

Amplifying Patient Voices Using the Rapid Method of Social Listening: Pericarditis

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BACKGROUND

Pericarditis

- Pericarditis is inflammation of the pericardium or sac surrounding the heart, possibly linked to viral infection in the majority of cases in developed countries.
- One of the hallmark symptoms of pericarditis is chest pain, and about 5% of emergency room patients with chest pain are diagnosed with pericarditis.¹
- Pericarditis typically manifests as a single event and resolves without complication, but in 15 to 30% of the cases, pericarditis can recur.²
- The primary driver of recurrent pericarditis is considered to be autoinflammation, mediated by interleukin-1 (IL-1).

Patient-reported Outcomes (PROs)

- Outcomes as reported by the patients (patient-reported outcomes, or PROs) are typically captured through surveys and interviews and included in the data explored in clinical trials.
 - Rare or emerging diseases pose a particular challenge regarding PRO collection.³
- Real-world data (RWD) can be a resource for gathering PROs regarding patient experience with rare disease in a more time- and cost-effective manner.⁴

Social Listening

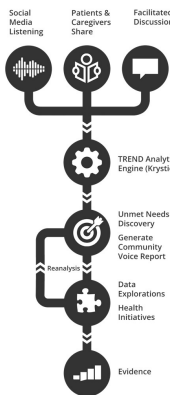
- Social listening is the process of utilizing and analyzing real world data available on social media networks.
- Patients tend to share their experience within social networks, and the resulting data can provide information regarding:
 - Symptoms associated with disease
 - Disease impact on daily life
- Using machine learning and a custom analytics engine, TREND Community developed a rapid customized social listening methodology for analyzing large amounts of social media conversation content data from groups united around particular diseases; the de-identified data were utilized with permission from site administrators.

METHODS

Aim

To evaluate patient perspective of pericarditis disease burden using a new method of real-world data collection, social listening

- Analysis of social listening data using this approach could be helpful in:
 - Clarifying natural history of pericarditis
 - Filling gaps in the medical literature
 - Better understanding quality of life issues
 - Informing clinical trial design
 - Informing medical and support teams
 - Educating family members
 - Spreading awareness and advocacy
- Social listening data were collected from Global Pericarditis Support Group, a closed community for pericarditis patients and their caregivers on Facebook.
- TREND received permission from site administrators to access de-identified data.
- No group member names were included in the analysis.
- Data was analyzed using the TREND Community analytics engine.
 - The engine uses supervised learning and natural language processing techniques to identify disease burden and disease management concepts.
 - The engine tallies mentions of words and concepts (groups of highly-related terms, e.g., the concept "tired" includes counts of tired, fatigue, and fatigued).
- This social media listening method follows the FDA Guidelines for Patient-Focused Drug Development.⁵



RESULTS

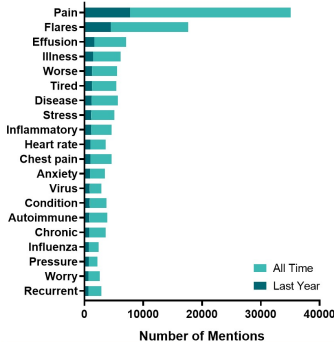
- Countries with the highest membership were the United States, United Kingdom, Australia, Canada, and Saudi Arabia
- 67% of participants were female, and 33% were male

Key Point

Pericarditis is a significant concern for people affected by pericarditis, and they seek a platform to share and exchange information about it with their peers.



Impact of Pericarditis on Patients



- Pain, including the words 'Pain' and 'Chest pain', was mentioned more frequently than any other word, highlighting the fact that pericarditis carries significant negative impact on the patient's life and is a regular topic in conversations
 - 27,319 mentions during the entire duration of time captured (November 19, 2012, to July 11, 2020)
 - 7,745 mentions during the last year (July 11, 2019, to Jul 11, 2020).
- Psychological impact, inferred from the use of words such as 'Stress', 'Anxiety', and 'Worry', also seems to be significant in these patients
- The words 'Recurrent', 'Autoimmune', 'Chronic', 'Inflammatory', and 'Flares' may indicate that patients are educating themselves on the nature of their disease and that pericarditis is a concern in this population

LIMITATIONS

- Data are not necessarily representative of all people living with pericarditis; limited to those who are literate, with social media access, and with the means, time, interest, and ability to participate.
- Honest representation by participants of their diagnosis, illness, symptoms, and disease progression is an assumption.
- The analysis does not account for context in which a term is mentioned; for example, the mention of a symptom could be in the context of not having the symptom at the time the comment is made.
- Social listening is a form of inductive qualitative research that is hypothesis-generating research as opposed to deductive hypothesis-testing research.⁶

ACKNOWLEDGEMENTS AND DISCLOSURES

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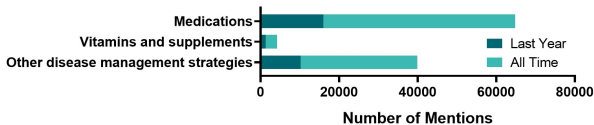
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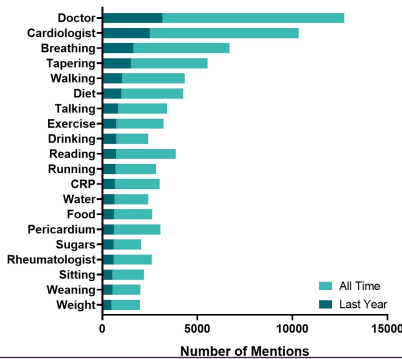
Disease Management

Based on number of mentions, management of pericarditis fell into 3 major categories:

- Medications (entire duration: 48761; last year: 16001),
- Vitamins and supplements (entire duration: 2905; last year: 1265)
- Other disease management strategies (entire duration: 29742; last year: 10168)



Additional Common Terms



- Commonly-mentioned terms suggest that patients may be seeking additional support from health care providers.
- Frequent mentions of "walking", "running", and "diet" are indicative of potential impact of pericarditis on patient quality of life, including impact of the disease by imposing physical limitations.

CONCLUSIONS

- This analysis brings further understanding of the impact of pericarditis on patients' lives and highlights the richness of the conversations shared between community members:
 - Pain, psychological impact, and discussion about the nature of pericarditis seem to be prominent.
- Particularly in the context of rare disease, where real-world information is often limited, the ability to interrogate social media conversation data can be valuable to:
 - Patients and their caregivers
 - Physicians
 - Researchers
 - Pharmaceutical developers
- Patients may be seeking avenues for communication about their pericardial disease due to a deficiency in resources for information; this may point to a disparate level of care and disease management across the globe.