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▶ To cite this version:

Katja Reuter, Atul Deodhar, Souzi Makri, Michael Zimmer, Francis Berenbaum, et al.. COVID-19 pandemic impact on people with rheumatic and musculoskeletal diseases: Insights from patient-generated health data on social media. Rheumatology, 2021, 10.1093/rheumatology/keab174/6149307 . hal-03153678

HAL Id: hal-03153678
https://hal.sorbonne-universite.fr/hal-03153678v1

Submitted on 26 Feb 2021

Concise Report

COVID-19 pandemic impact on people with rheumatic and musculoskeletal diseases: Insights from patient-generated health data on social media

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ABSTRACT

Objectives: During the COVID-19 pandemic, much communication occurred online, through social media. This study aimed to provide patient perspective data on how the COVID-19 pandemic impacted people with rheumatic and musculoskeletal diseases (RMDs), using Twitter-based patient-generated health data (PGHD).

Methods: A non-probability, convenience sample of Twitter messages in English was examined using thematic analysis. Twitter messages that mentioned keywords and hashtags related to both COVID-19 (or SARS-CoV-2) and RMDs posted between February-July 2020 were included.

Results: The analysis included 569 tweets by 375 Twitter users with RMDs across several countries. Eight primary themes emerged: (1) understanding of SARS-CoV-2/COVID-19; (2) change in health behaviour; (3) challenges in healthcare practice and communication with healthcare professionals; (4) difficulties with access to medical care; (5) negative impact on physical and mental health, coping strategies; (6) issues around work participation, (7) effect of the media; (8) awareness-raising.

Conclusion: Twitter can serve as a real-time data source to understand the impact of the COVID-19 pandemic on people with RMDs. The platform provided “early signals” of potentially critical health behaviour changes. Future epidemics might benefit from the real-time use of Twitter-based PGHD to identify emerging health needs, facilitate communication, and inform clinical practice decisions.

Clinical trial registration number: N/A

Keywords: COVID-19; coronavirus; infoveillance; patient-generated health data; rheumatic and musculoskeletal diseases; social media, Twitter

Key Messages

- Twitter serves as a data source to understand the impact of the COVID-19 pandemic on people with RMDs.
- Twitter provides "early signals" of critical health behaviour changes among people with RMDs.
- Future epidemics might benefit from the real-time use of Twitter-based patient-generated health data to identify emerging needs.

INTRODUCTION

The coronavirus disease 2019 (COVID-19) pandemic [1] and resulting safety measures have impacted people's lives in multiple ways, including their medical care access. People had to adjust to social distancing and self-quarantine rules, lockdowns and movement restrictions, wearing masks, and a rapid transition to telework and telehealth approaches. Whether people with rheumatic and musculoskeletal diseases (RMDs) are at an increased risk for poorer outcomes is currently debated [2].

This study provides a thematic analysis of perspectives about the impact of the COVID-19 pandemic among people with RMDs. We used patient-generated health data (PGHD) from the social network Twitter. PGHD is defined as "health-related data created, gathered, or inferred by or from patients and for which the patient controls data collection and data sharing" [3].

With the restrictions on public life, much information seeking and conversation about the pandemic occurred online, including social media (SM). Public opinions expressed on SM provide valuable insight to better understand the dynamics of the COVID-19 pandemic. Research has demonstrated the usefulness of Twitter user data to understand public perspectives on various diseases and health topics [4,5].

METHODS

Data collection and analysis

A thematic analysis was conducted, including public Twitter messages (tweets) in English that mentioned keywords and hashtags related to both Covid-19 (or SARS-CoV-2) and RMDs (Table 1) and were posted between February 1, 2020, and July 14, 2020. A hashtag is a word or phrase preceded by a hash sign (#) and used to identify Twitter messages on a specific topic (e.g., #arthritis). A non-probability, convenience sampling method that relied on the manual monitoring of posts using Twitter's public search interface was used. The hashtags used in the search were selected based on previous research [6] and the Symplur Signals disease hashtag project [7]. The RMDs monitored focused on inflammatory-driven (joint) conditions, namely Ankylosing Spondylitis, Rheumatoid Arthritis, Psoriatic Arthritis, Lupus/Systemic Lupus Erythematosus, and Gout.

