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"The real question is why someone had to say #DoctorsAreDickheads to be heard":
Qualitative analysis of a Twitter hashtag

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PRISM Symposium December 8th 2019

San Francisco CA

Background

- Twitter has 126 million users worldwide

- 61% of Americans use Twitter for health information

- In October 2018, a youtube user posted her diagnosis story on Twitter, closing with "Doctors are dickheads"…and a hashtag was born

Study Aim ▶

Describe:

- WHO is posting the hashtag #DoctorsAreDickheads (as per their healthcare-related role)

- WHAT common medical conditions are associated with the hashtag

- HOW dialogue and prevalent experiences arose in relation to the hashtag.

Methods

- Sampled Tweets from 10/24/2018-12/31/2018, using Symplur

- Coded random sample of 5% (N=500)

- 20% dual-coded, the remainder independent

- Abstracted Twitter user role and clinical conditions

- Thematic, phenomenological analysis of content, focused on experience
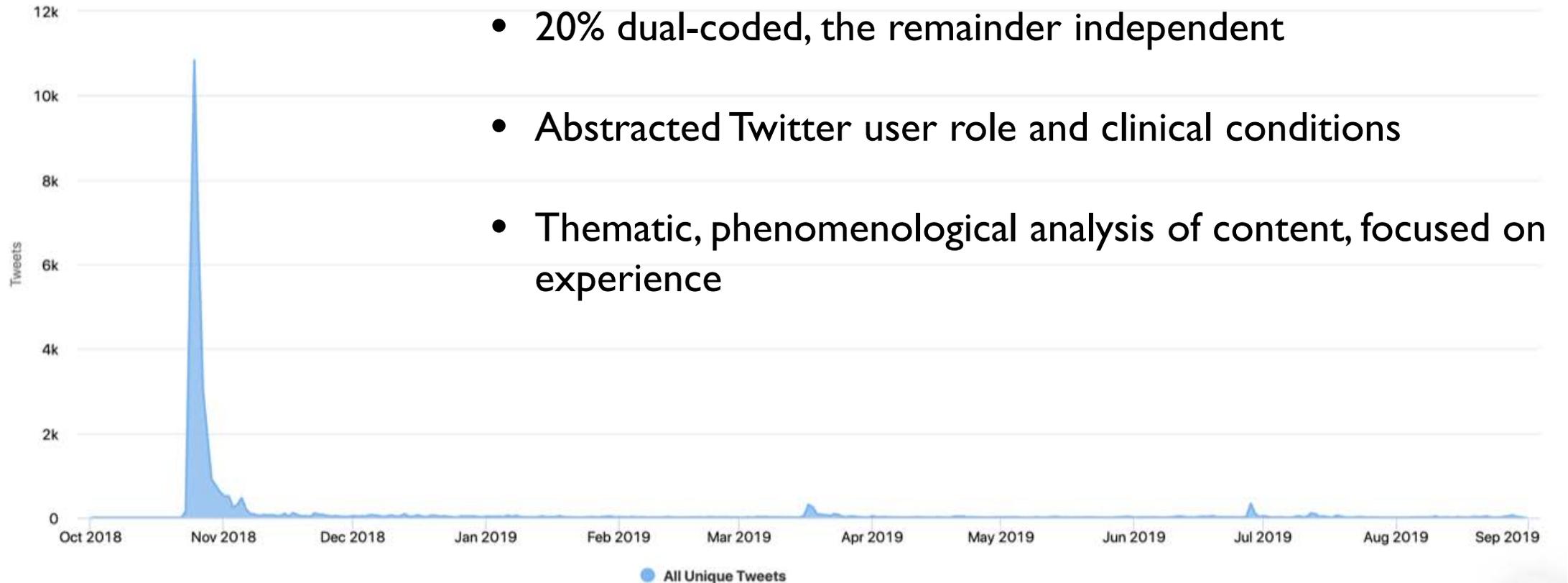
Results:

Demographics	N (% of 483 tweets)
Patient/ patient advocate	244 (49.8)
Caregiver/family member	21 (4.3)
Healthcare provider	46 (9.4)
Researcher/Academic	7 (1.4)
Media, non-healthcare organization	17 (3.5)
Unknown/Other	155 (31.6)

*note, some Twitter posts pertained to multiple demographics

Condition	N
Chronic pain	43 (General pain: 38; Fibromyalgia: 5)
Mental health	31
Musculosketetal conditions	26 (Ehlers Danlos Syndrome: 19; other: 7)
Ob/gyn conditions/ procedures	21
Neurological conditions:	18 (Myalgic encephalitis/CFS: 5; POTS: 4; other conditions: 9)
Disability	17
Chronic illness (unspecified)	14
GI conditions	8
Autoimmune conditions	7 (Mast Cell Activation Syndrome: 4; other autoimmune: 3)

Results: Theme 1, "Belief and Diagnosis"

It took 10 years for them to diagnose multiple sclerosis. Doctors thought I was embellishing my symptoms and looking up too much on the internet. If they had only been listening to me, running the correct tests, and treating me appropriately, I might not be this disabled to the point I am right now.

