

Patient Experiences and Insights on Chronic Ocular Pain from a Social Media Listening Study

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Financial Disclosures

Kashish Goel, Nikita Parashar, Sathyaraj Aasaithambi, Himanshu Verma are employees of Novartis Healthcare Pvt. Ltd.

Paul O'Brien is an employee of Novartis Ireland Ltd.

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Introduction

- Ocular pain has multifactorial aetiologies and affects daily activities and psychological well-being having a large impact on patients' health related quality of life^[1]
- Chronic ocular pain (COP) is a persistent eye pain symptom lasting for a period longer than 3 months^[2-3]
- Damage to the ocular surface or changes to peripheral or central nerves in the ocular surface sensory pathway may result in ocular surface pain ^[1]
- There is a paucity of data on the disease characteristics, the underlying causes, management and overall impact on quality of life (QoL) of COP

COP, Chronic ocular pain; QoL, Quality of life.

References:

1. Mehra D, Cohen NK, Galor A. Ocular Surface Pain: A Narrative Review. *Ophthalmol Ther*. 2020 Sep;9(3):1-21. doi: 10.1007/s40123-020-00263-9. Epub 2020 Jun 5.
2. Galor A, Levitt RC, Felix ER, Martin ER, Sarantopoulos CD. Neuropathic ocular pain: an important yet undervalued feature of dry eye. *Eye (London, England)*. 2015;29(3):301-12. 2.
3. Yamanishi R, Uchino M, Kawashima M, Uchino Y, Yokoi N, Tsubota K. Characteristics of Individuals with Dry Eye Symptoms Without Clinical Diagnosis: Analysis of a Web-Based Survey. *J Clin Med*. 2019;8(5):721.

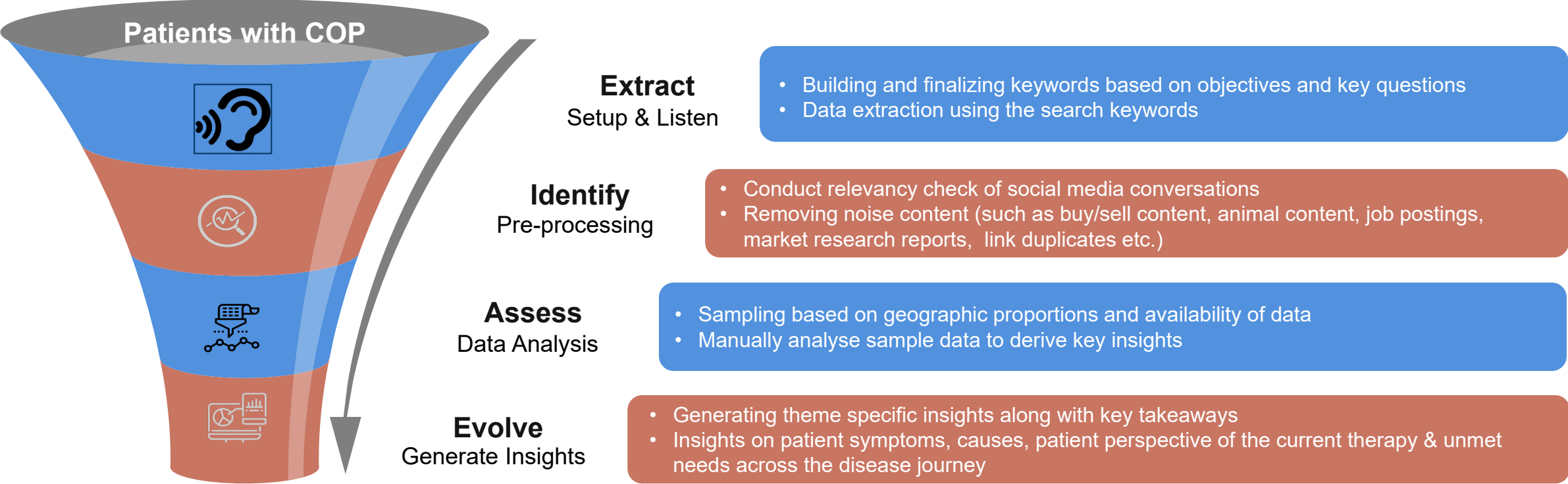
Objective

The objective of this social media listening study was to better understand COP and related symptoms, identify the perceived causes and comorbidities, its impact on QoL and understand the patient journey from social media posts

Key questions on COP

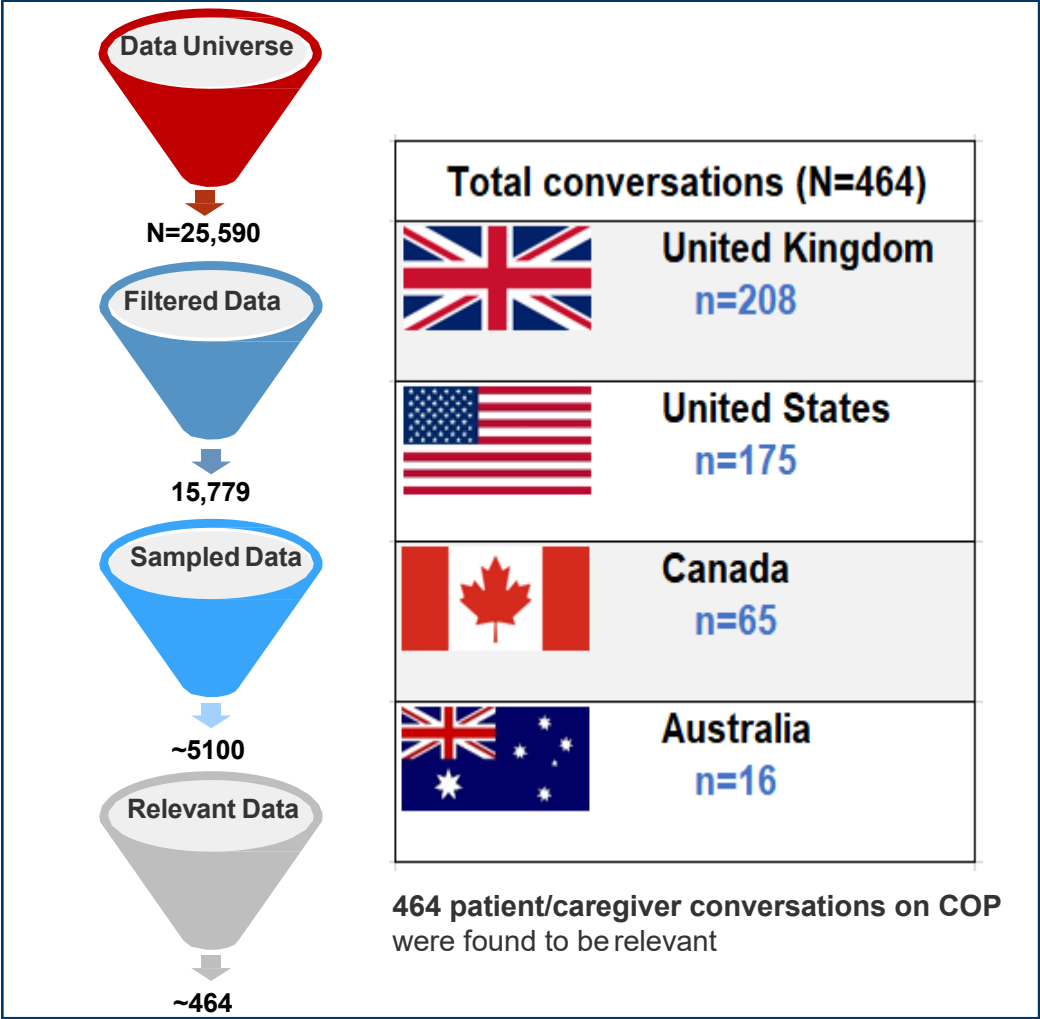
Categories (themes of Conversations)	Questions (What are the top themes of conversation?)
Demographics	Who are the active online segment in the disease area ? What is the social landscape of patient demographics?
Aetiological factors for COP	What are the perceived causes of COP?
Health-Related Quality of Life (QoL)	What do patients and caregivers report about the impact of the disease/condition on their QoL (physical, emotional, functional and social impact of COP)?
Disease Management	What do patients do beyond medical treatment to manage their condition? How do patients cope with their disease? E.g., Peer support on online forums, educational/informational websites etc.
Unmet Needs and Concerns	What are the reported unmet needs and concerns by patients and caregivers?

