

GENERATING PATIENT INSIGHTS IN DRY EYE DISEASE WITH A SOCIAL MEDIA LISTENING STUDY

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BACKGROUND

- The new 'Digital Age', in which there is a ubiquitous use of social media, is providing innovative ways to gain insight into the patient experience
- Valuable disease specific insights can be generated by analyzing (anonymized) publicly available social media information¹, without inflicting any additional burden on the patients (i.e. no requirement to complete forms or participate in a research survey)
- A study in Dry Eye Disease (DED) was conducted using an approach called Social Media Listening (SML) analysis in order to generate patient insights to inform early drug development

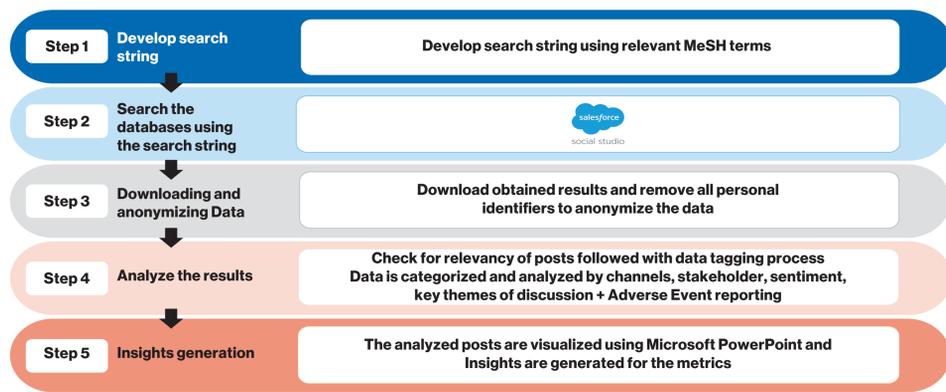
OBJECTIVE

- To understand the needs and perceptions of DED patients using Social Media Listening (SML) and generate valuable insights with respect to disease burden, diagnosis, treatment, unmet needs and health-related quality of life (HRQoL)

METHODS

- This retrospective, cross-sectional study used an SML approach to gather data from Twitter, Blogs/Media, Forums and Newswires between December 1, 2016 and February 28, 2017
- A search string was developed using the Medical Subject Heading (MeSH) terms for DED and a social media data aggregator tool (Sales Force Social Studio[®]) was used to download data. Data from Facebook was not accessible considering the contract limitations with the data aggregator tool
- The downloaded data was anonymized to remove all personal identifiers and categorized for analysis, based on channels, stakeholders, sentiments and key themes of discussion, along with any adverse event reporting
- The study was conducted across multiple geographies (US, EU5, Japan and Australia), however, only English language posts were included in the analysis
- After data categorization, text algorithms and manual curation techniques were used to perform the analysis and generate insights

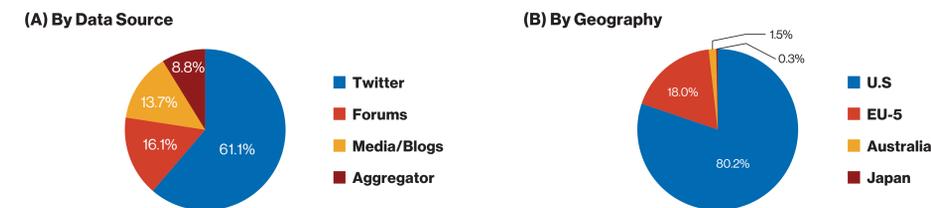
Figure 1: Study Methodology



RESULTS

- A total of 2,641 relevant posts were included for analysis
- Twitter was the primary source of information, contributing to 61% of total posts followed by other sources such as Forums (16.1%) and Media/Blogs (13.7%) (Figure 2)
- Most of the posts were from the U.S (80%) and Europe (18%) (Figure 2)
- Key discussion themes identified by SML analysis were DED symptoms (3,025 mentions), treatment options (1,866 mentions), causes (1,328 mentions), diagnosis (539 mentions) and management (101 mentions)