#DoctorsAreDickheads

Results: Theme 2, "Healthcare hierarchy and the Patient-Provider Interaction"

It's not really that doctors are super mean or completely ableist. It's more that they carry so much inherent power that when they do go wrong, it's not like you are working with a rude plumber or rude car mechanic. #DoctorsAreDickheads
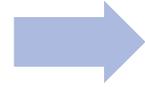
Results: Theme 3, "Hashtag Commentary"

This hashtag #DoctorsAreDickheads comes out of the experiences of patients. As we deliver it, healthcare nowadays is hurtful, wounding, and raw. These are direct accounts from the front lines, not polite statements from panels. For the support group and public sphere, not the board room or salon.

If you're not out there involving patients, I encourage you to start doing so. Heck, there are many patients that have experience in organizing change within large medical spaces   We are here with expertise and even degrees. Hire us to help you. #DoctorsAreDickheads 🖐🏻
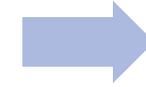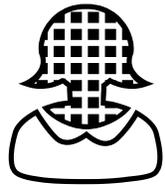
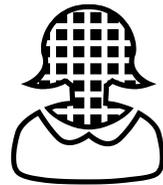# Discussion/Conclusions

Before Visit: context	→	During Visit: how treated	→	After Visit: outcomes

Before Visit:

- Provider burnout/mental health

- Power differential
- Intersecting vulnerable identities
- Stress of illness

During Visit:

- Disbelief
- Dismissal
- Gaslighting
- Inappropriate treatment

↕ Power differential

- Self- advocacy
- Questioning care
- Self-editing to protect

After Visit:

- Negative impression of patient
- Defensiveness vs learning
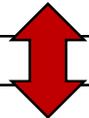
- Adverse diagnostic events
- Harm
- Negative patient experience of care

- Trauma
- Avoiding care/seeking support elsewhere
- Advocacy for change

Discussion/Conclusions

- Patients share how they are treated (and mistreated) publicly.
  - consequences for patient SAFETY as well as patient experience

- Gaslighting/disbelief are a common theme; <u>how</u> patients are treated matters just as much as the correct diagnosis and treatment

- If we can avoid defensiveness, there are opportunities:
  - learning from patient narratives
  - many positive recommendations can be enacted
  - recognizing potential patient partners in system redesign

Thanks!

- Study team

- Patients, advocates, and clinicians on Twitter

- Tom Lee
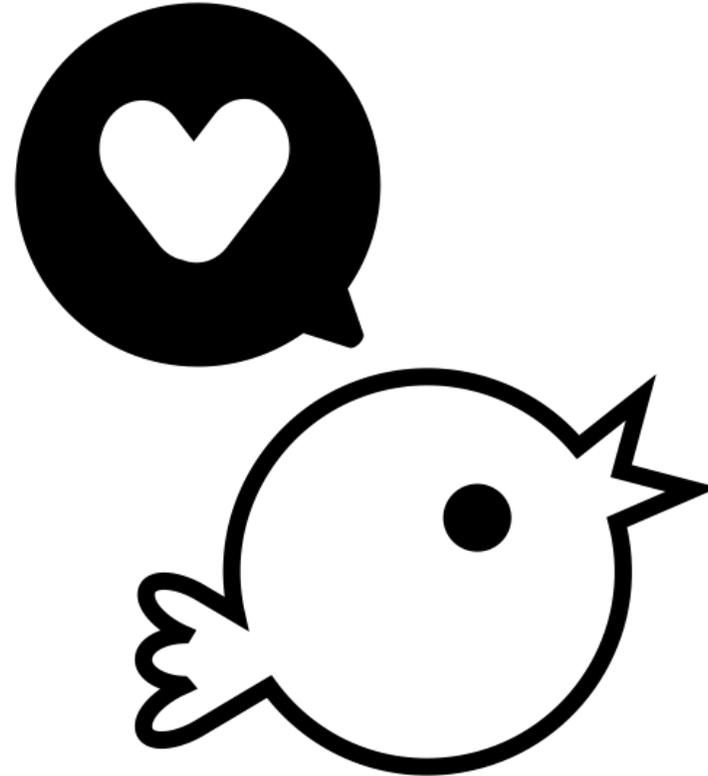
Created by Oksana Latysheva
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