Project Methodology



Social Media Volume Analysis

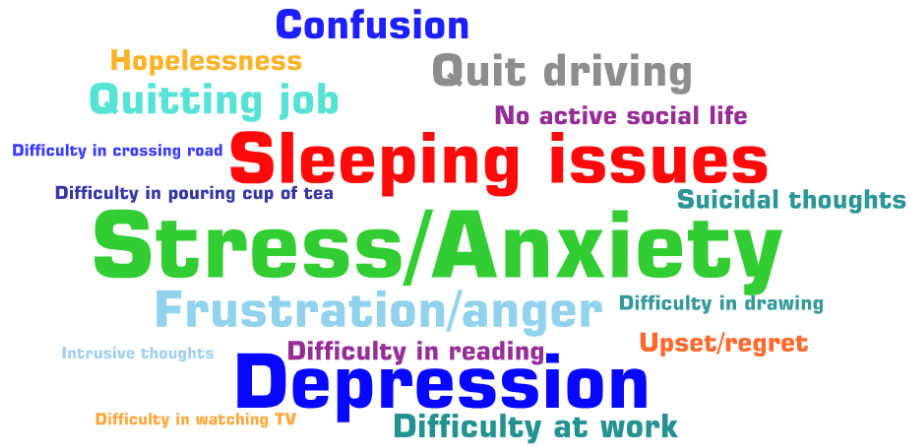
Data curation and conversations analyzed



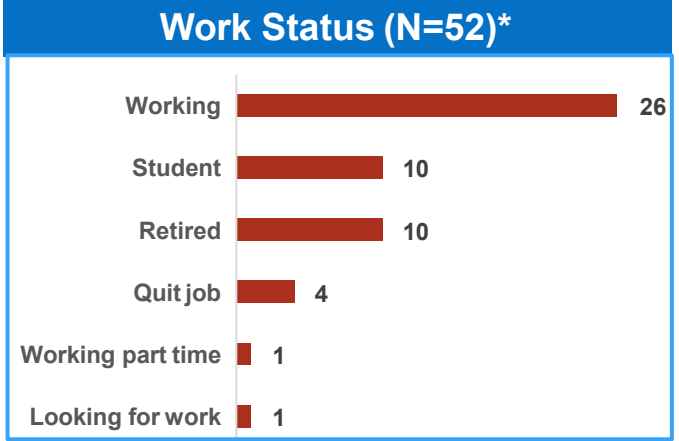
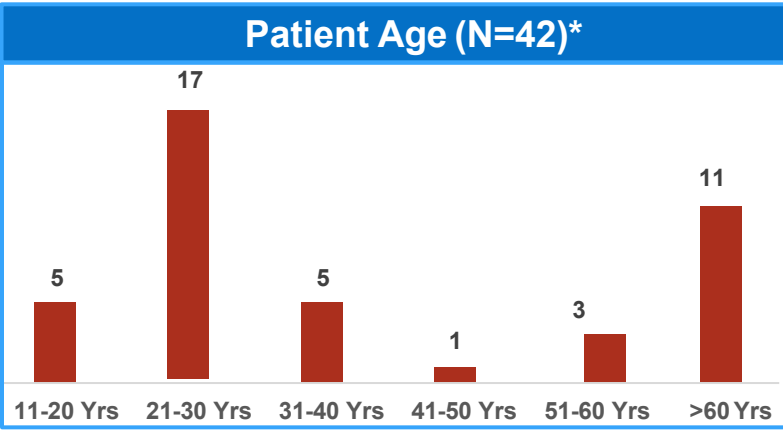
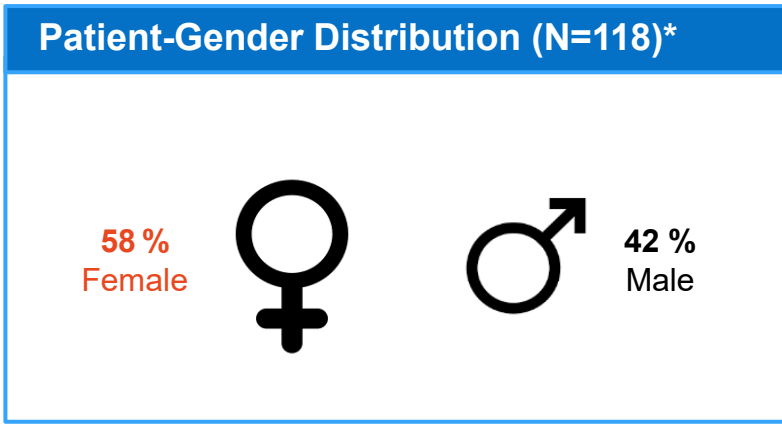
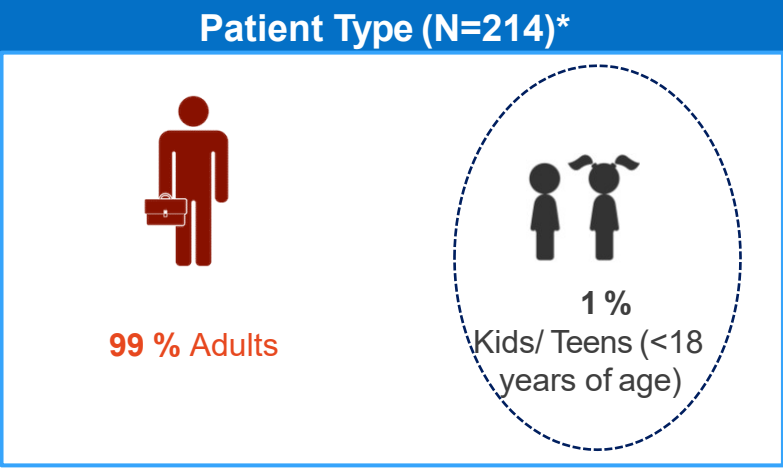
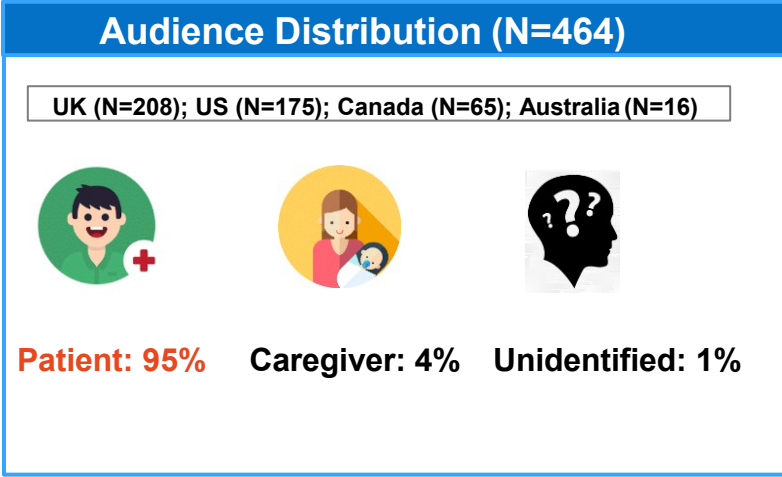
COP symptoms - Word Cloud



