

SMH (Social Media & Health): Less Head-Shaking With A Rare Disorder

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Introduction

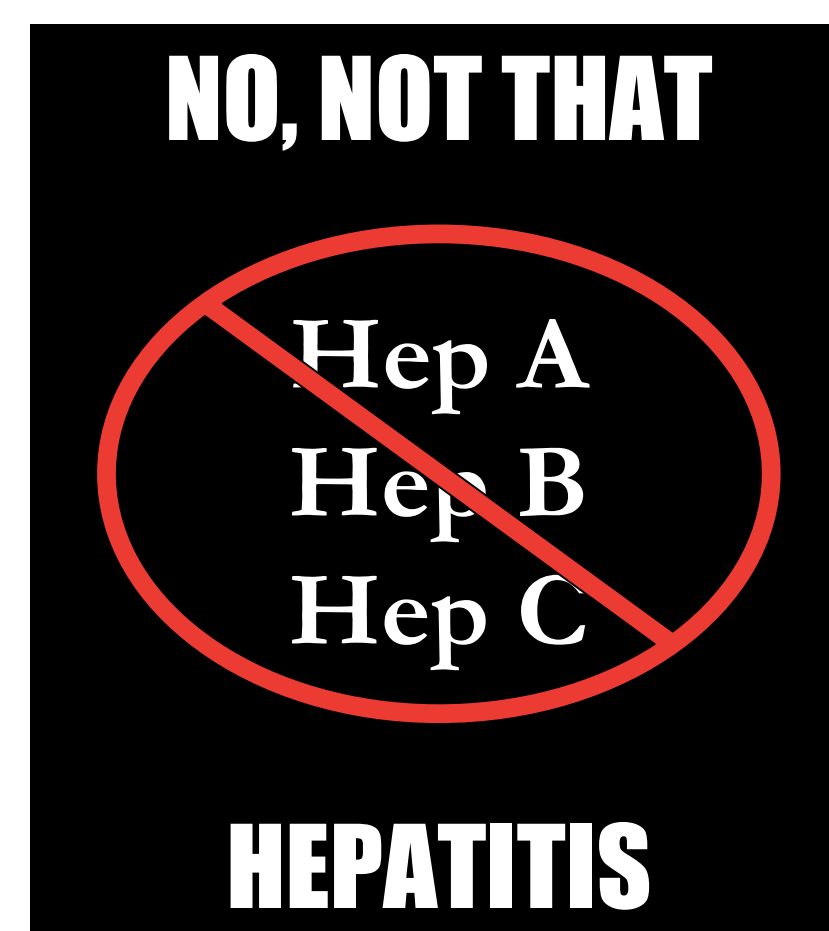
Social Media (SM) consists of a large and diverse groups of websites, also known as SM venues or social networking sites (SNSs). Popular SM venues, such as Facebook(TM) and Twitter(R) have become household names over the past 15 years.

SM has been a major research interest for analysts in fields ranging from business analytics to health and medicine. However, the use of SM in health research is less popular because of the difficulties in extracting data, reliability of the data, and due to privacy concerns.

Here, we show evidence of detailing the medications taken by individuals with Autoimmune Hepatitis (AIH), a rare disorder of unknown cause that might be triggered by medications.

AIH: Autoimmune Hepatitis

- **Not** viral hepatitis!
- Body attacks its own liver, destroying it
- **Extremely** rare: No more than 100,000 people diagnosed worldwide (1)
- Symptoms caused by liver destruction: Debilitating pain, fatigue, swelling
- Untreated, leads to liver failure and death
- Treated patients: Normal life expectancy, but low quality of life
- **No single cause has been proven – medication reactions** (2) and genetics are the two major suspects.



Above: An actual Internet meme about AIH.

How can we reach a large number of patients with AIH and learn more about them in hopes of preventing the disease and/or finding better treatment guidelines?

One Answer: Facebook

We found a Facebook(TM) group for AIH patients (group users) and downloaded data directly from the web browser's source code feature. Then, we condensed it.



The condensed XML data show who posted what, when they posted, and who commented and what they said. User narratives documented everything any given user said.