Included in this study were original messages by people with RMDs (regardless of their location). The program BotOrNot [8] was used to analyse the Twitter user handles (e.g., @JohnSmith) and distinguish human users from automated accounts. Due to this study's focus on original patient perspectives, we excluded the following types of tweets from the analysis dataset: (i) fake, commercial, and bot-like accounts, (ii) retweets, (iii) non-English Twitter posts, and (iv) posts from Twitter users not clearly stating in their Twitter profile description or their tweet(s) that they have an RMD.

Two authors (KR, EN) independently reviewed the tweets to classify the content based on a priori and emergent coding categories (Table 2, column 1). The coding categories were developed, incorporating COVID-related research [9–10] and input from rheumatology experts. The authors (KR and EN) discussed their coding decisions and any discrepancies until they reached consensus.

This study relied on publicly available Twitter data. The authors adhered to Twitter’s terms and conditions, terms of use, and privacy policy. The Institutional Review Board at King's College London confirmed that no additional institutional ethical approval was necessary to analyse public tweets. We received consent via Twitter from the Twitter users whose verbatim tweets are included in this manuscript.

Patient and Public Involvement

A patient research partner (SM) was involved in the study's design and conduct, including the outreach and consent messages and interpretation of the data.

RESULTS

The analysis included 569 tweets published by 375 Twitter users that we identified as people with RMDs in several countries (e.g., UK, Portugal, USA, Taiwan, Australia, Canada). In addition to previously existing hashtags (e.g., #arthritis, #lupuswarrior), the sampled population used newly emerging user-generated hashtags related to COVID-19 in their messages, such as #coronavirusUK, #HighRiskCovid19, #COVIDarthritis, #covidsurvivor, #SocialDistancing, #SelfIsolation, #QuarantineLife, #WithoutMyHCQ, #covidtest, #TreatmentRationing #RationingOfCare, #WearAMask. We did not identify relevant tweets related to gout.

Eight primary themes related to the pandemic emerged in the sampled messages: (1) a lack of understanding of SARS-CoV-2 and the COVID-19 disease; (2) health behavior and acceptance of public health measures; (3) healthcare practice and communication with healthcare professionals; (4) access to medical care including medication and COVID-19 testing; (5) impact on physical and mental health including coping strategies; (6) work participation, (7) effect of the media, and (8) awareness-raising. Table 2 shows the thematic analysis for each topic and representative tweets. A greater variety of representative tweets and their timing during the pandemic (month posted) are shown in the supplementary material Table S1.

DISCUSSION

This study is the first to our knowledge to use and demonstrate the value of Twitter as a real-time data source to understand the impact of the COVID-19 pandemic on people with RMDs. Despite the hundreds of scientific manuscripts that have emerged since the onset of the pandemic focusing on quantitative research and specific patient and disease-related associations with COVID-19 outcomes, studies exploring the direct patient perspective have been scarce. The COVID-19 outbreak has placed people with RMDs at the centre of this pandemic, due to the multiple uncertainties, including medication shortages [11] and their underlying, chronic, autoimmune disease and their treatment needs. Attempts to date to identify how the pandemic affects these individuals have been based primarily on quantitative research but these studies lack the direct patient perspective. Compared to traditional methods to obtain patient perspective data (e.g. surveys/telephone interviews), researchers have described the benefits of SM-based patient-generated health data as “unprimed by researchers,” and “without instrument bias” [12].

SM has been proposed as an essential communications tool in global health crises, including the current COVID-19 pandemic [13]. Opinions expressed by RMD patients on SM can provide valuable insights to better understand the COVID-19 pandemic dynamics, for example, gauging their attitudes towards safety measures and mapping physical and mental health symptoms.

In our study, the data provided ‘early signals’ of health behaviour changes that could potentially adversely affect people’s health outcomes (e.g., medication rationing, missing face-to-face lab monitoring appointments). Similar behaviours have been seen in other pandemics such as the 2015 Middle East Respiratory Syndrome (MERS) outbreak in South Korea, where people avoided hospitals even when sick [14]. Additionally, our study detected 'signs' of increased anxiety and depression levels among people with RMDs, as reported previously [15]. The presence of patient ‘signals’ provides opportunities for future pandemics. Automated SM surveillance efforts through the rapid analysis of vast amounts of text (i.e., natural language processing) [16] and monitoring for keywords that indicate health-harming health behaviours could help identify individuals for targeted health promotion interventions during a pandemic. Data from a recent survey study suggests that SM has a "positive influence on public health protection” against the COVID-19 pandemic with public health awareness and public health behavioural changes acting as “partial mediators” [17]. However, the effects of SM interventions on public health protection against a pandemic are still poorly understood.