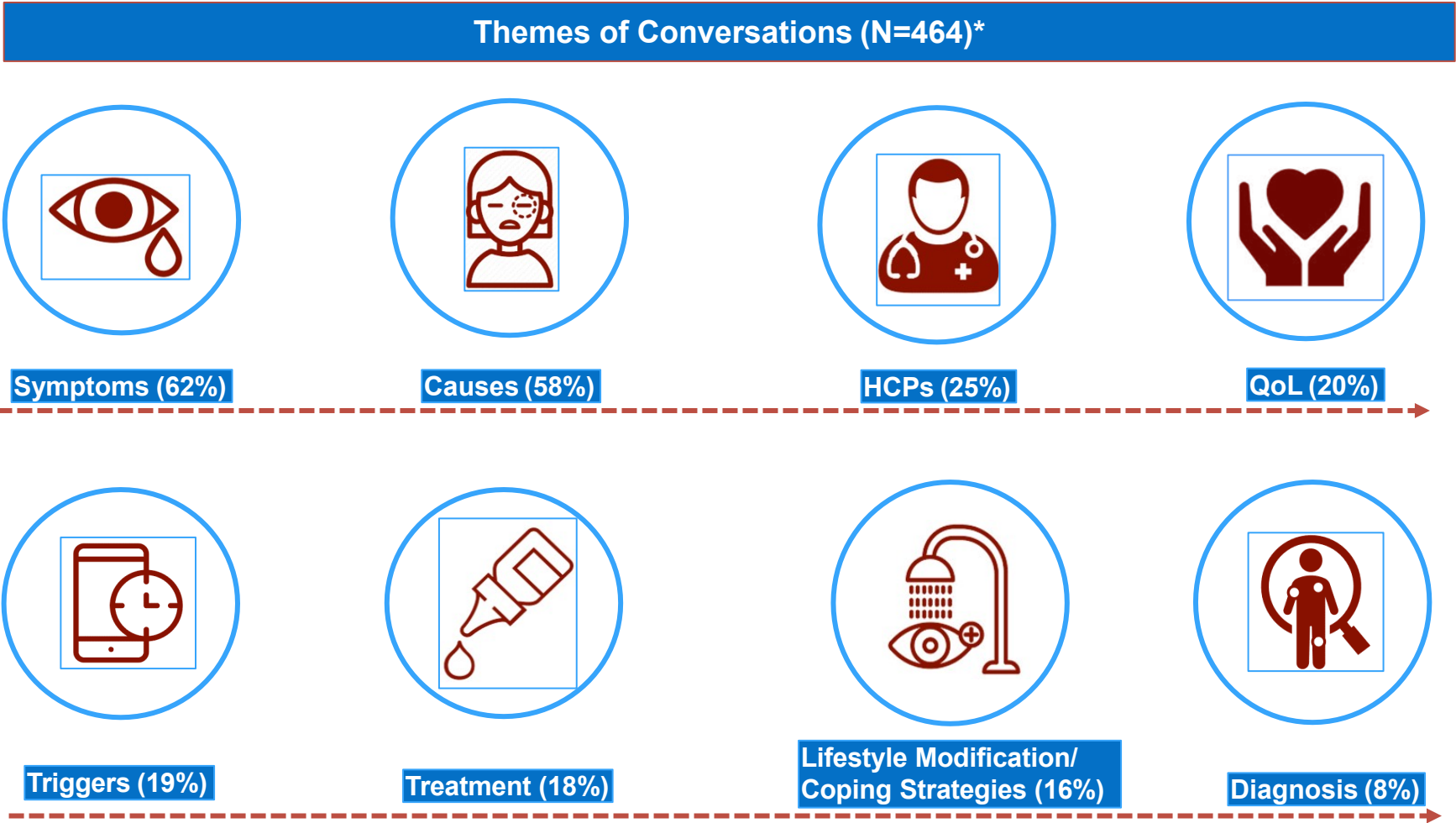
Patient burden - Word Cloud



Majority of the conversations on COP were from patients. Adult patients are actively sharing their experiences with eye pain; some conversations mentioned the patients age and work status

