



# Evaluation of the Experiences and Challenges of Patients with Vertigo: A Social Media Listening Infodemiology Study

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## ABSTRACT

Vertigo is a common presentation in clinical practice. Treatment of vertigo also poses its own subset of challenges to the clinicians. Patients often have recurrent attacks of vertigo regardless of the medications. The current digital era has completely transformed the practice of medicine. Patients are increasingly using online platforms to discuss their medical conditions, with peers as well as experts.

### Aim

- To use social media-based feeds to assess patient experiences, patient knowledge about causes/triggers and treatment options of vertigo.
- To gain insights into common queries and misconceptions patients have regarding vertigo.
- To address insights gained from social media-based feeds to map a more effective and informative treatment approach to vertigo in Indian patients.

**Methodology:** A universe of key words was curated around Vertigo. Using an enterprise grade social listening tool (Brand watch), a comprehensive search around these keywords was conducted across diverse open social media platforms. These key words were used to gain insights from social media conversations from Twitter, YouTube, Facebook, Instagram, Forums and Blogs. Conversations in English and 9 other regional languages (Hindi, Tamil, Telugu, Kannada, Malayalam, Gujarati, Punjabi, Marathi and Bengali) were analyzed during the time period: June 2020-May 2022.

**Result:** Twitter was the most used platform for vertigo sufferers (51%), where they sought advice and shared their experiences related to dizziness and its treatments. Medical forums were used by sufferers (46%) to seek HCP advice and validate the medications prescribed by their treating doctor. YouTube was used by sufferers to ask queries about their treatments and disease management. The top 4 queries were about treatment options and specialist of vertigo, symptoms of vertigo, diagnosis of vertigo and triggers of vertigo. Users also had questions regarding treatment options for vertigo, efficacy of treatment options of vertigo.

**Conclusion:** In-depth analysis of the increasing interactions of patients with vertigo and diverse healthcare specialists on social media platforms can provide helpful insights and improve the balance between patient expectations from their physicians and the treatment plans offered to them. This could result in improved adherence to treatment to effective anti-vertigo drugs.

**Key Words:** Vertigo, Social media

## Introduction

Vertigo is a common presentation in clinical practice. Vertigo is an abnormal sensation of motion caused by a mismatch between various sensory modalities involved in maintaining balance. Vertigo could be due to central or peripheral causes. Vertigo can be intensely debilitating for some patients [1]. The most common vestibular syndromes associated with vertigo include Vestibular Neuronitis (VN),

Meniere's Disease (MD) and Benign Paroxysmal Positional Vertigo (BPPV) [2]. Arriving at the diagnosis of vertigo by taking cues from the clinical symptomatology of the patient and the prudent use of investigations can guide clinicians in the diagnosis and management of their patients with vertigo. Treatment of vertigo also poses its own subset of challenges to the clinicians. Patients often have recurrent attacks of vertigo regardless of the medications. The mismatch between the treatment

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and patient expectations and perceptions are an uphill and daunting task faced by clinicians.

It would provide great insights to clinicians if they were to understand patients' lived experiences and journey navigating the burden of condition such as Vertigo.

Patients often face anxiety about needing to take long-term medication to manage symptoms. Recurrence of symptoms leads to poor adherence to treatment and thus the vicious cycle of recurrent attacks and poor adherence sets in. Patients then seek answers for their queries regarding vertigo from online platforms such as YouTube, Google, Twitter, Facebook, among others to seek advice regarding the diagnosis, management of Vertigo. This leads to self-treatment without doctor visits.

The current digital era has completely transformed the practice of medicine. Patients are increasingly using online platforms to discuss their medical conditions, with peers as well as experts. This provides access to large volumes of spontaneous/unprompted conversations, which we can analyze to understand their genuine opinions, emotions concerns, fears as they progress in their journey from diagnosis to treatment to managing the condition. Complementing the erstwhile research methodologies of surveys, post marketing surveillance-based experience, Social Media Listening (SML) studies offer a novel approach to understand the voice of patients and caregivers. With the use of appropriate technology and methodology, we can translate social media-based data collected into scientific information and derive insights into patient perceptions; experiences, expectations, challenges as well as HCP based insights into treatment, adverse effects of drugs and patient counselling [3]. The current study is a new age study utilizing data about vertigo collected from diverse online platforms to gain insights into patient perceptions, disease burden, and challenges in day-to-day life when dealing with vertigo treatments. The conversations between Health Care Professionals (HCPs), caregivers, and patients of vertigo can give further insights into the way ahead in the diagnosis and management of vertigo which is closer to fulfilling patient expectations and increase patient awareness about vertigo.

