Longitudinal Medical Insights from Internet Fora

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Abstract

Background
Several research projects have explored the utility of using social media to augment traditional safety surveillance, with varying degrees of success. Some of the limitations of social media include the number of characters that can be posted (Twitter) and the "what's on my mind at this moment in time" context in which people post.

Objectives:
To evaluate if linking social media posts from the same individual in a longitudinal fashion would allow for a more holistic assessment of an individual's journey with a chronic disease.

Methods:
We obtained publicly available, de-identified social media posts (01 January 2015 to 01 November 2015) from the Scleroderma Foundation Support Community and Arthritis Foundation Support Community fora on Inspire. Each author was given a unique identifier so that posts from the same individual could be linked together longitudinally. Expert reviewers manually curated a random sample of 2,817 threads containing 21,313 individual posts from 3,601 unique authors. To help systematically identify which collection of posts offered the best medical insights we generated a complexity score, comprised of 28 indicators, for each author's collection of longitudinal posts. The group of posts with the 16 highest complexity scores were further evaluated for relevant medical insights.

Results:
The top 16 groups contained 1,672 posts, an average of 104 posts (median 34, range 11-534) per author. Relevant medical insights included: medical history 16/16 (100%), disease burden 15/16 (94%), use of non-medical treatments 15/16 (94%), lab results 14/16 (88%), treatment history 13/16 (81%), and concomitant medications 12/16 (75%). The above insights were seen across groups of postings rather than being on the same posting (only 1 post out of the 1,672 contained all 6 of the medical insights above). Additionally, these posts also included important data elements related to adverse events (time to onset, dose of medication, mention of rechallenge/dechallenge, outcome of the event, statements of attribution, and treatment of adverse event).

Conclusions:
Linked social media posts can provide medical insights not apparent from individual posts and might be relevant for pharmacovigilance activities.

Background

Spontaneously reported adverse events play a critical role in post-marketing safety surveillance. However, underreporting and data quality are key limitations. More recently, there have been several studies evaluating how individual social media posts can contribute to the safety surveillance process.[1,2,3] There are significant limitations of much social media, which include limited characters (e.g., Twitter), spur of the moment context of posts (e.g., Facebook), as well as information shared in prior posts not being repeated within subsequent posts in the discussion thread (drug name in original post but referred to as "drug/med" in subsequent posts).

Objectives

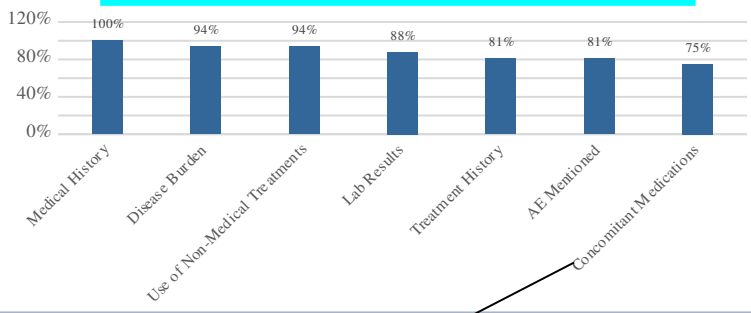
To evaluate if linking social media posts from the same individual in a longitudinal fashion would allow for a more holistic assessment of an individual's journey with a chronic disease.

Methods

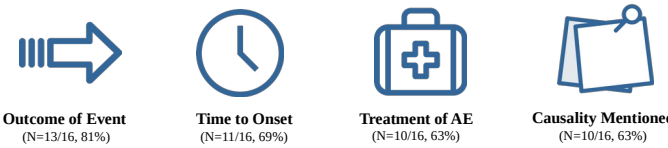
The Scleroderma Foundation Support Community and Arthritis Support Community fora on Inspire were used for this study. The Scleroderma and Arthritis community have approximately 64,000 and 23,000 global members, respectively. Posts from the 3,601 unique authors were linked together and then each group of posts were evaluated using an automated quality scoring algorithm. The 16 groups of posts with the highest quality scores were then evaluated for key attributes.

Results

Relevant Medical Insights (see example posts at bottom in blue)



Adverse Event Insights (see example posts at bottom in yellow)



Outcome of Event (N=13/16, 81%)
Time to Onset (N=11/16, 69%)
Treatment of AE (N=10/16, 63%)
Causality Mentioned (N=10/16, 63%)

Example Insights Posted From a Single Individual

8/7/15
I am on so many pills:(nifedical, levothyroxine, colchicine, meds for GERDS..just got off plaquenil and they want me to start methotrexate. ….Sometimes the side effects are as bad as the symptoms!!!