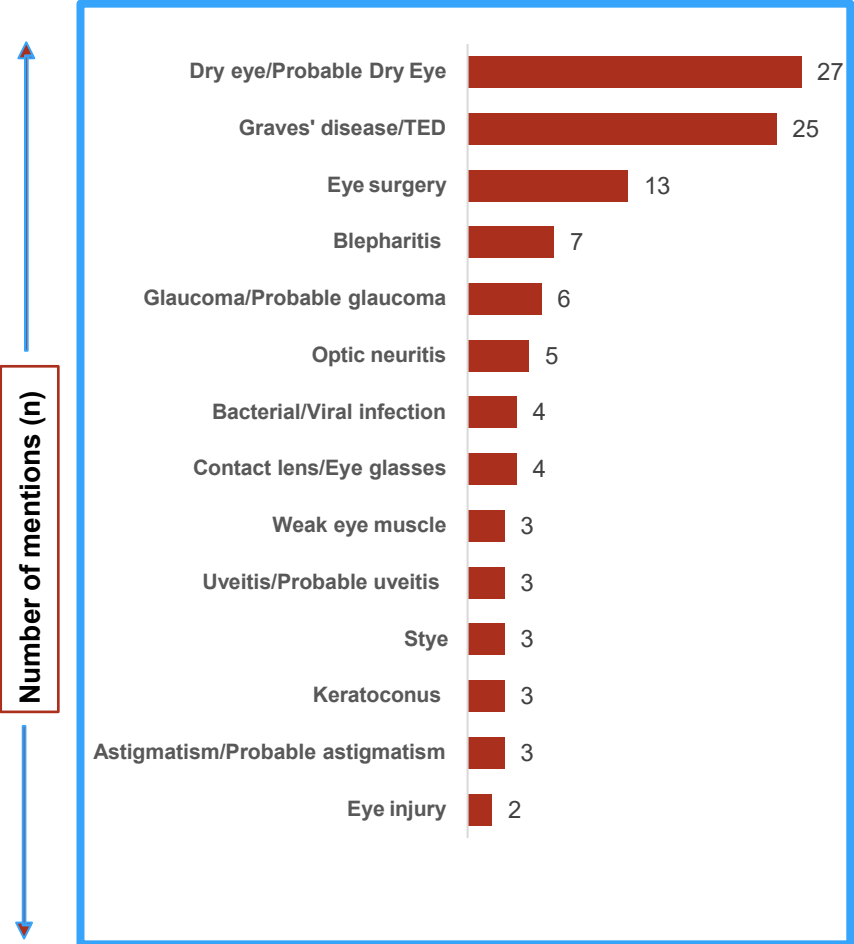


Patients/caregivers discussions across social media platforms were primarily around the symptoms (62%) and causes (58%) of eye pain



Ocular conditions contribute to ~46% of the causes of COP mentioned by patients; dry eye disease and Graves' disease were the most frequently cited causes

Types of ocular causes with multiple mentions=14



Verbatims

Just found out that my shooting eye pain is a mix of
”

“I have chronic eye pain due to weak eye muscles,
hypersensitivity to light, and ;”

“When your eyes are sensitive to light and cause migraines, but
you also can't see well in the dark either. Just being able to see is
a balance between pain and necessity #”

“Eye specialist diagnosed a lazy eye in childhood,
later. Kept going back to Dr with eye pain”

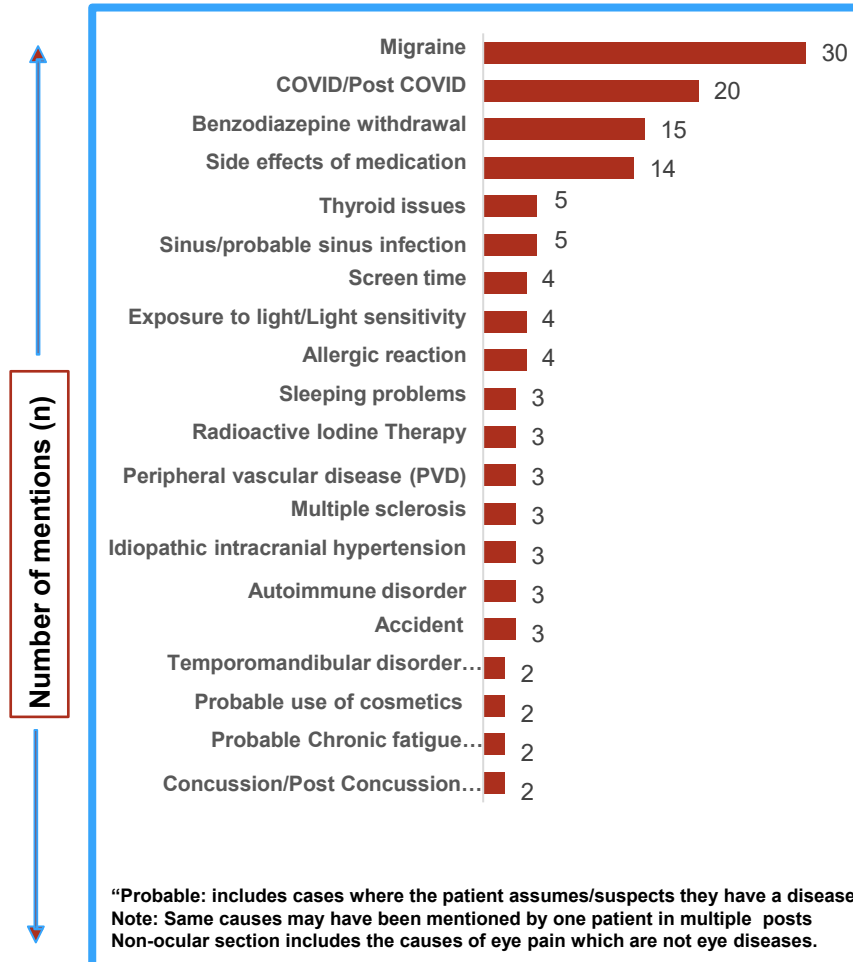
““I had in 1990, 4 days after my eldest son started
school. It left me with hemeralopia/photophobia, eye pain is not
nice.”

“I have chronic eye pain from nerve damage in my eyes as a
result of ”

“I'm bored of having a now like. My doctor
warned me about this years ago.”

