Side Effect Insights

and the Informal Wisdom of Online Communities

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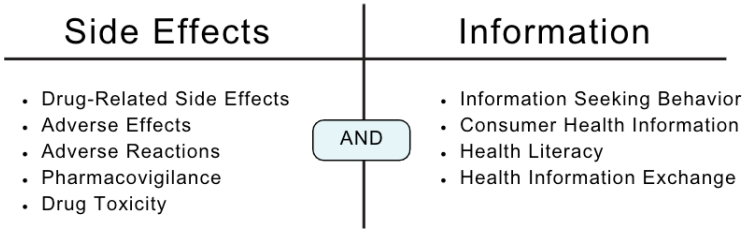
18.9

minutes[1]

The median length of primary care office visit

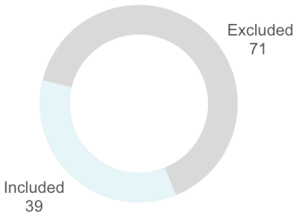
Patient centered care is an iterative, conversation-based process.[2] Subjective and personal decisions may require significant discussion and consideration.

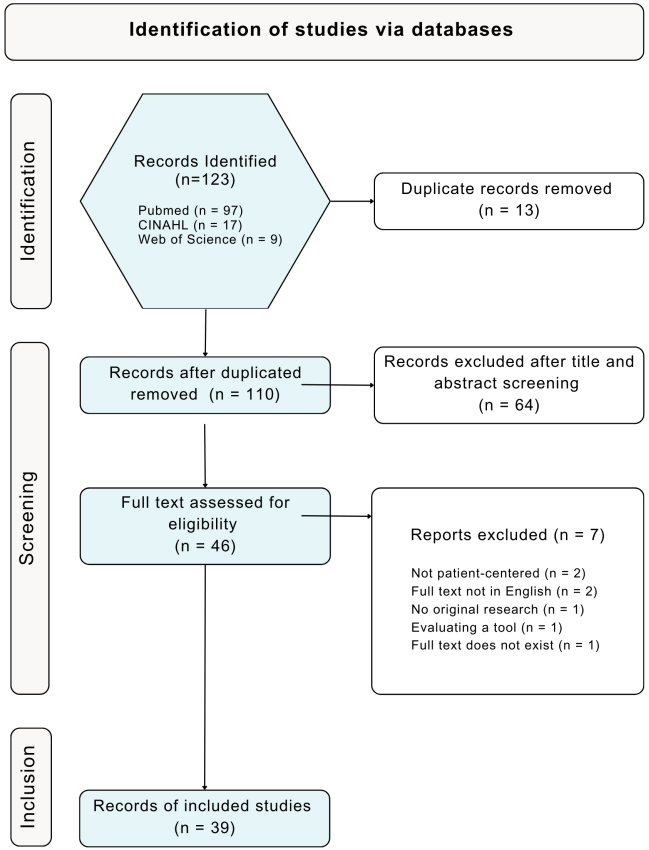
Literature Review



Literature Review

Side Effects		Information
• Drug-Related Side Effects • Adverse Effects • Adverse Reactions • Pharmacovigilance • Drug Toxicity	AND	• Information Seeking Behavior • Consumer Health Information • Health Literacy • Health Information Exchange





Take Aways

- The format of presentation significantly impacts patient understanding [4,10,18,27,29,33, 36]
- Patients' understandings of side effects are limited [2,17, 23, 28,38]
  - Potential due to:
    - Illegible, average text size in documentation[5,35]
    - Long, complex sentences[5,6,31]
    - An overwhelming amount of information[32]
    - Information hidden in difficult to find footers or fast-passed commercials[7,31]
    - Optimism bias[26]
- Certain populations are especially impacted, uneducated, elderly, low socioeconomic status, cognitive deficits [3,8,12,19,24,37]
- Online resources are unreliable [13, 16, 25, 21]
- Patients care greatly about side effects, and are increasingly relying on the internet for information[1,5,11,13, 14,30,34]

Exploring the Wisdom of

Online Communities

A pilot study

An Exploratory Example

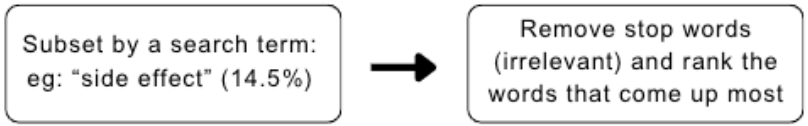
- **Pilot Project:**
  - ADHD Medications
    - 1) Subjective decisions[3,4]
    - 2) Active online community of discussion
  - Reddit: free