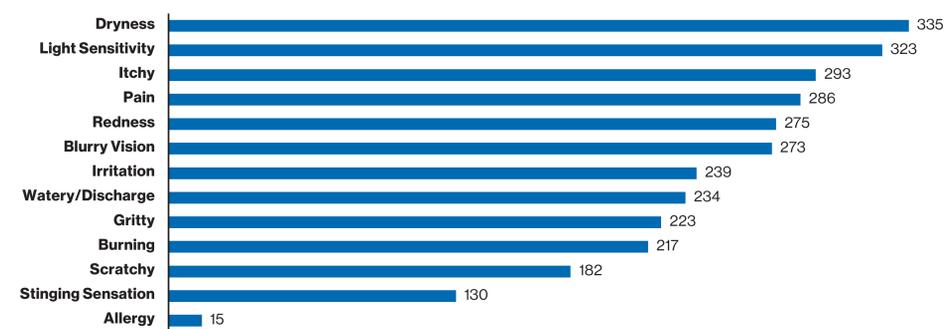
Figure 2: Percentage split of posts by data source and geography



Symptoms of dry eye

- A wide range of symptoms were discussed by patients through social media, of which dryness, light sensitivity, itchy, pain, redness and blurry vision were the most frequent (Figure 3)

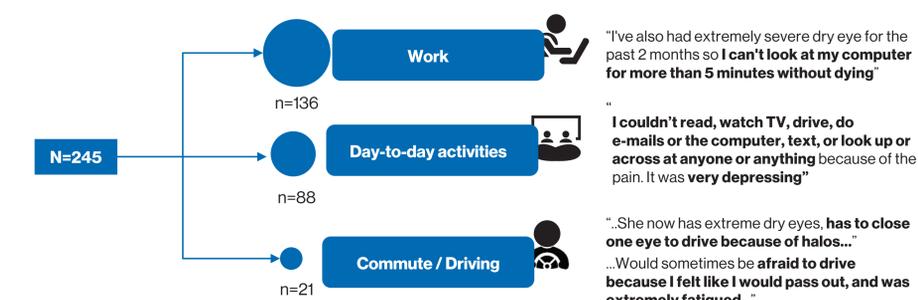
Figure 3: Social Media mentions on symptoms of Dry Eye



Impact of Dry Eye on Patients' Health Related Quality of Life

- There were 245 mentions by patients about the impact of DED on HRQoL. A significant number of mentions were related to the impact on work followed by daily activities such as driving and use of electronic devices (Figure 4)
- DED has a significant impact on patients' QoL which results in lower work productivity, limiting activities of daily living and affecting the psychological wellbeing of the patient which is illustrated by the patient verbatims in Figure 4

Figure 4: Dry Eye - Impact on Patients' Health Related Quality of Life

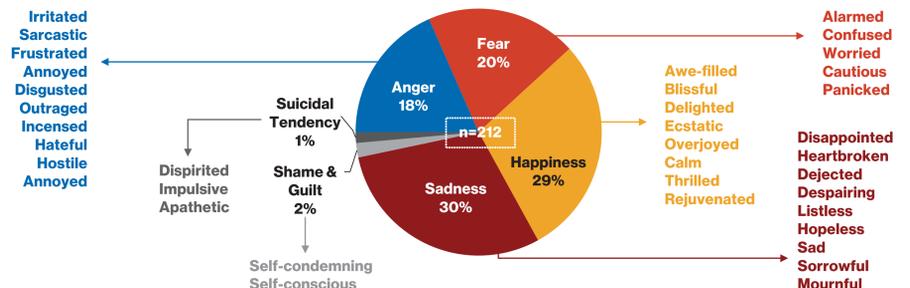


Note: The size of the bubble represents number of mentions referring to QoL

Dry Eye Patients' State of Mind

- A further exploration of QoL also revealed a huge gap in patient emotional needs. The majority of emotions were negative (Figure 5), which expressed the frustration patients undergo while living with DED. Fear, anger and sadness were expressed by 20%, 18% and 30% posts respectively
- Of note are the suicidal tendencies which were present in around 1% of the total analysed posts which depicts the impact of DED on the psychological wellbeing of patients
- A few instances of happiness and joy were also expressed when patients received effective treatment and experienced relief from the symptoms of DED

