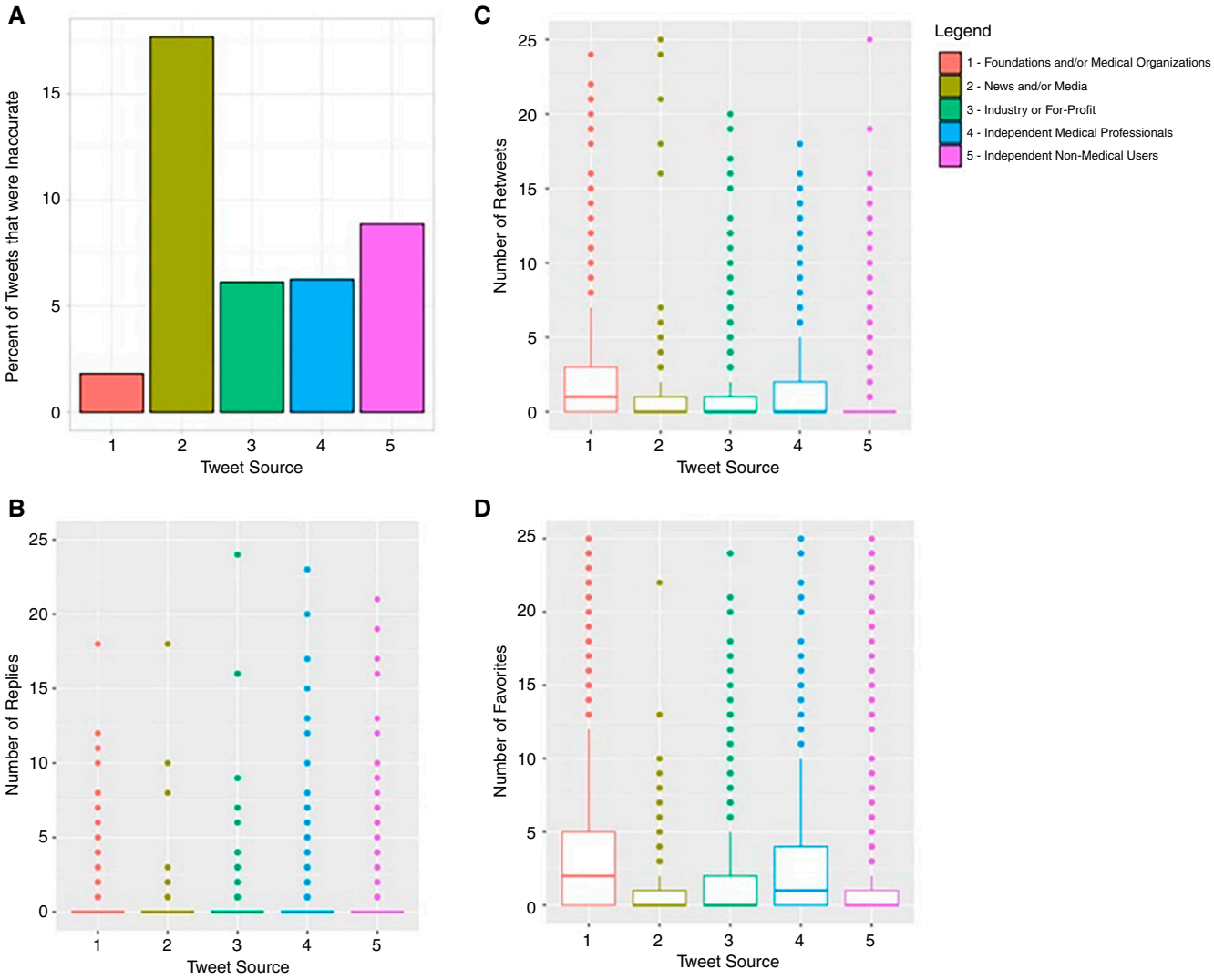

Figure 3. (*A*) Bar graph depicting the percentage of inaccurate tweets by source. (*C–D*) Box plots depicting engagement metrics by source. The *y-axis* is truncated to 25 because of the presence of significant outliers in favorites and retweets.

count of six. The median number of retweets per tweet was zero (IQR, 0–1), with a mean retweet count of two. Median replies per tweet were zero (IQR, 0–0), with a mean reply count of 0.4.

Tweets with accurate information had higher engagement metrics in the form of favorites and retweets. Tweets with accurate information had a median favorite count of one (IQR, 0–4), whereas tweets with inaccurate information had a median favorite count of zero (IQR, 0–0) ($P < 0.001$). Median retweets for tweets with accurate information were zero (IQR, 0–2) versus tweets with inaccurate information zero (IQR, 0–0) ($P < 0.001$). There was no association between tweet accuracy and the number of replies ($P = 0.54$). There was also no difference in engagement metrics across tweet sources (Figures 3B–3D).

DISCUSSION

To our knowledge, this is the first study to assess the quality of the content of information regarding IPF on Twitter.