Non-ocular conditions contribute to ~54% of the causes of COP mentioned by patients; migraine and COVID were commonly cited causes

Types of non-ocular causes with multiple mentions=20



Verbatims

“Anyone else get like 1-2 a year that start off with blurry vision then transform into total head pain, eye pain and neck pain then throwing up. “

“I can't do the things I love most because of #My eye pain only goes away if I look down at the floor”

“Even on and saline rinses my right maxillary sinus is swollen and not happy. Everything is right sided — I get pain in my top teeth, pain behind my eye, pain in my temple but also in other parts of my head”

“At my first appointment with the rheumatologist, I told him that I probably had . He raised his eyebrows at my self-diagnosis, did the blood work, and agreed with it.....Ongoing issues include: GERD and other digestive troubles, overall dryness, eye pain”-

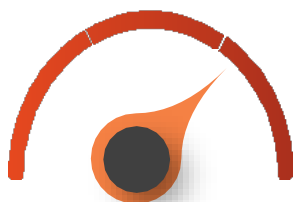
““I'm really ok until I try reading on and then I'm screwed ”

“I pushed myself and worked all day and didn't stop working when the ”

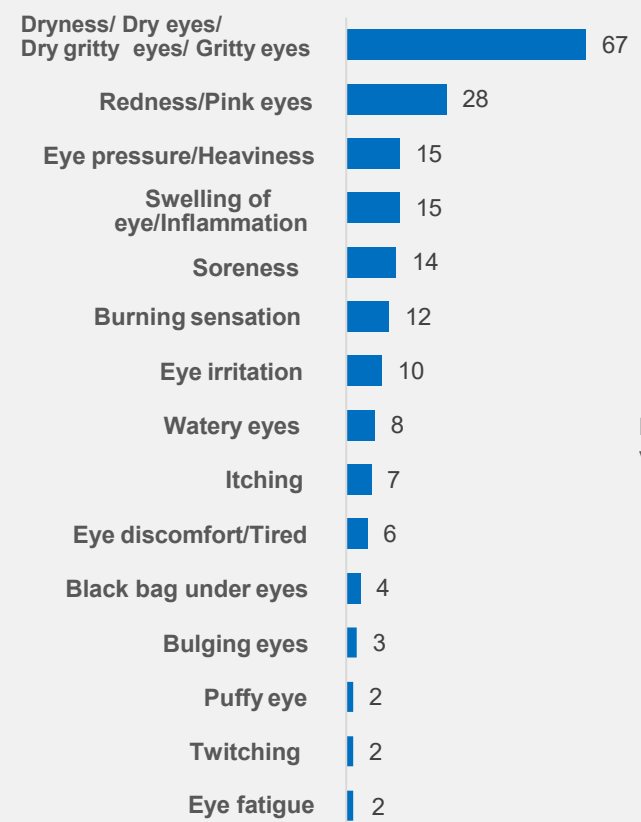
“I'm , so I'll not be around as much”

Patients mentioned suffering from an array of symptoms associated with COP; some of the commonly mentioned symptoms were headache/head pressures, dry/gritty eyes, light sensitivity etc.

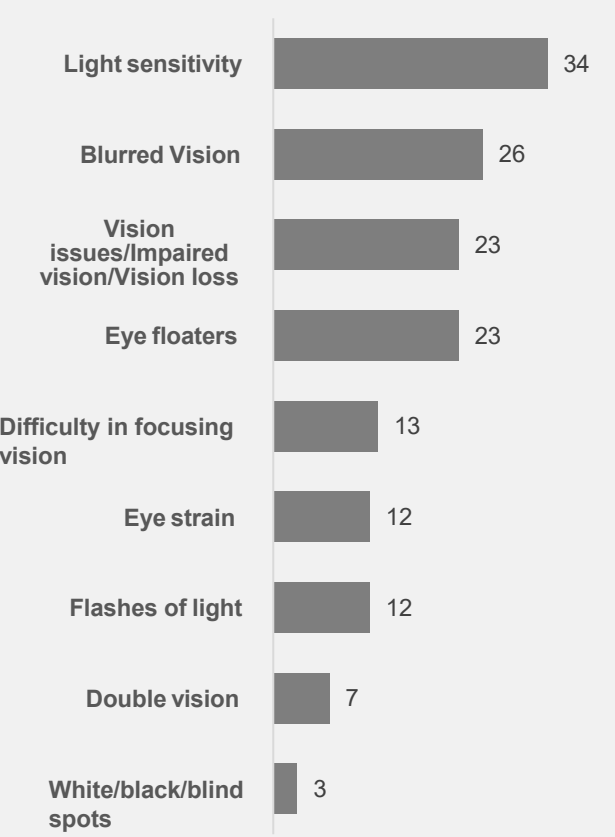
Severity of Symptoms (N=261)



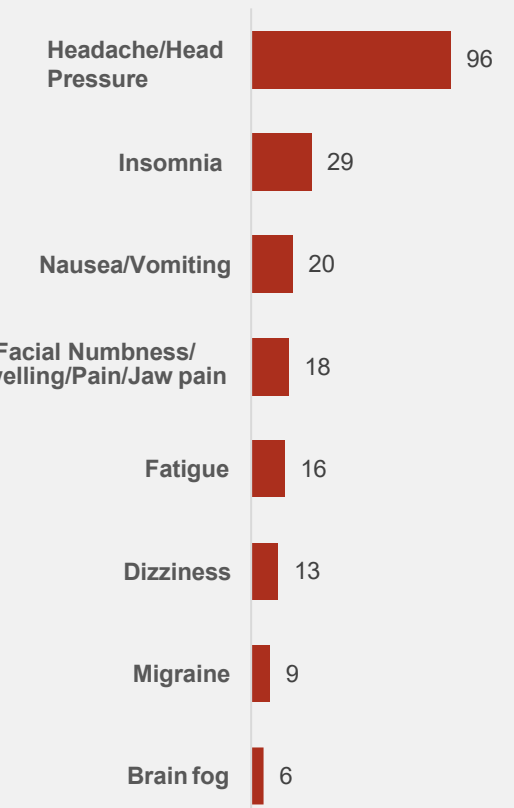
Eye Pain-Related Symptoms (n=195)



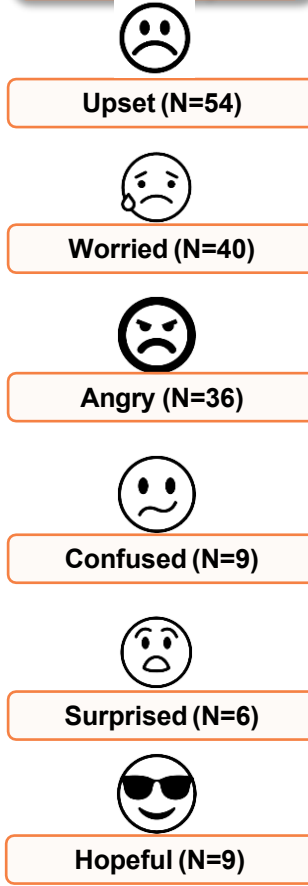
Vision-Related Symptoms (n=153)