- (Eventually) will also scrape Twitter and build a pipeline that can easily be applied other medication classes

Building Tools:

- Scraped ~10,000 posts from r/Concerta
- Understand 10K posts without reading them

- 1. Word Frequency



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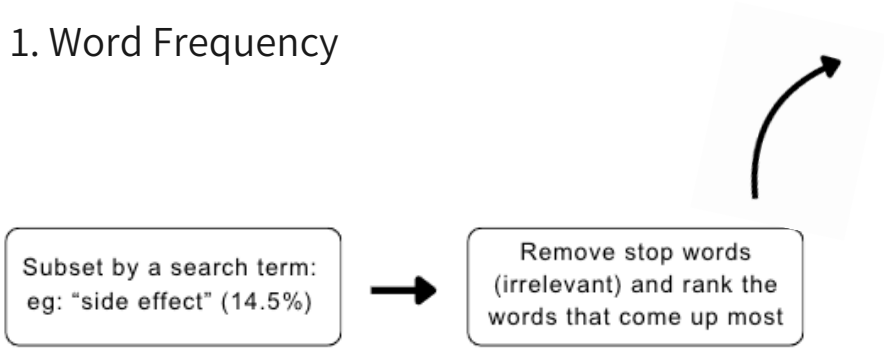

Most common words:

concerta: 2420
side: 2019
effects: 1824
feel: 1443
taking: 1061
day: 1049
take: 837
started: 821
dose: 809
time: 742
days: 724
first: 700
anyone: 629
medication: 619
adhd: 612
know: 610
week: 604
much: 595
felt: 588
effect: 569
meds: 532
work: 529
even: 510
anxiety: 499
doctor: 488
feeling: 479
weeks: 470
go: 430
took: 402
back: 398
hours: 397
got: 394
heart: 382
ago: 381
better: 377
else: 369
mg: 369
anything: 367
focus: 360
something: 358
going: 354
experience: 349
think: 349
good: 338
help: 335
lot: 333
bad: 332
sleep: 331
months: 328

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mg: 369
anything: 367
focus: 360
something: 358
going: 354
experience: 349
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Building Tools:

- 2. Sentiment Scoring

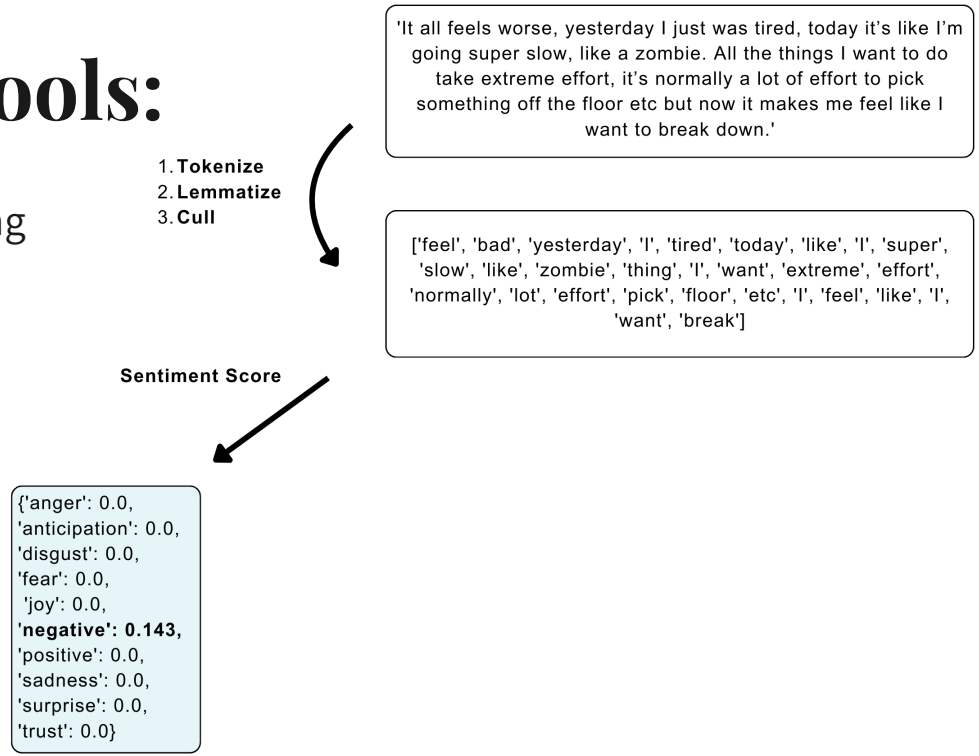
1. **Tokenize**
2. **Lemmatize**
3. **Cull**

'It all feels worse, yesterday I just was tired, today it's like I'm going super slow, like a zombie. All the things I want to do take extreme effort, it's normally a lot of effort to pick something off the floor etc but now it makes me feel like I want to break down.'