Table 2. Logistic regression analysis of tweets containing verifiable medical statements by the source of origin

	Unadjusted OR	Adjusted OR
Medically inaccurate		
Foundations and/or medical organizations	*Reference*	*Reference*
News and/or media	11.6 (5.7–26.2)	12.0 (5.9–27.2)
Industry or for-profit	3.5 (1.5–8.7)	3.8 (1.6–9.4)
Independent medical users	3.6 (1.5–9.1)	3.4 (1.4–8.5)
Independent nonmedical users	5.3 (2.7–11.6)	5.6 (2.8–12.3)
Recommended nonindicated therapies		
Foundations and/or medical organizations	*Reference*	*Reference*
News and/or media	6.1 (3.7–10.4)	6.3 (3.8–10.7)
Industry or for-profit	2.0 (1.1–3.4)	2.0 (1.2–3.5)
Independent medical users	1.8 (1.1–3.2)	1.8 (1.1–3.2)
Independent nonmedical users	1.6 (1.0–2.5)	1.7 (1.1–2.6)

Definition of abbreviation: OR = odds ratio.
Adjustments were made for tweet age and character count in adjusted analyses. ORs are displayed with associated 95% confidence intervals in brackets. The source "Foundation and/or medical organization" was used as reference. All sources in comparison to reference had significantly higher odds of tweeting inaccurate information ($P < 0.001$).

There is a critical need to better understand the quality of information presented on social media platforms such as Twitter that are increasingly used by patients to both relay and receive information. Similar to what has been reported on other platforms (6, 7), we found that Twitter frequently contains inaccurate and sometimes harmful information.

Inaccurate information was found in 7% of tweets, similar to the findings of a content analysis of posts regarding IPF on Facebook, which found that 5% of posts contained potentially harmful information (6). These results differ from another study by our group on information regarding IPF on YouTube, in which the frequency of videos recommending nonindicated therapies was 17% (7). Although these percentages appear low, the consequences of approximately 1 in every 14 tweets containing inaccurate information may be important, particularly if patients follow harmful recommendations or lose trust in a healthcare provider who is contradicted by these tweets.

Our study identified a low engagement rate in tweets regarding IPF during our sampling period, with median favorites, retweets, and replies for tweets sampled of zero for each engagement metric. This trend, though, does reflect typical engagement statistics of content on Twitter, with the median engagement, as measured by a combination of favorites, retweets, and replies, being 0.5 for tweets overall in a report on the basis of data from 2018 (19). In a more global context, original tweet frequency has decreased

overall between the years 2013 and 2018, with an increase in retweet frequency and a tendency toward sharing content produced by users with higher engagement (20). For example, despite overall low engagement metrics, our data captured users with single tweets with favorite counts upward of 8,000. This emphasizes the importance of individuals with large Twitter followings in disseminating accurate and clinically relevant information to the public.

We identified medical foundations and organizations, as well as medical users, as prevalent sources of tweets regarding IPF on Twitter. These two sources made up 39% of tweets, as opposed to 10% of posts on Facebook (6). In contrast to both Facebook and YouTube, inaccurate information also had a significantly lower engagement in the form of favorites and retweets, suggesting that misinformation was less frequently perpetuated by Twitter users (6, 7). These discrepancies may be accounted for by differences in user demographics on Twitter compared with other platforms. Topics of discussion around IPF on Twitter may also be different from other platforms, with many posts on Twitter discussing guidelines, scientific evidence, or clinical information, whereas Facebook is more commonly used as a source for community engagement and sharing news. This is evident, as the most common posts about IPF on Facebook were related to news or other information, with guideline-related posts constituting only 1% of all posts (6). As well, differences in the platform itself may affect both topics of discussion on social media platforms, as well as the accuracy of post content. For example, videos on YouTube with multiple points of discussion may have a higher chance of having an inaccurate or potentially harmful statement compared with character-limited commentary on Twitter. Different approaches to information policing may also play a role, with Twitter's platform rules stating that sharing of synthetic and manipulated media is prohibited (21).

The use of snscrape and the availability of an abundance of data on Twitter as a social media platform allowed for this study to assess a large number of tweets over the span of years. As such, this study was well-powered to uncover the trends detailed here.

Given the large quantity of Tweets between 2011 and 2019, we elected to only analyze the tweets between 2018 and 2019 for specific content. This approach was favored over analyzing a random selection of tweets between 2011 and 2019 as the 2018–2019 analysis would be more likely to reflect current discussions surrounding IPF on Twitter, given the preceding publication of clinical practice guidelines on both the diagnosis and management of IPF and the absence of any major changes in approaches since these documents were published (1, 2).

Limitations

This study provides a novel evaluation of the sources, content, and validity of tweets regarding IPF, but it is not without several limitations. News and media sources had the highest likelihood of containing inaccurate information and recommending nonindicated therapies, but we were unable to differentiate news sources beyond what information was available in the user descriptions and usernames. As a result, our study lacked the ability to differentiate between reputable and nonreputable news sources. Similarly, within-source differences pertaining to medical users and industry or for-profit sources were not differentiated.

We did not consider posts regarding basic science as having a verifiable medical statement, given that this information would be less likely to influence medical decision-making when viewed from a patient's perspective. We were also unable to blind reviewers to tweet source, given the need to use the tweet's original link on the Twitter website to view multimedia information not obtained entirely through snscrape. This lack of blinding could be a potential source of confirmation bias; however, we attempted to minimize the effects of this bias by using two separate reviewers who independently assessed each eligible tweet. Furthermore, our study found that medical users were an important source of misinformation, which this bias would be at risk of obscuring. Lastly, we were unable to perform the search for tweets using the abbreviation "IPF" because of the lack of specificity of this term for idiopathic pulmonary fibrosis. As such, our search may not have captured the entire body of IPF-related tweets.

Conclusions

We conclude that although medical information regarding IPF on Twitter is frequently accurate, a substantial minority of tweets contain inaccurate information that may be harmful to patients. This emphasizes the importance of healthcare professional engagement both within and outside Twitter as a resource for information for patients with IPF and their caregivers.

Author disclosures are available with the text of this article at www.atsjournals.org.

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