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### Objectives

- To use social media-based feeds to assess patient experiences, patient knowledge about causes/triggers and treatment options of vertigo.

- To gain insights into common queries and misconceptions patients have regarding vertigo.
- To address insights gained from social media-based feeds to map a more effective and informative treatment approach to vertigo in Indian patients.

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### Methodology

#### ■ Study design and data source

A universe of key words was curated around vertigo. Using an enterprise grade social listening tool (Brand watch), a comprehensive search around these keywords was conducted across diverse open social media platforms. These key words were used to gain insights from social media conversations from Twitter, YouTube, Facebook, Instagram, Forums and Blogs. Conversations in English and 9 other regional languages (Hindi, Tamil, Telugu, Kannada, Malayalam, Gujarati, Punjabi, Marathi and Bengali) were analyzed during the time period: June 2020-May 2022. These feeds were augmented with e-commerce reviews, desk research and relevant Google search analytics. Secondly, wherever possible Influencers (those with minimum 1000 followers, who post regular content) were identified from YouTube, Instagram and Facebook.

#### ■ Data clean-up

The dataset was filtered in order to ensure that the most representative data – that of patients and caregivers is analysed. These were then manually analysed by SML and life sciences experts to answer the study objectives.

#### ■ Ethical considerations

The data in this study was collected from open social media platforms that are accessible to the public and in compliance with data protection laws. All data in this study is aggregated and anonymized and does not include any Personally Identifiable (PII) or Personal Health Information (PHI).

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### Result

In the two-year timeline, roughly 6,900 posts were collected. There were 4,353 conversations on vertigo.

#### ■ Platform insights

This study brought to light how different online platforms cater to the different needs of patients and caregivers. Twitter was the most used platform for vertigo sufferers (51%), where they sought advice

and shared their experiences related to dizziness and its treatments. Medical forums were used by sufferers (46%) to seek HCP advice and validate the medications prescribed by their treating doctor. YouTube was used by sufferers to ask queries about their treatments and disease management. They also sought information about exercises done for vertigo and how this disorder is treated. Instagram and Facebook offered informational posts by influencers discussing vertigo symptoms, causes, diagnosis and treatment (mostly exercises and lifestyle changes). In select cases, blogs were used by vertigo sufferers to share informational posts and their personal experiences related to being diagnosed and treated for vertigo.

### ■ Google search insights

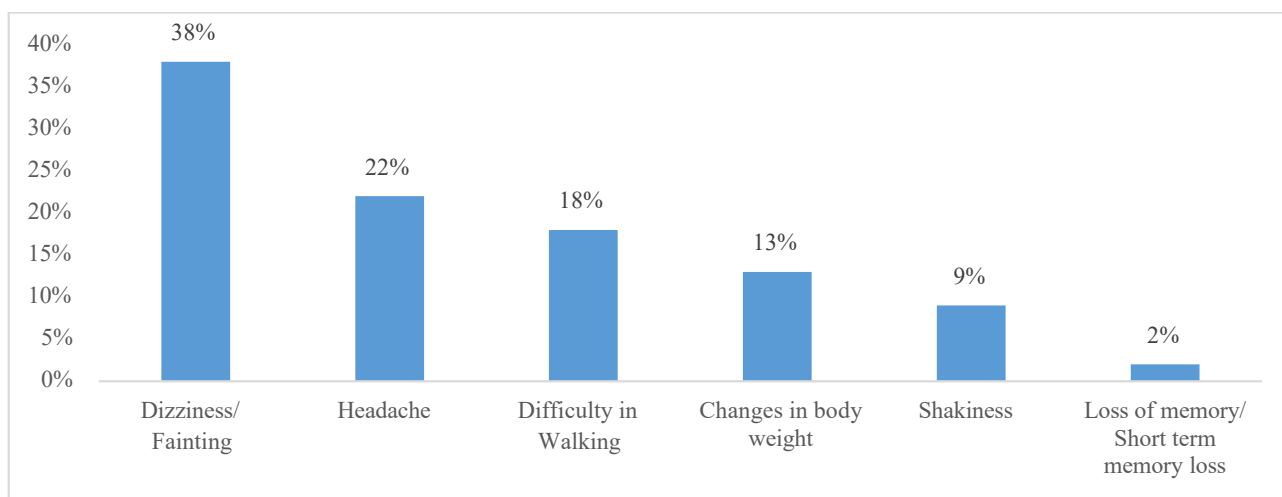
Analysis of the Google search keywords indicated that amongst Vertigo-related disorders, Meniere's disease and BPPV were the most searched (10,000 to 100,000 monthly searches). 51% people wanted to understand more about the disease, its cause

and diagnosis. Amongst symptoms, one of the most searched key words was dizziness (10,000 to 100,000). The key words most searched for pain association were neck pain and ear pain (100 to 1000) and for the treatment domain the most searched keyword was vertigo treatment (1000 to 10,000)

English was the predominant language (78%) followed by Gujarati (17%), Hindi (2%), Malayalam (1%) and others (2%). The top three regions were Gujrat (28%), Maharashtra (20%) and Delhi (12%).

