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Background

Coronavirus Disease 2019 (COVID-19) caused by severe acute respiratory syndrome coronavirus 2 (SARS CoV-2) emerged as a pandemic in early 2020. Early on, little was known about the clinical course and symptomatology of the disease prior to hospitalization or from cases that did not result in hospitalization.

Patients often research symptoms and alternative therapies before seeking medical advice. In the case of COVID-19, online support forums have become avenues to share experiences with the disease, discuss symptoms and treatment options, and request medical advice from other patients.

Our objective is to utilize qualitative analysis methods to analyze patient-reported COVID-19 experiences from the social media website Reddit to better understand patient symptomatology, testing experiences, and medication use during the early phase of the COVID-19 pandemic. We also aim to identify potential knowledge gaps by comparing findings to the CDC's published list of signs or symptoms associated with COVID-19, which was updated with new information as the pandemic progressed.

CDC Publication Date	Sign or Symptom
February 4, 2020	Fever or Chills Cough Shortness of breath (SOB) or difficulty breathing
April 26, 2020	Muscle or body aches Headache New loss of taste or smell Sore throat
May 25, 2020	Congestion or runny Nose Nausea or vomiting Diarrhea Fatigue

Methods

Data Collection

An application programming interface (API) was used to collect data from a specific Reddit community forum, or **subreddit**, called "covid19positive." The original posts (OPs) and comments to posts were collected for March 2020 through May 2020.

6,398 OP
 87,584 comments
 15, 625 unique authors (users)

Data Filtering

Flairs: posts tagged with "Tested Positive" or "Tested Positive- Me"
Engagement: 30+ posts per calendar month
Exclusions include automated posts, deleted or removed posts, authors who had a moderator role in the community, or authors who explicitly stated they were outside the U.S.

31,759 OP and comments
 720 unique authors (users)

Data Coding

Patient case files were created for those classified as **Tested Positive (280)** to be qualitatively coded using NVIVO qualitative data analysis software.

Results

General Demographics:

(not reported by all patients)
Location (within US): NY, CA, NJ, FL, MA, CT, DE, MN, TX, IL, GA, CO, VA, PA, LA, IN, MI, AZ, OH, IA, UT, MO, MD, NC
Age: 155 total: <20 (4), 20s (85), 30s (48), 40s (13), 50s (4), 60 (1)
Sex: 122 total: F (74), M (53)

Symptoms

All signs and symptoms published by the CDC were reported by patients, but later-published symptoms were reported much earlier in the subreddit. Many of the symptoms reported were expected, but patients also provided additional valuable descriptions of their symptoms that may not necessarily reflect those listed by the CDC or otherwise be reported in standard clinical or electronic health record (EHR) data.

Initial Symptoms: 91 authors indicated their first symptom(s) experienced

Single	Count	Multiple	Count	Combined	Count
throat	10	headache	16	throat	25
GI	9	ache	15	fever/chills	21
cough	8	fever/chills	15	cough	19
fever/chills	6	throat	15	headache	19
ache	3	cough	11	ache	18
headache	3	fatigue	9	GI	14
SOB	3	nose	7	fatigue	10
chest	2	GI	5	nose	9
loss of senses	2	chest	4	SOB	7
nose	2	SOB	4	chest	6
dizziness	1	dizziness	1	loss of senses	3
fatigue	1	loss of senses	1	dizziness	2
TOTAL	50	TOTAL	103	TOTAL	153

Most common symptoms:

Fever/Chills (148), Aches/Pains (115), Cough (114), Fatigue (108), Chest/Lungs (102), GI (88)

Symptom Descriptions:

In addition to more general common symptoms identified by patients such as fever, cough and shortness of breath, some symptoms were described in greater detail to provide additional insight to how patients experience the disease. For example, rather than experiencing a "sore throat" as described by CDC, some patients experienced mild tingling or congestion. While CDC altered the pain-related symptom description from "muscle pain" to "muscle or body aches," patients reported other types of pain as well, such as sharper pain in the joints or lungs, or neuropathic pain. Other examples of note include:

Chest/Lungs: CDC included "persistent pain or pressure in the chest" as an emergency warning sign, but patients described chest-related symptoms in other ways not reflected by that description; less severe chest-related symptoms were reported frequently. This included descriptions in which patients explicitly described a lack of concurrent SOB or cough.