Physical Symptoms (n=207)



Emotions Related to Symptoms (N=154)



N=Indicates number of conversations;
n=Indicates total number of mentions
Note: Symptoms could be associated with eye pain or the originator condition; most of the conversations do not provide clarity on this
Note: One patient may have reported more than one symptom



Patients/Caregivers Verbatims

Severity Related Verbatims

High Severity

"Constant pain in eye, rubbing tears, Headach,ear ache, and pain in ribs of nose and throat pain like some one is scraping in my throat with knife, Drs are not able to find out cause and"

"like im sure being blind has its own huge issues. and migraines"

"My eye pain is the when I can't control the smells that trigger it! Weather plays a big part and sadly I can't control that I also get floaters, can't focus them probably & blurry! So much Fun"

Moderate-Low Severity

"I . The Eye Hospital where I was sent several years ago told me the danger signs to look out for and that these could come on at anytime. Many people have floaters have floaters for decades and they are causing no harm whatsoever."

"I had but nothing else in relation to it and then after 6 months most of my eye pain stopped and my neck pain began. Thank you for your help!."

"To be honest the , I don't even take any painkillers for it, but it's somewhat anxiety-inducing to not know what it is even if it's nothing serious - so I was wondering if I should try something else;"

Emotions Related Verbatims

Angry

"Cant wait for work to end so i can go to my eye exam and maybe figure out why myeyes ache all the time. :/"

"The f**k am I getting a radon eye pain I havnt gotten one of those in so long and I do not miss the feeling s**t hurted"

Upset

"Between a full time job and being a student, spending all hours in front of a screen, my poor eyes are exhausted."

"Headache pain, eye pain, nausea, and general PAIN. Today is one of those days and it's laying me out flat good lord"

Confused

"My migraines are usually crushing pain in my right eye accompanied by nausea, but once in middle school during class I developed a giant blind spot right in the middle of my vision and it was the scariest thing to experience especially with no idea what was happening"

Worried

"I've really had eye pain and headaches for like a year now. Ya think I should go to the dr or just look it up on google?"

Surprised

"its interesting you have pain too though. why they say theres no pain with PVD is baffling me as you're the third or fourth to say it too now. I'll let you know my findings again here when I go to my docs."

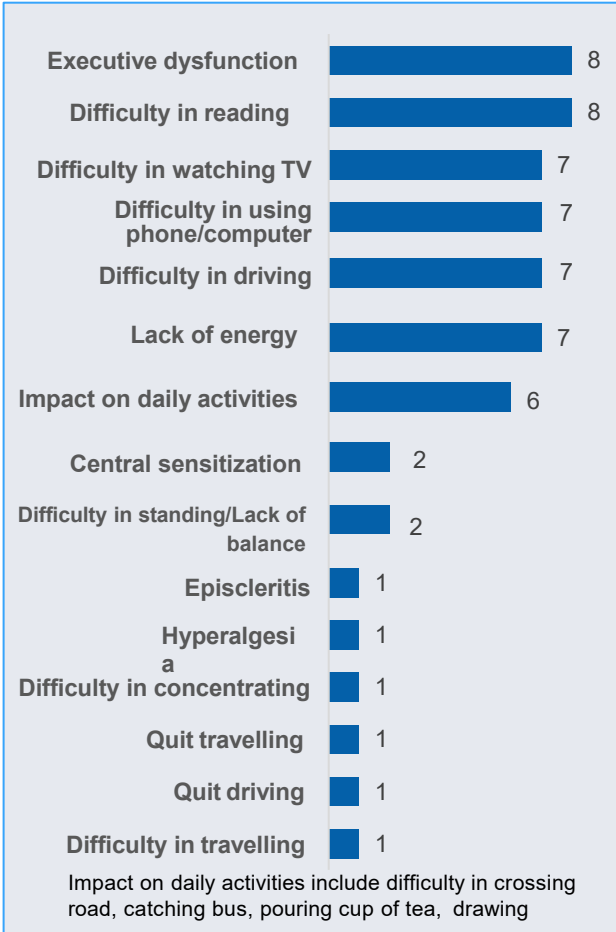
Hopeful

"Three months into therapy, I'm averaging 8-12 hours a day looking at screens with very little pain/strain."



Patients posted that their COP impacts day-to-day activities such as reading, driving, sleeping; it also affects their social, mental and functional well being

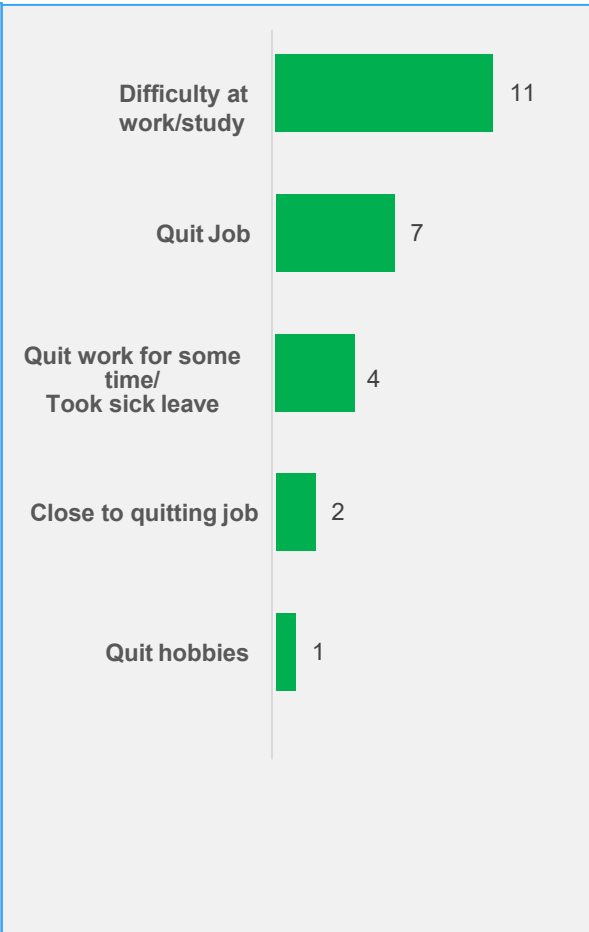
Physical Impact (n=65)