### ■ Demographic features

Primarily middle-aged adults (54%), teenagers and kids (27%), elderly patients (19%) asked queries related to vertigo symptoms on online healthcare platforms to get a second opinion on the condition. A female predominance (65% vs. 35%) was observed (Figure 1).



**Figure 1:** Symptomatic Burden of Vertigo as reported by sufferers/caregivers. n =2,000

### ■ Patient interactions regarding vertigo

Users were commonly concerned about their symptoms of vertigo. Users shared posts about vertigo symptoms such as nausea, dizziness and vomiting. They shared experiences about vertigo such as onset of vertigo in college, vertigo in diabetic parent. Dizziness and nausea were the most mentioned symptoms by patients. Posts also mentioned tinnitus and headache. The symptoms of dizziness, headaches and issues with mobility, impacted the patients' quality of life, hindering their daily activities. Patients mentioned restricting themselves from traveling, joy rides, and other activities as precautionary

measures to avoid triggering vertigo.

### ■ Patient discussions about triggers of vertigo

Ear infection/Diseases, BPPV, Tinnitus, and Hypertension were among the major triggers of vertigo that negatively impacted sufferers.

Users shared posts about vertigo, its causes, and triggers of vertigo. The triggers mentioned included menses, neck spasms, high altitude, etc. Lack of adequate sleep was a commonly reported trigger of vertigo by users.

■ Patient discussions about questions about vertigo

People had queries about signs and symptoms of vertigo, treatment of vertigo, and the impact on emotional QoL due to the imminent worry of triggering vertigo.

Patients were concerned about the health implications of vertigo. Some users had queries regarding whether vertigo was due to their comorbid diseases such as diabetes, hypertension, and cervical spondylosis. Users had questions about the difference between vertigo and dizziness. Some users shared educational and research articles on vertigo to help other users to find answers to their queries. Multiple articles about celebrities who shared their experiences with vertigo and their treatment choices were observed. Queries posted included whether change of country or altitude during flying would relieve vertigo or aggravate vertigo. Users had queries whether the motion sickness they experienced while taking a boat ride was vertigo.

■ Patient discussions about vertigo treatment

The top 4 queries were about treatment options and specialist of vertigo, symptoms of vertigo, diagnosis of vertigo and triggers of vertigo. Users also had questions regarding treatment options for vertigo, efficacy of treatment options of vertigo. Some of the users, suggested names of experts treating vertigo. Users also shared their experience with the treatment options of vertigo including medications and man oeuvres they performed under expert guidance. The role of

exercises like Epley’s performed by the specialist was mentioned by some users.

Patients mentioned their treatment options and shared their treatment experiences with the same. They sought advice from online peers and physicians on pharmacological and non-pharmacological options for the treatment and management of vertigo. Patients with vertigo described their physician visits and shared details about the prescribed diagnostic tests. Some mentioned seeking HCPs (Health Care Practitioners) such as neurologists and ENTs. While most patients mentioned in-person consultations, a few described online appointments. Few patients shared their experiences and motivated online peers to consult HCPs.

■ Patient discussions on key challenges and impact of vertigo on quality of life

Patients with vertigo shared the physical and emotional distress they experienced due to vertigo. Misdiagnosis and delay in diagnosis about the cause of vertigo was a trending topic of discussion between sufferers of vertigo on diverse forums. The challenge of recurrent episodes of vertigo, and the absence of a cure for vertigo were distressing for the patients of vertigo. Patients with vertigo cited adverse effects as the most common reason for discontinuation of treatment. Patients were unhappy about the adverse impact of vertigo on their quality of life. They mentioned that vertigo hindered their work, travel and had an overall negative impact on their quality of life (Figure 2).