Our study highlights an unmet need: to provide clear and consistent information and communication between healthcare professionals and RMD patients. Future research could explore to what extent Twitter might serve as a platform to bridge the communication gap with RMD patients through different health promotion interventions. Research has shown that pandemics call for unique health communication and education strategies in which public health agencies need to satisfy the public's information needs about possible risks while preventing risk exaggeration and dramatization [18]. More proactive health promotion activities on SM to inform about the pandemic and safety measures are also highly relevant in light of the COVID-19 ‘infodemic’, i.e., the overabundance of both accurate and inaccurate information that occurs during an epidemic [19]. Platforms such as Twitter are particularly relevant in pandemics since they can provide a dynamic reflection of the impact of a pandemic. The analysis of tweets over the crucial months of the COVID-19 pandemic in our study, enabled the exploration of secular trends in health behaviours among vulnerable people with RMDs.

The fact that patients proactively shared research opportunities might indicate a heightened level of research readiness, which could help recruit people with RMDs into research studies during and after a pandemic. Studies reported the successful use of SM for research participant recruitment efforts across different diseases [20], a notion supported by our patient research partner who stated: “The importance of this study lies in the fact that it [uses patient-generated] real-time data, [where] patients do not have the stress of answering questions by a researcher, do not worry if they give ‘the right answer’ so their responses are more spontaneous and authentic.”

Study limitations include the lack of representation of perspectives from social networks other than Twitter and, hence, the wider RMD patient community. The analysis was limited to a convenience sample of tweets in English, by individuals that we could identify as people with a subset of (inflammatory) RMDs based on their profile descriptions and tweet content. Finally, this study was limited to the thematic analysis of emerging themes in tweets from people with RMDs during the COVID-19 pandemic, not including a frequency analysis.

Despite these limitations, our study has several strengths, including its use of direct patient perspective data on a worldwide pandemic, highlighting a range of issues concerning physical and psychological health, access to medication and medical care, work participation, and other stressors. The data provide a better understanding of how safety measures and medical care could be communicated and delivered in the future, e.g., through regular webinars by health professionals that address the emerging questions and concerns of people with RMDs during a pandemic. We advocate using patient-generated health data from the social network Twitter as a knowledge source, similar to focus groups, to help shape the response of health care professionals and government authorities to a pandemic.

Acknowledgements

We thank the Twitter users who allowed us to include their public tweets as examples in this article. We were overwhelmed by their enthusiasm for this research and positive feedback. Their tweet contributions make this report much more tangible, showing first-hand how they experienced the COVID-19 pandemic. The following individuals have agreed to be identified directly as contributing to this paper (listed alphabetically): @annakatarinaz; Anna @skeptikosbel; Carmen S. Heath; ChronicallySingle; David Meldrum @vicardave; Debbie Fenelon, Don @drfrasher; Elisa Comer; @Eviljohna; Fiona Grant; Jackie Dillon, Jennifer @UnxpctdAdvocate; @joelvsarthritis; Judy Nagy; Kate Betteridge; @kimberleyscribe; Marcie Rhysling; Martin Hale; Michael Kuluva @MichaelKuluva; Miss D @Miss_Danielle82; Molly Schreiber; @NessMonet; @Phant0mGam3s; Platypus Custard; @PurpleGimp; Randi Vinton-Stewart @randistewart80; @SpoonieMomBlog; Thérèse @TerezHumphrey; Tinu Abayomi-Paul @Tinu; @twility; and Wendy Hunter. Thank you for supporting this research.

Funding Statement

No specific funding was received from any bodies in the public, commercial or not-for-profit sectors to carry out the work described in this article.

Competing Interests

The authors declare no conflicts of interest.

Ethics Statement

This study relied on publicly available Twitter data. The authors adhered to Twitter's terms and conditions, terms of use, and privacy policy. The Institutional Review Board at King's College London confirmed that no additional institutional ethical approval was necessary to analyse public tweets. We received consent via Twitter from the Twitter users whose verbatim tweets are included in this manuscript.