- Chest tightness
- Chest congestion
- Bubbling in chest
- Lungs feel inflamed
- Mild chest discomfort
- Tickle in the bottom of my lungs
- Felt warm and stuffy in my chest
- Tickling in chest & ribs...no shortness of breath. Actually able to hold breath if needed
- Lungs started to feel "irritated." It wasn't difficult to breathe but I could tell my lungs were inflamed
- My chest feels kinda heavy and sore- like someone punched me and my diaphragm area also feels sore. All of that said, I have no real shortness of breath
- Chest heaviness/fullness, chest irritation/burning...No cough, no shortness of breath

Loss of senses: CDC listed "new loss of taste or smell" as a symptom, but this did not accurately reflect the experiences felt by many patients. Rather than a full loss, many patients experienced an alteration or attenuation of senses.

- Food tastes strange
- Altered sense of smell and taste
- Very weird, metallic aftertaste
- Weird lingering taste...metallic bad breath taste
- Layers of flavors missing in certain foods
- Still can feel in my mouth if something is sweet, spicy, or salty
- My taste was limited to being able to discern salty, sweet, and spicy, but not actual flavors
- Occasionally smelling dust that wasn't there
- Could smell almost a tutti frutti smell for a couple of days
- Constantly had a burnt/chemical smell in my nose
- Bleach smell in my sinuses...can taste sweet, salty, bitter and such, but not distinct flavors
- I can only really taste bitter, sour, and very spicy things

Results (continued)

Non-linear symptom recovery: Some patients described a relapse or recurrence of symptoms following initial recovery, indicating non-linear symptomatology. Multiple symptoms were described in this way, such as:

- Sometimes I have days where I can taste and smell everything, only to eat something the next day and its gone again.
- The "I feel almost normal" fakeouts are the worst. But at least the "I feel horrendous" pockets are transitory as well
- feel like im at a relapse. was feeling a ton better but now dealing with head cloudiness, alot of fatigue, body aches and random chest pains
- Fever's back. Cough is back. Cough is worse now.
- was 100% symptom free for the entire month of April...and now all of sudden it seems my mucus and chest tightness are starting to come back.

Medications: Prescription and OTC medications were used to treat symptoms, as well as medical oxygen based on pulse oximeter readings.

Common Prescription:
 Antibiotics (32)
 Steroids (15)
 Inhalers (29)

Common OTC:
 Cough
 Pain/Fever
 GI
 Sleep
 Combination

Other:
 Oxygen (13)
 Anxiolytics
 Vitamins/Herbals

Testing:

Repeat tests: Patients had multiple tests for a variety of reasons; these did not always follow a positive to negative pattern. Some patients had multiple positive tests, or negative then positive tests.

Reasons for testing: Patients sometimes expressed what specifically led to them getting a test. These fell generally into categories of employment requirements, hospital/healthcare visits, experiencing a specific symptom of having a high-risk comorbidity, exposure to positive cases, or in anticipation of travel.

Limitations

Unlike standardized clinical records, social media data has limitations involving lack of standardization of content and elicitation of data, making quantifiable data difficult to capture. The large volume of data frequently contains redundant information that impacts ability to efficiently capture and filter relevant information. Even with carefully planned inclusion and exclusion criteria, the anonymous nature of reporting and lack of screening capabilities may impact the ability to discern validity and reliability of reporters.

Conclusions

Social media can be a valuable resource for understanding patient perspectives regarding many aspects of disease experience and medication use, and it can also provide insight that traditional clinical records may not be able to provide. Early clinical information in the COVID-19 pandemic focused on presentation of severe disease cases, but patients with less severe cases reported symptoms through social media that may have provided researchers with earlier signals of disease and allowed for faster communication of warning symptoms to the public. The depth and detail of information conveyed in social media can give clinicians and researchers a broader understanding of indicators of disease and provide an additional resource for tracing longer-term progression of both acute and chronic disease. Refining methods of utilizing social media data can allow clinicians and researchers early access to real-world evidence of disease.

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