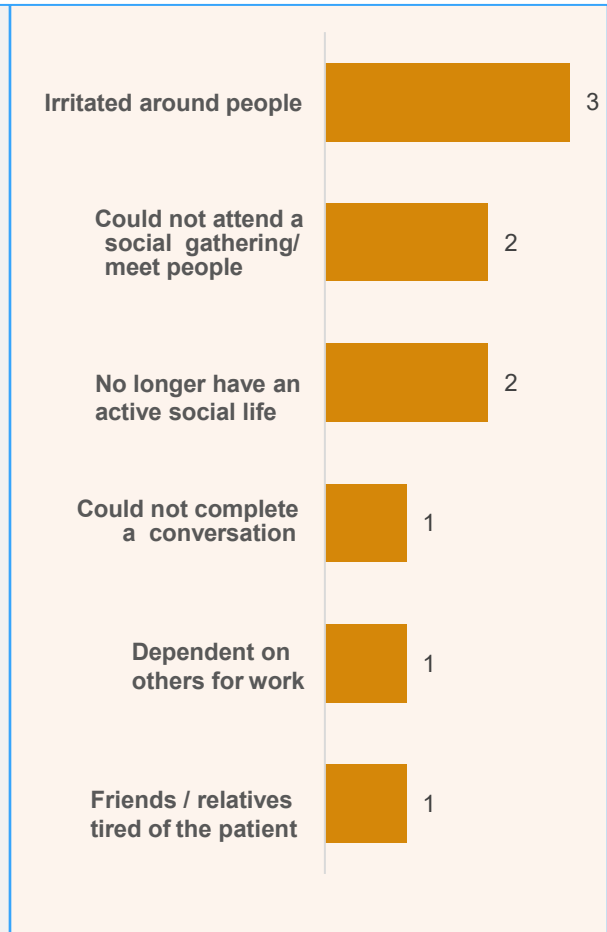
Emotional Impact (n=59)



Functional Impact (n=25)



Social Impact (n=10)



Patients/Caregivers Verbatims

Physical Impact

"I could not read watch television and ..."

"before the disruption to executive function from eye pain triggers and ramps up... so I"

"the eye pain I have prevents me from aiming [via executive dysfunction], to hit any mark more than a moment ahead of me"

"She had to learn to accept her new limitations, learn ... She had to discard her cherished collection of high heels and farewell her books."

"I don't know what to do anymore. Always tired, always in ... , always ..."

"I ... during flare ups to begin with, and staring at ... can cause some ... ! Basically, I've learned to just accept and live with it, and I know now that when it crops up,"

Emotional Impact

"I woke up crying todaythat I'm finding it ... , I find it difficult to wake up. It frustrates me. It confuses me and infuriates me."

"I have endured eye pain and light sensitivity, insomnia to the point ..."

"I did not have Depression or anxiety but was getting ... because of my symptoms and the fact that no one would listen to me or take it seriously when I told them how I felt!"

"I've been very ... since the mention of dissections because all of this eye and neck pain has been going on since 2018 and literally disabled me"

"its making me ... sick again can someone shed some light on what this could be, my main concern is the black dots and weird colours now"

Functional Impact

"Light exposure = eye pain .."

"I've ... a few times but not due to wd. The ... and brain fog, and eye pain were so bad this month I but I hope they're over now."

"I'm close to ... job because it is so embarrassing walking in everyday with bloodshot eyes and people asking me if its pink eye. Any advice?"

"I have use ... in the day sofight my way onto the lab schedule at times I could work when eye pain would be at it's lowest"

"Chronic is right. It took 8 months for the headaches and eye pain to start. Without real changes, we'll start to see ... etc."

"I've had dry eyes pretty bad now that im over 40 and ive ... as a result"

Social Impact

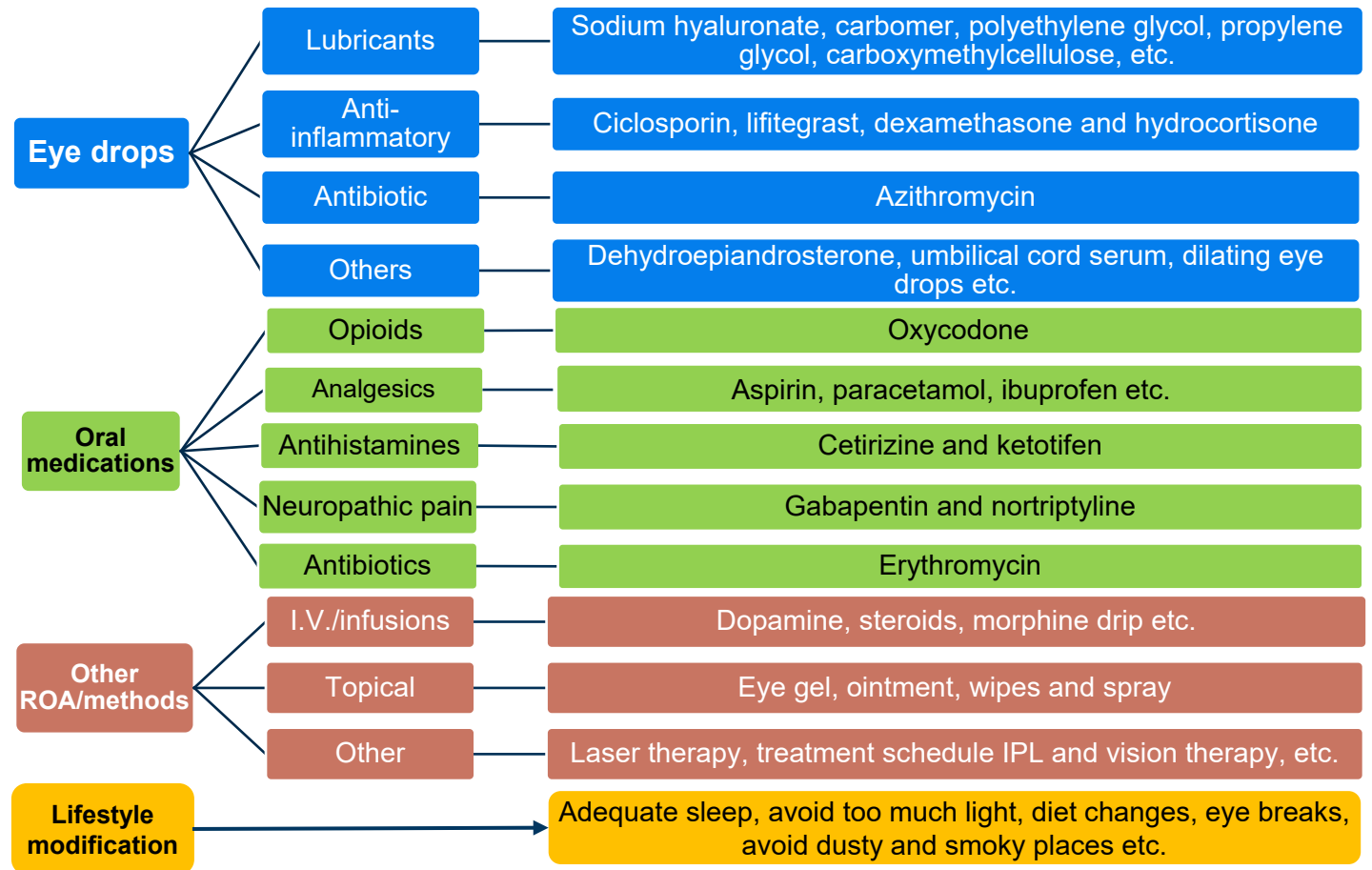
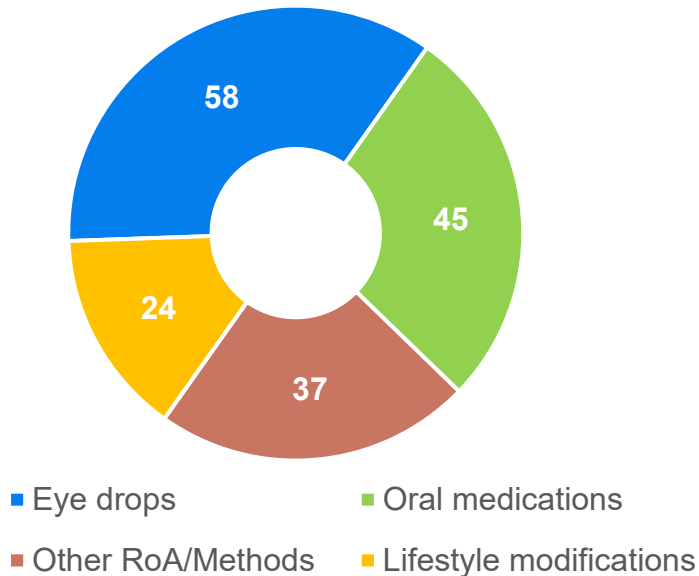
"I had a good paying job, ... no more work, car, friends were replaced with dozens of 'blind mans' glasses all of different shades, sometimes I have to wear 'double glazing to keep out the glare'"