Data Availability Statement

The study data will be available upon request due to the fact that it includes original Twitter messages and user accounts that can be identified.

Contributorship

KR and EN conceived the presented research idea, developed the study protocol, coded the data, and wrote the first draft of the manuscript. SM: Served as a patient research partner on the project providing input into the study's design and conduct, including the outreach and consent messages and interpretation of the data. MZ: Provided expertise in Internet research ethics. He verified and advised on all aspects of the data use and outreach to Twitter users. AD and FB verified the approach and coding methods. All authors discussed the results and contributed to the final manuscript.

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Table 1. Hashtags related to COVID-19 and RMDs used in the Twitter search.

Topic	Hashtag examples
SARS-CoV-2 infection	#SARS-CoV-2, #SARS_CoV_2, #SARSCoV2
COVID-19 disease	#COVID-19, #COVID_19, #Covid19, #coronavirus
General, related to rheumatic diseases	#rheum
Ankylosing spondylitis	#AnkylosingSpondylitis, #Spondylitis, #spoonie (or #spoonies), #spoonieproblems, #spoonieChat, #spondyloarthritis, #SpA, #ASWarrior, #axialSpA
Rheumatoid arthritis	#arthritis, #rheumatoidarthritis #rheumatoid
Lupus (Systemic Lupus Erythematous)	#lupus, #lupuswarrior, #SLE, #lupuschat
Psoriatic arthritis	#psoriaticarthritis

Table 2. Primary health themes, thematic analysis of tweets per theme, and representative tweets.

Tweet themes	Thematic analysis	Representative tweets (paraphrased)
Understanding of SARS-CoV-2 and COVID-19 disease	Early on in the pandemic (February and March 2020), RMD patients, including those with comorbidities (e.g., diabetes, asthma) and pregnancy, expressed a lack of clarity regarding the outbreak. Topics included uncertainty regarding finding reliable information, whether to see their physician, the risk in the context of their chronic condition and immunosuppression, their immunity status, differentiating between a SARS-CoV-2 and other infections, preventive measures (e.g., self-isolation, shielding), use of immunosuppression, and treatment options.	*Anyone on here take an anti-TNF drug? Immune system suppressants? I have Ankylosing Spondylitis so take a drug called Cimzia for it. Just want to know if it has any affect with Coronavirus. Can I still take my injection?*
Health behaviour	Perhaps most importantly, the sampled patient group described changes to their health behaviour in response to the pandemic, e.g., rationing medications, reluctance in attending face-to-face healthcare and lab monitoring appointments.	*Today I've decided to miss my medication and stay off it for the foreseeable. It's not a decision I've taken lightly – this medication gave me my life back. But ultimately, I lived through 10 years of undiagnosed pain. I'm sure I can deal with a few months more of it to give myself the best possible chance of avoiding and fighting #COVID19.*
Acceptance of public health measures	Patient's posts implied a high degree of adherence to the safety measures and greater confidence in dealing with the outbreak due to their experience living with a chronic disease. However, they also raised concerns around the stigma associated with wearing a mask before the pandemic, which carried on at the start of the outbreak when mask-wearing was introduced but not yet consistently applied. Simultaneously, this group expressed frustration about those people who did not take safety measures seriously.	*I am trying to get enough sleep each night plus drinking tons of water. I am not touching my face or trying to touch as many surfaces as I can. I keep washing my hands plus using my mask and gloves when I leave to go out. Trying to be as diligent as possible.*

Healthcare practice	Regarding medical care, patients commented on healthcare staff's professional behaviour, expressing confidence in front-line workers, e.g., nurses, "as if nothing phased them." Still, they also voiced concern about "non-staff" not adhering to safety measures, e.g., wearing masks in the hospital.	*My doctor will not let me go to the lab (or anywhere medical if possible). All appointments except for therapy if I'm having unbearable symptoms are cancelled. My home health nurse has been requested to take them and drop them off for me instead.*
Communication with healthcare professionals	In March, as the pandemic began to impact healthcare measures, patients expressed a lack of communication with healthcare professionals, e.g., attending drug infusion appointments and their risk. On the other hand, posts reflected proactive communication where healthcare providers suggested changes to medication intake to comply with the pandemic restrictions, such as shortages of specific medications.	*I usually have mine done every 4 weeks. Luckily had them done just before lockdown but have no idea if I'm still supposed to go to the hospital in the next few weeks to have them and my IV infusion. No info yet. will need to phone the hospital next week.*
Tele- or home-health	Patients acknowledged the healthcare providers' adjustments in support of people with RMDs, e.g., home nurse support, medication home delivery. Patients expressed the benefits of care at home and having the ability to communicate with their healthcare professionals virtually.	*Home health care has been very easy. When my nurse was here, he was able to draw blood. I've heard from others that home health worked for them as well to get their blood testing done. [paraphrased]*
Access to care and medication	It was evident that patients were concerned and frustrated about medication shortages for their underlying conditions, e.g., hydroxychloroquine. An issue for new patients, in particular, was the delay in being seen by a rheumatologist during the pandemic.	*I was supposed to go on Plaquenil for arthritis but now I can't because of the shortages. I have to wait and have only been prescribed anti-inflammatory and pain meds. I am also scared hoping not to need any major medical care.*