['feel', 'bad', 'yesterday', 'I', 'tired', 'today', 'like', 'I', 'super', 'slow', 'like', 'zombie', 'thing', 'I', 'want', 'extreme', 'effort', 'normally', 'lot', 'effort', 'pick', 'floor', 'etc', 'I', 'feel', 'like', 'I', 'want', 'break']

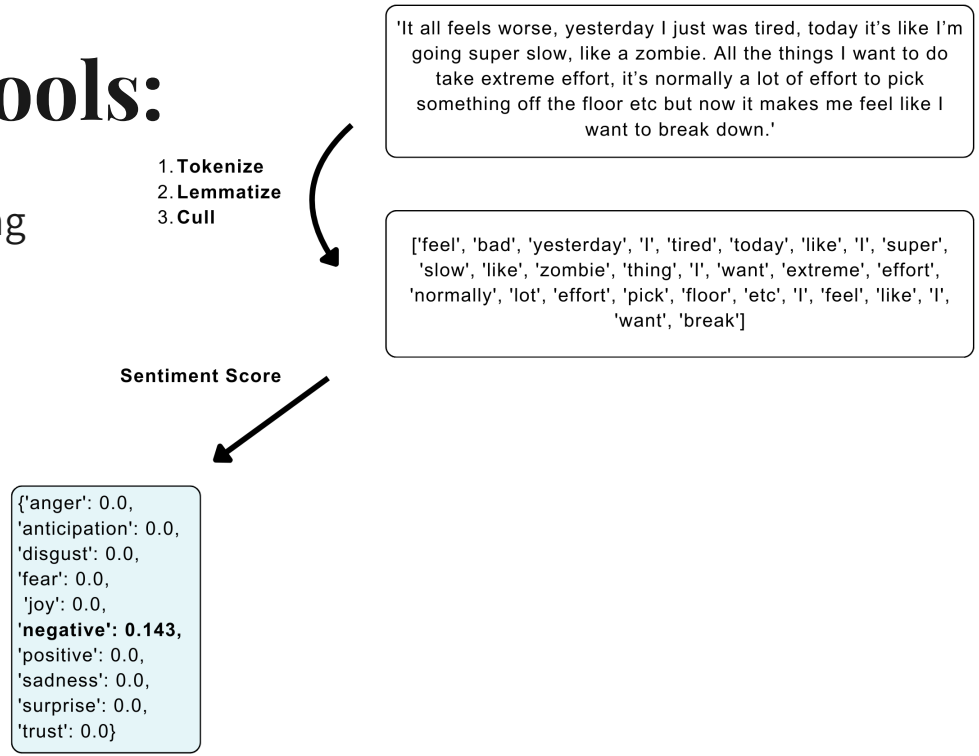
Building Tools:

- 2. Sentiment Scoring



Building Tools:

- 2. Sentiment Scoring
- 3. Clustering



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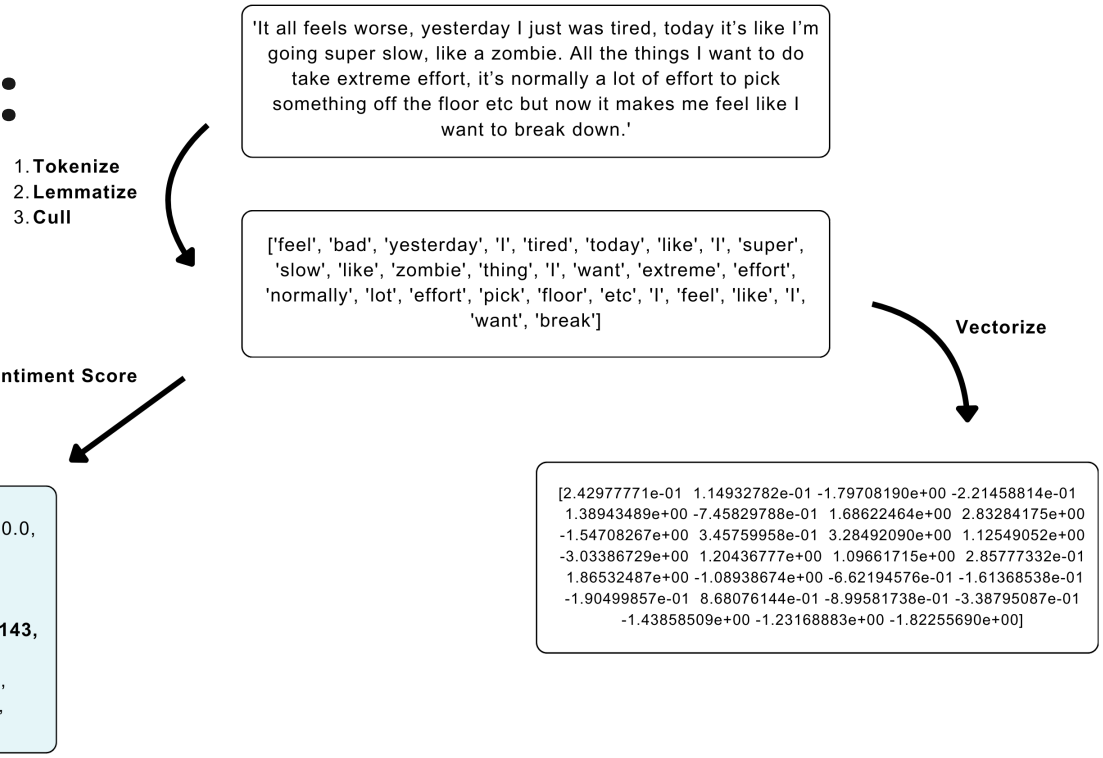

Building Tools:

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'It all feels worse, yesterday I just was tired, today it's like I'm going super slow, like a zombie. All the things I want to do take extreme effort, it's normally a lot of effort to pick something off the floor etc but now it makes me feel like I want to break down.'

1. **Tokenize**
2. **Lemmatize**
3. **Cull**

['feel', 'bad', 'yesterday', 'I', 'tired', 'today', 'like', 'I', 'super', 'slow', 'like', 'zombie', 'thing', 'I', 'want', 'extreme', 'effort', 'normally', 'lot', 'effort', 'pick', 'floor', 'etc', 'I', 'feel', 'like', 'I', 'want', 'break']

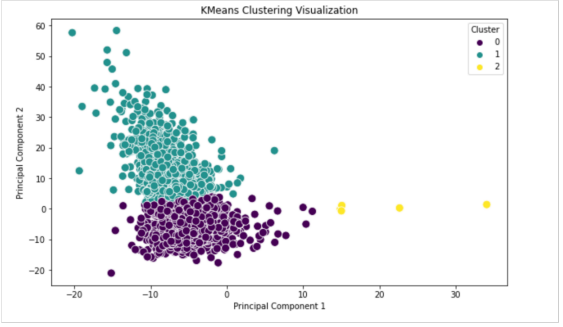
Sentiment Score

{'anger': 0.0,
'anticipation': 0.0,
'disgust': 0.0,
'fear': 0.0,
'joy': 0.0,
'**negative': 0.143,**
'positive': 0.0,
'sadness': 0.0,
'surprise': 0.0,
'trust': 0.0}

Vectorize

[2.42977771e-01 1.14932782e-01 -1.79708190e+00 -2.21458814e-01
1.38943489e+00 -7.45829788e-01 1.68622464e+00 2.83284175e+00
-1.54708267e+00 3.45759958e-01 3.28492090e+00 1.12549052e+00
-3.03386729e+00 1.20436777e+00 1.09661715e+00 2.85777332e-01
1.86532487e+00 -1.08938674e+00 -6.62194576e-01 -1.61368538e-01
-1.90499857e-01 8.68076144e-01 -8.99581738e-01 -3.38795087e-01
-1.43858509e+00 -1.23168883e+00 -1.82255690e+00]

Cluster (unsupervised)



An Evolving Methodology

- Do patients trust their physicians? I can pull all the posts that mention the words “doctor” or “physician,” and read a few. Then I can compare how the emotion “trust” scores on these post versus the rest of the corpus.

- How important is dose in the side effect conversation? I can pull all the posts that use the words “mg” or “milligram.” With a little work, I could even search for a number and bin by dose. Do certain side effect terms come up more in groups of higher doses?

- People go online when they’re angry, can we find out what’s making them angry? Pull posts that express the highest scores for anger. Read a few. Rank the words that come up most.

- People use online platforms to talk about their previous conversations with clinicians. I can look at all the posts that use quotes, or use phrases like “doctor”/”physician”/”physiatrist” in series with “said”/”told”/”was like.” How do patients view their interactions with their doctors?

Acknowledgments

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