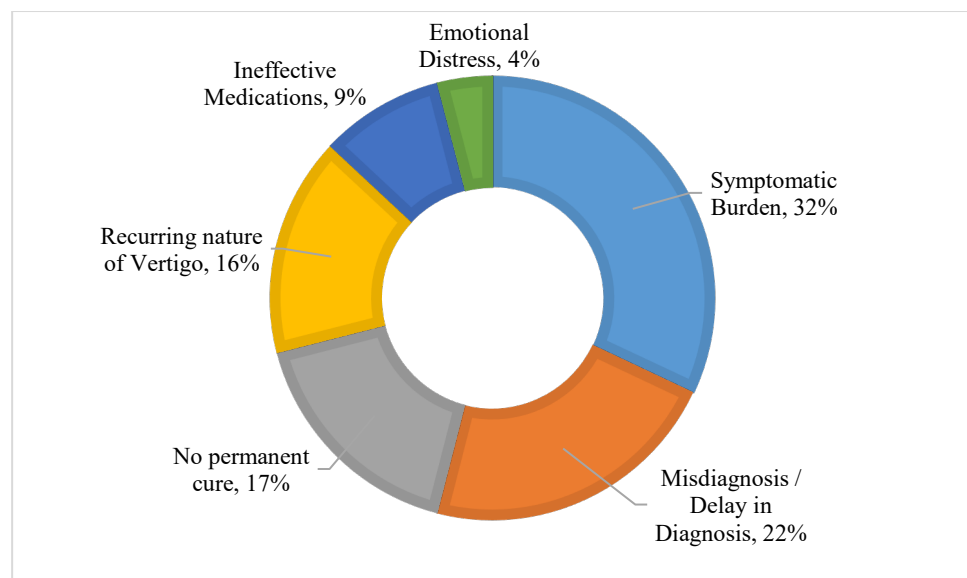


Figure 2: Common struggles and concerns reported by Vertigo sufferers and caregivers n=178

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## Discussion

This infodemiological study provided real-time, dynamic information from vertigo sufferers about their symptoms, severity, frequency, times of the day, and use of pharmaceutical and nonpharmaceutical treatment patterns. The knowledge, attitude, and practice patterns amongst Indian vertigo patients are inadequate, highlighting the need for awareness and scientific education among these patients in India. Moreover, healthcare providers should be trained to provide counselling to these patients effectively [4].

Patients are now turning to social media as an instant source of information about vertigo, symptoms, causes, treatments available, and side effects of the drugs they have been prescribed. When patients read about other people suffering from vertigo, they feel they are not alone in their journey of vertigo and may have reduced anxiety related to their vertigo. The role of physicians, specialists, and influencers in these forums cannot be undermined. They can provide more validated opinions about the diagnosis and treatment to the patient of vertigo and can build confidence of the patients in the treatment plan they have been prescribed. This improved patient confidence would translate into improved patient adherence to treatment and improved outcomes of treatment. Social media listening offers a better understanding of patient awareness about vertigo, patient perceptions about vertigo, and their expectations about the treatment and their physician.

The current analysis indicated that patients are unaware of the causes of vertigo. They are actively seeking information about triggers of vertigo, diagnostic tests, and treatment options. They want to be reassured that vertigo is a treatable condition with lifestyle changes and drug treatment. Patients need reassurance about the good results with drug, exercise, and low incidence of side effects. These insights can help overcome the mismatch between patient fears and expectations and the medical fraternity treating patients of vertigo. Counselling of patients will help allay the fears of the patients and improve adherence to maneuvers and drug therapy.

Vertigo continues to be a challenge to treat in Indian patients. Drugs and man oeuvres are commonly used to treat vertigo [5-15]. Prudent counselling of the patients using available resources and new technology and online

platforms can improve outcomes of treatment by improving patient adherence to treatment.

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## Conclusion

Vertigo is a common presentation in clinical practice. The knowledge and adherence regarding vertigo amongst vertigo patients are inadequate in India. In-depth analysis of the increasing interactions of patients with vertigo and diverse healthcare specialists on social media platforms can provide helpful insights and improve the balance between patient expectations from their physicians and the treatment plans offered to them. This could result in improved adherence to treatment to effective anti-vertigo drugs.

Recurrence of vertigo attacks, self-medication and not visiting HCPs are common themes emerging from patient and caregiver conversations online and HCPs need to take this into consideration in their interactions with sufferer's in-clinic. Healthcare specialists can take cues from the insights gained from patient interactions on online platforms to improve their counselling of patients of vertigo and can improve patient adherence to therapy.

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## Limitations

Only publicly available information has been accessed and used for the analysis. Channels that are not publicly available are not included in the research. This may lead to lower conversation volumes than actuals.

The main limitations of SML are related to the quality and reliability of the conversations, which may affect accuracy. We cannot confirm with certainty whether all patients have clinically verified diagnoses or are self-diagnosed. Another limitation is that not all patients are equally likely to write about their medical experiences online. As a result, we may only have the opportunity to view and analyze the experiences of a certain segment of the population.

Social Media usage across the country also varies, and this could impact the representative

population which is discussing Vertigo online.

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### Conflict of Interest

None declared.

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