Leveraging Social Media for Patient Experience Insights in Rare Disease

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BACKGROUND

Capturing the voice of the patient is essential in pharmaceutical drug and device development. Understanding patient-centered concerns can aid clinicians and manufacturers in the development of tools that assess patient experience and improve care.

Underscoring the importance of capturing the voice of the patient, the U.S. Food and Drug Administration (FDA) formally developed the Patient-Focused Drug Development (PFDD) initiative in 2012 to take a deeper look at symptoms and approaches to treatment from the patient perspective.

The PFDD initiative provides valuable insight, but reports are not encompassing of all disease states and may not be available when needed. Therefore, other avenues to capture patient centric concerns are necessary.

The ability to capture patient insights in real time from an unbiased data source can provide a unique and timely perspective, complementing traditional qualitative research.

OBJECTIVE

To determine the feasibility of utilizing social media to generate insights on patient experience around treatment, quality of life, and burden of illness for a sample rare disease.

METHODS

The Phonos was developed using data from the cystic fibrosis subreddit /r/CysticFibrosis on Reddit.com using the process outlined in **Figure 2**.

Discussion threads ("posts," in Reddit terminology) from July to December 2021 were reviewed and tagged as relevant if they contained discussion points of potential relevance to clinicians or manufacturers.

Individual statements within threads were manually labelled to one of four main categories: Patient Journey, Treatment Effect, Treatment Switching, and Life Milestones and then further sub-characterized according to **Figure 1**.

Within Treatment Effect, posts containing mentions of relevant drug names from a prespecified list were tagged.

Labels were applied through the Phonos that allows the user to select a portion of text, choose a label for it, and enter additional subcategorization (e.g., product, sentiment). The labeled text then appears highlighted in the system.

As part of labeling, the text is tokenized using the Python spaCy natural language processing library (spacy.io).

Figure 1: Posts were categorized into one of four overarching topics, then subcategorized based on content.

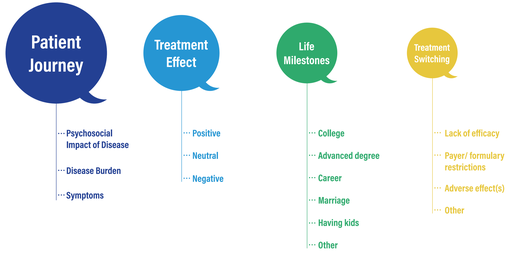
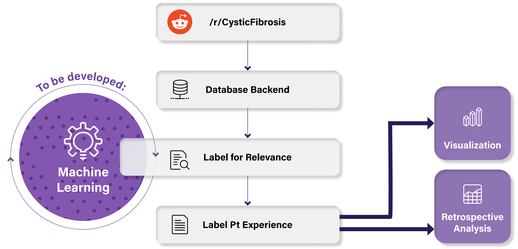
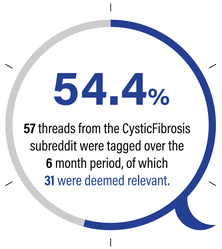


Figure 2: Posts were collected from the cystic fibrosis subreddit /r/CysticFibrosis using the Reddit API and stored in a database. The posts were then reviewed and labeled using Phonos. The labeled data then support both visualization and retrospective analysis. Machine learning can be applied in the future to automate relevance filtering and labeling.



RESULTS



103 comments had at least one label, with **117** labels being applied

Patient Journey	51
Treatment Effect	39
Milestones	24
Treatment Switching	1
Other	2

Mentioned within the Patient Journey category:

the psychosocial impact of disease	(N=22)
disease burden	(N=14)
symptoms	(N=11)
other	(N=2)

Milestones included:

going to college	(N=4)
having kids	(N=3)
marriage	(N=2)
career	(N=11)
advanced degree	(N=1)
other	(N=3)

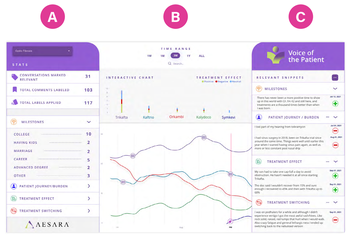
Mentioned within Treatment Effects,

Positive	Negative	Neutral
15	21	2

Trikafta	(N=22)
Kaftrio	(N=14)
Kalydeco	(N=11)
other	(N=2)

An interactive dashboard was created to provide a real-time dynamic view of the patient experience data (Figure 3).

The dashboard is a real-time dynamic view of the patient experience data. A) The quick stats panel on the left displays the number of comments in each category/ subcategory. B) An interactive chart displays product mentions over time. C) Relevant snippets of conversation are displayed on the right, which link to the original post.



A
The dashboard contains at-a-glance statistics with the number of comments and labels tagged as well as those in further sub-categories

B
An interactive chart* identifies relevant products mentioned within the posts, providing a dynamic visual representation of which products are being mentioned. The user can add tags of noteworthy events to contextualize product mention in real-time.

C
Organized by the identified labels, relevant snippets of conversation are displayed along with a corresponding positive, negative, or neutral rating. Snippets are linked to the original, complete post, which can be viewed by the user.

*Note: for the purposes of demonstration, a fictional time series plot was generated. With more labeled data, it will be possible to plot the volume of mentions of a product over time.

CONCLUSION

Repeated concepts revealed patient level sentiments about the psychosocial impact of disease of cystic fibrosis that can and should be considered as relevant to patient quality of life.

Results demonstrated that social media hold considerable potential for obtaining real-time, treatment-level insight into patient experiences that may not be readily identifiable through traditional research methods.

Harnessing the patient voice through the Phonos allows an evolving understanding of points in the patient journey that can be used for a multitude of decisions in healthcare and in biopharma drug and device development.

Capturing real time voice of the patient via social media to provide patient-centric feedback can contribute to FDA's commitment to incorporating the patient's voice in drug development and evaluation.

FUTURE DIRECTION/ NEXT STEPS:

Machine learning applications can be used to automate the top-level relevance filtering for threads as well as the more challenging semantic role labeling task.

Treatment specific data can provide market insights, aiding in competitive intelligence and the development of market shaping efforts.

Categories can be customized based on disease state and specific areas of interest.

Patient centric feedback related to the patient journey and disease burden can be used to shape early stages of PRO development, understanding patient preferences and elements of the patient experience may not be captured via traditional qualitative research methods.

REFERENCES
FDA-led Patient-Focused Drug Development (PFDD) Public Meetings page. Food and Drug Administration Web site. https://www.fda.gov/industry/prescription-drug-user-fee-amendments/fda-led-patient-focused-drug-development-pfdd-public-meetings. Accessed April 14, 2022.

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