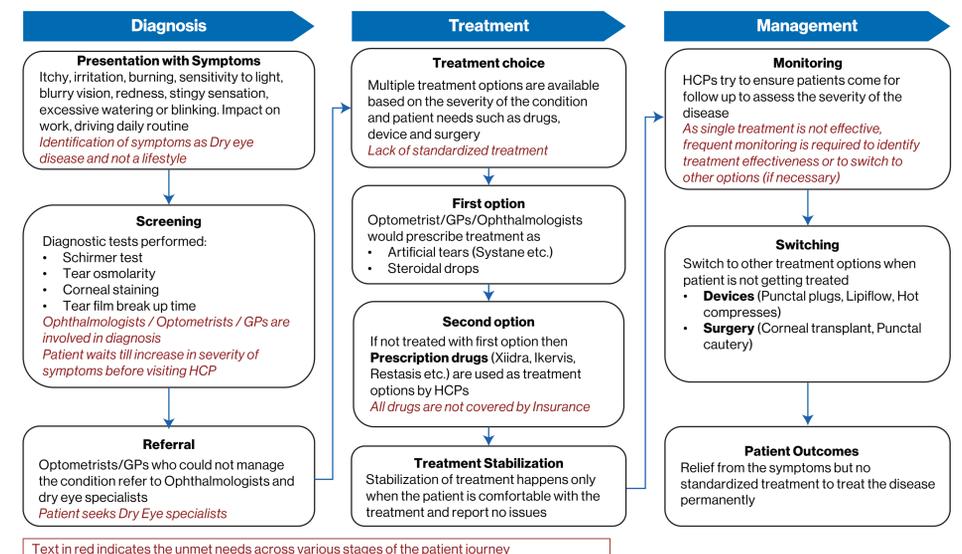
Figure 5: Patient Emotions and State of Mind



Patient Pathway and the Perspective on DED

- The analysis provided key insights into the patient journey (Figure 6) and unmet needs (Figure 7). While this study clearly suggests a need to increase disease awareness, lack of standard diagnostic tools, treatment options and specialists emerged as key unmet needs (Figure 6)

Figure 6: Patient Pathway in the Healthcare System



- Patients suffering with DED expressed concerns around the use of digital devices. Performing daily activities such as checking e-mails, watching television, using smartphones was becoming difficult and this had a severe impact on their HRQoL, leading to depression (Figure 4, Figure 7)

Figure 7: Patients' perspective on DED

- No standard treatment**
"There aren't any quick fixes. Each intervention can take a few months to make a significant difference and often you need a combination of treatments for relief"
- No proper diagnostic process / tool**
"I ask again, 'what is the actual diagnosis? What is causing those symptoms?' They can't answer because the real underlying cause has not been identified. In many cases, they were prescribed medicines or therapies without receiving a diagnosis at all."
- Patients feel frustrated by undergoing series of tests to confirm dry eye**
"Just completed my annual eye exam with Dr.XXX. Obviously not fun sitting through a battery of tests but Dr. and staff were extremely thorough and competent as they explored and addressed all potential issues."
- Lack of dry eye specialists**
"I assumed that any 'regular' ophthalmologist would be able to treat dry eye. I have since learned that there aren't a whole lot of doctors who specialize in dry eye, and there are even fewer who are truly competent at treating it."
- Lack of Disease Awareness**
"Tell me about it (lights everywhere)!!! I didn't realize dry eye would create a light sensitivity as well!! Ugh"
- Impact on QoL**
"After getting dry eyes I became very frustrated and almost depressed for a while"
"I've also had extremely severe dry eye for the past 2 months so I can't look at my computer for more than 5 minutes without dying"
"I had to stop driving, because I couldn't see through the heavy tear production & stopped working, as a film maker -I couldn't focus my camera"

CONCLUSIONS

- The results of this study suggest SML is a valuable approach for gathering patient insights
- Insights from Social Media Listening can be used to inform early drug development in combination with traditional techniques such as literature reviews and qualitative/quantitative patient market research
- Understanding the patient experience and their unmet needs early in the drug development process allows clinical trials to be customized with outcomes measures which are of greatest importance to the patient

REFERENCES

- Learning by Listening, Digitally <https://www.ispor.org/ValueOutcomesSpotlight> Accessed on 29th August 2017

Disclosure

All authors are full-time employees of Novartis group of companies and have nothing to disclose

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