8/8/15
raynauds was first -then it has progressed from there. now, I have pericarditis, scleroderma (just diagnosed - they said it was SLE for years), moderate AKI, the GERD etc. I was definitely exposed to many chemicals at the airport..glycol, jet fumes..also fire suppression chemical raining down……I get horrible headaches from the nifedical

08/09/15
my LDH was quite elevated as was my creatine. C4 quite low as always. Trying to figure out my sudden weight loss as well... 18 pounds in a few months.... always something:)

10/13/15
Although nothing seems to be helping the raynauds, I'm on nifedipine, and use nitro cream as well. Have been advised to get surgery, …..I get headaches from the meds:(

10/20/15
My chest xrays were clear (YAY) but I had PFT testing then the CT scan, which confirmed I have ILD…

10/26/15
I've lost almost 30 pounds since last Nov…They finally checked my thyroid and wala... that was it. …. my body is always swollen!

10/17/2015
My DLCO is 60%, the other one 68% I do have SOB and chest pain/tightness during exertion… My cardiologist diagnosed as pericarditis and put me on colchinine, which I have quit on the advice of my rheumy… I spent a month in northern Idaho,, I actually felt better ….. my raynauds didn't act up, my appetite was better... even the air felt easier.

11/21/2015
I have 'oral shingles.' It is so painful:(The blisters are in my mouth, throat, esophagus, all the way down!! I got a 'magic mouthwash' and viral antibiotic, plus hydrocodone. Nothing helps much though.. Lol I've tried rinsing with hydrogen peroxide..baking soda..Orajel.. throat spray. I'm told it's an opportunistic infection. I'm off my cellcept until it goes away. My platelets are low due to the blisters 'bleeding.'

11/23/15
Now I also am getting this 'rash' on my face, ear cartilage, arms, and more.platelets were low at 128…liver tests were also elevated….

11/27/15
I'm 46... Lol, I need to 'get healthy' in order to get some vaccinations.. The last few months have been rough. Sometimes I don't even know if it's the scleroderma, the treatments, side effects or what is causing everything.. I'm hoping things stabilize. I always respect this disease..but lately it has suddenly 'blown up'..I didn't expect so many things to hit at once. It's like being in an ocean and waves keep coming before I get a chance to come up for air!!

Results (cont.)

A total of 1,672 posts were evaluated, which averaged to average of 104 posts per author (median 34, range 11-534). Relevant medical insights mentioned by the authors in the posts included medical history 16/16 (100%), disease burden 15/16 (94%), use of non-medical treatments 15/16 (94%), lab results 14/16 (88%), treatment history 13/16 (81%), adverse events (81%) and concomitant medications 12/16 (75%).

Of the posts that contained adverse event information additional details were provided such as: outcome of the event 13/16 (81%), time to onset 11/16 (69%), treatment of the event 10/16 (63%), mention of causality 10/16 (63%), dose of the medications 9/16 (56%), and mention of rechallenge/dechallenge 3/16 (19%).

Notably, the above insights were seen cumulatively across the various postings of an individual rather than being within a single posting (only 1 post out of the 1,672 contained all 7 of the medical insights above).

Discussion

Linking social media posts together offers significantly richer medical insights as compared to individual posts. These insights included traditional pharmacovigilance information such as adverse events, relevant/confounding medical history, time to onset and outcome. Additionally, non-traditional insights such as environmental factors (exposure to pollutants, impact of weather, etc.), prevention of adverse events, as well as impact of the events on attitude and quality of life were also provided.

Although linking posts together offers greater breadth and depth of insights as compared to a single post, researchers need to continue to employ safeguards to protect privacy. Additionally, linking posts together may introduce additional sources of bias and confounding (e.g., people with negative experiences may post more than people with positive experiences).

Conclusions

Linked social media posts can provide medical insights not apparent from individual posts that may be complementary to traditional pharmacovigilance activities.

Future research is needed to better characterize linked posts, including other social media channels, to better understand strengths/limitations of this approach and how it can optimally be used.

Conflicts of Interest

We have no specific conflicts of interest, however Greg Powell and Andrew Bate are employees of GSK and Jeff Painter was a GSK employee at the time of study execution

References

1. Freifeld CC, Brownstein JS, Menone CM. et al. Digital Drug Safety Surveillance: Monitoring Pharmaceutical Products in Twitter. *Drug Saf*. 2014;37(5):343-350.
2. Yang CC, Yang H, Jiang L. Postmarketing Drug Safety Surveillance Using Publicly Available Health-Consumer-Contributed Content in Social Media. *ACM Trans. Manage. Inf. Syst*. 2014;5(1):1-21.
3. Yang CC, Yang H, Jiang L, Zhang M. Social media mining for drug safety signal detection. *Proceedings of the 2012 international workshop on Smart health and wellbeing - SHB 12*. 2012.