Physical health	In April and July, we found patients expressing their COVID-19 infection status. Those who tested positive described both mild symptoms, not necessarily different from a flare related to their underlying rheumatic disease, and more intense symptoms affecting different parts of my body and in unpredictable ways. Between March and up until June 2020, patients mentioned experiencing symptoms that could reflect a COVID-19 infection and concern about not being able to access testing despite their immunocompromised status.	*Will this include people like me who are on immunosuppressants (methotrexate) for chronic conditions? Diabetic as well. How is the list being compiled? Can't get a grocery delivery so have to go out. #Coronavirus #PsoriaticArthritis #Psoriasis #Fibromyalgia #Diabetes #Osteo*
Mental health	Aside from physical symptoms, patients described the pandemic's psychological impact on their sleep, anxiety levels, and depression. They expressed a heightened feeling of isolation but also positive attitudes and hope that "that life will return to normal" and that this "crisis has the potential to unite us".	*Oh, bloody hell. Super stressed now. Super tired at 11:30 p.m.; too anxious to sleep.*
Work-related issues	Patients discussed the impact of the pandemic on their work-life. We found a range of issues expressing positive and negative perspectives, including a lack of employer support, pressure to take sick leave instead of remote work agreements, pressure to either remain or return to work, non-compliance with recommended safety measures, and appreciation for remote work processes.	*Place of work isn't enforcing distancing or masks. As you can see here the barrier was moved up out of the way. I was wrote-up for taking pics. But breaking policy and putting others at risk goes unchecked.*
Coping strategies	Patients shared coping strategies around leisure activities and expressed the importance of their family and friends, caregivers, and online community during the pandemic, e.g., generosity and support by loved-ones, advice from peers, for example, on securing timely medication refill, overall sense of connectedness and fighting the pandemic together.	*Organizing my meds, writing more, playing with my dog, watching too much Law and Order SVU, trying anything not to succumb to anxiety and fear...*
Peer support	Patients posted questions actively seeking input from their peers about the outbreak and the use of specific medications (e.g., non-steroidal anti-inflammatory drugs, biologic immunosuppressives). They also shared opportunities to participate in COVID-related research efforts.	*So much support online! I'm checking in regularly with close friends. I'm taking time to be outside every day with my dog. And I'm vacillating between intense anxiety over #COVID19*

		and what it means to us patients and how I can help and shutting down 4 self-care.
Advocacy efforts, i.e., raising awareness	Patients attempted to raise awareness of their immunocompromised status and of people downplaying the severity of COVID-19 (e.g., "it's just the flu"). They were appreciative of public health campaigns (e.g., #HighRiskCovid19 on Twitter) that stressed the importance of keeping distance for the most vulnerable. Patients described the campaign's positive impact in making them feel more informed and "less alone."	*Feeling really guilty now for not making more of my immunosuppressed status at other hospital admissions. The alert cards barely get a glance and my problems are treated like hypochondria. Doctors must be taught about biologics, not just rheumatologists.*
Effect of the media and misinformation, response to media content	Despite the need for information, patients commented on the adverse effects of mainstream media during the pandemic, which prompted them to actively limit their exposure. They recognized the importance of being vigilant in checking medical information sources as misinformation is circulated. Patients expressed a general lack of focus in the media on the needs of vulnerable groups.	*I am limiting my exposure to the news and other media stories about #Covid_19. I am a news junkie, but the anxiety is more than I can bear.*