"I'm ... because I'm constantly in pain, and I feel the most depressed and hopeless that I've ever felt."

"One thing I haven't seen discussed is the ... of losing sight. I'm an athlete, a man who believes in doing things for himself and working through pain. As you might imagine, my self confidence took a big hit when I I still don't like asking."

Eye drops are the commonly mentioned treatment options by patients; other therapies such as analgesics, hot compress, eyeglasses and steroids have been commonly used to manage the causes and symptoms of COP

Management of eye pain (n=164)



Alternative medicines: Hot compress (n=11), blue light filter glasses/lenses (n=9), eyeglasses (n=8), eye mask (n=6), cold compress (n=2), sunglasses (n=2), etc.

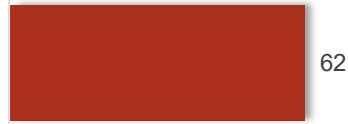
Failure to get diagnosis of the underlying cause of eye pain, even after undergoing multiple tests, emerged to be the primary concern; it also led to loss of confidence in HCP consultation in most cases

Unmet Needs (n=157)

Insights

Verbatims

Diagnosis Related



Most patients expressed concerns about not getting a diagnosis of the underlying cause of their eye pain, even after undergoing multiple tests and consulting different HCPs

Some patients also mentioned suffering for years before getting proper diagnosis

"Drs are not able to find out cause and eyes burns like he'll can anyone guide me"

"After almost two years of chronic eye pain a diagnosis may have finally been made"

HCP Related



Patients often express concern about lack of awareness among HCPs about the cause of eye pain

Patients also mention experiencing little to no improvement in condition from the treatments prescribed by HCPs

"I have gone to the eye dr (ophthalmologist, Nuero-ophthalmologist, & retina specialist) numerous times due to eye pain, floaters, flashing lights, & light sensitivity. Every time, the doctors tell me that my eyes are normal"

"Even my neurologist has gave up and just been told I'm sorry with no help. The last eye specialist I saw called it visual phenomena and it has been progressing so fast the last few months it is not explainable."

Treatment Related



Many patients do not get relief for their eye pain even after trying multiple pain management options; in some cases patients ultimately perceive inefficacy of a treatment to be the result of misdiagnosis.

Some also expressed a need for better management options for post-LASIK eye pain

"I've tried every medication under the sun, (paracetamol, ibuprofen, syndol) but it doesn't help one bit at all.."

The stem cell treatments won't, aren't able to target main source of pain - post-LASIK eye pain ."

Price/Access Related



Some conversations revolve around COVID related delays in accessing HCP appointments and diagnostic tests

Some were concerned about their inability to pay a huge consultation fees/bills of diagnostic tests due to lack of insurance

"The optometrist office was to book me an ophthalmologist appt to do laser LPI first then she would look at the floater. However, now a pandemic, all elective work has been put on hold and it has not been booked."

"I live in Canada and although our health care is paid for by the government getting an appointment with a specialist take sooo long"

Study Limitations

- **Only publicly available information** on digital platforms has been accessed and used for research; all the **personal identifiers are anonymized** in the report
- All social media research is based on the assumption that the information provided by patients is authentic and **was voluntarily shared with other patients publicly**
- Quality of insights gathered from the analysis of digital conversations is **dependent on the richness of patient conversations**, i.e., the details shared by patients about their health condition, treatment, medication, disease management challenges, quality of life, etc.
- Because of the unstructured nature of social data, it is not always possible to find information on every research question; the team has objectively determined if the available information supports a research question or not, and accordingly reported the findings
- **The unstructured nature of data also leads to variation in sample size related to each key research question**
- The nature of available digital content varies by platform, primarily due to format (e.g., Twitter vs. forums); during the sampling process, the research team has determined the most appropriate platform to derive in-depth consultative insights
- **US and UK contributed to the maximum volume of conversations.** Publicly available information from other geographies is less

Conclusions