The Group: By Numbers

**2 years
of talk**

- **1,052 active members**
- **1,476 posts**
- **16,646 comments**

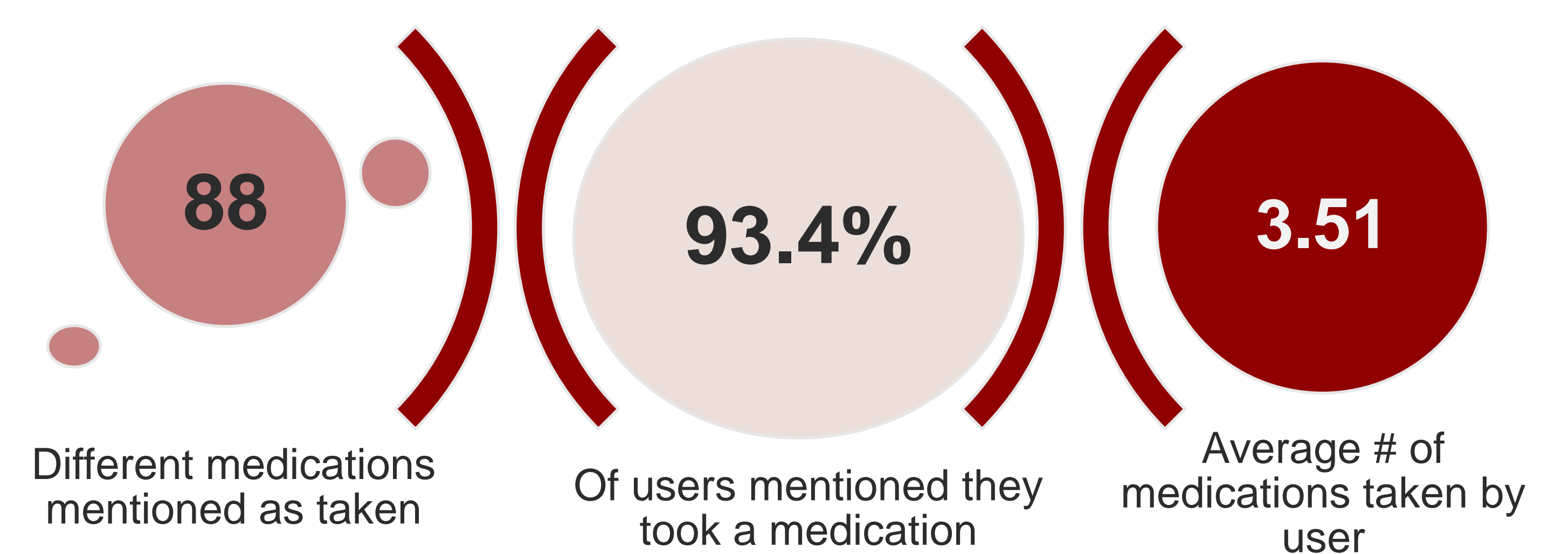
Privacy & Integrity

- All data downloaded directly from the web browser (no back-end bots or hacking)
- All User IDs encoded (de-identified)
- Non-encoded user IDs only stored on encrypted hard drives
- No contact is made between the primary researcher (AK) and the group users
- Study and protocol filed and approved with the Institutional Review Board (IRB)

Digging: For Medication Usage

Medications may trigger AIH – Possibly because most ingested chemicals have to pass by the liver. We need to know the medications these users have taken.

Computers can tell us quite a bit, but detailed and reliable analysis means that data need to be analyzed by real human beings. We found the following from reading the user narratives of 61 users.



Lessons & The Future

- It is possible to download and organize SM venue (Facebook Group) data
- Manual analysis reveals a high rate of discussion of medications taken by users
- We discovered a “folksonomy” (a folk taxonomy) that let us know when users were literally saying they took medications.
- Known the folksonomy, the remaining 900+ users can be searched for medication usage by using a computer
- We can find much more than just medications: Signs, symptoms, environmental factors. AIH takes more than one cause! (2)

References

1. Gatselis NK, Zachou K, Koukoulis GK, Dalekos GN, *Autoimmune hepatitis, one disease with many faces: Etiopathogenetic, clinico-laboratory and histology characteristics*. World J Gastroenterology, 2015. 21(1): p. 60-83.
2. Ngu JH, Gearry RB, Frampton CM, and Stedman CA, *Autoimmune hepatitis: The role of environmental risk factors: A population-based study*. Hepatology Int, 2013. 7(3): p. 869-875.