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COMMENTARY

# Living with Dry Eye Disease and its Effects on Quality of Life: Patient, Optometrist, and Ophthalmologist Perspectives

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## ABSTRACT

Dry eye disease is a very common condition, especially among aging women. People often think of it as a very mild and non-harmful issue, but the reality is that it has a huge deleterious effect on patients' quality of life. Most publications usually focus on the scientific aspects of this pathology: its epidemiology, diagnosis, or management. However, in this article we highlight the patient's perspective and the challenges of living with dry eye disease. With prior informed consent, we interviewed a patient whose life has drastically changed since she first got the diagnosis. We also asked healthcare professionals based in Miami who were involved in this patient's care for their opinions. We hope that the messages and commentaries resonate with patients and physicians involved in the care of dry eye disease worldwide.

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**Key Summary Points**

A patient with diagnosed dry eye disease was interviewed.

This article details the patient's struggles since she was diagnosed with dry eye disease, her experiences with the different therapies she tried, and the impact the disease has had on her quality of life.

The perspectives of optometrists and ophthalmologists who specialize in ocular surface diseases are also provided.

## DIANA'S STORY

Diana is a 51-year-old Latin woman. She has worked in finance all her life. For her current company, she specifically works in the Department of Commercial Intelligence, so she spends a lot of time, sometimes as much as 12 h per day, in front of three giant computer screens. As a businesswoman, she cannot neglect the constantly changing and unpredictable market. She moved from her home country, Colombia, to Miami 15 years ago, and 5 years later, when she

was in her 40s, her journey navigating dry eye disease began. Before that time, she swears she never had any issues with her eyes. She never even wore corrective glasses or had ocular surgeries and is otherwise very healthy. The only other comorbid condition she has is fibromyalgia, which she treats with weekly physical therapy, topical analgesic creams, and herbal medications. Informed consent to record the interview and later publish Diana's story was obtained.

## HOW EVERYTHING BEGAN

It started with changes in her vision 10 years ago: Diana started having blurry vision, and this was accompanied by soreness, tearing, and discomfort in her eyes, especially towards the end of the day. In her 40s, she visited a local optometrist who prescribed reading glasses for the first time in her life. He also diagnosed her with "dry eye disease," something she had never been told before, and advised her to start using artificial tears. After that, she would visit him once or twice a year. Even though she was very compliant, using her glasses and artificial tears as advised, her vision and ocular symptoms (dryness, discomfort, burning, tearing, redness, foreign body sensation, etc.) kept progressively aggravating over the years. At every visit, she received a new prescription for glasses, as her formula kept changing, and a different artificial tear because the previous one was no longer providing any relief. She tried all the different formulations and brands that were commercially available over the counter: low and high viscosity, with and without preservatives, tears for redness relief (brimonidine), night gels/unguents, etc., but nothing seemed to help. Many years went by in this frustrating cycle until 2020: the year when the severity of her symptoms started to have a real impact on her quality of life.

## LOOKING FOR OTHER OPINIONS AND INTENSIFYING TREATMENT

In August 2021, after having more than 15 pairs of glasses and trying all types of artificial tears without noticing improvement of her symptoms, she decided to look for a second opinion. She clearly recalls that her new doctor used a yellow stain (fluorescein) and the blue cobalt light of the slit-lamp to look at her ocular surface and referred to it as a "kid's scraped knee" (corneal erosions). The doctor told her that she had inflammation and a very severe chronic dry eye that required a more intensive treatment than just artificial tears. The doctor prescribed a short cycle of steroids to treat inflammation (loteprednol 0.25% once daily for 14 days) and inserted collagen punctal plugs. She also recommended using microwaveable warm compresses for 5 min every night before going to sleep and a new, "more natural" artificial tear formulation that contained hyaluronic acid, antioxidants, and electrolytes. Diana went back for a follow-up 1 month later, but despite the changes in treatment, she continued having severe corneal staining. She was then prescribed a second round of a stronger steroid: prednisolone 1% four times per day for 14 days. Two months passed after her first visit, and although she was religiously compliant, nothing changed on her ocular surface. In fact, her symptoms became more severe every day. It was then that her optometrist suggested starting topical cyclosporine A 0.05%, a potent anti-inflammatory eyedrop [1] that may be used for longer periods of time than steroids because of fewer potential harmful side effects.

## DEALING WITH INSURANCE COVERAGE: A TEDIOUS AND DEBILITATING TASK FOR PATIENTS

After her optometrist placed the order for the drops, it took her almost 2 months to obtain her insurance's approval for coverage of the medication. According to the patient, in her pharmacy they told her that without insurance support, she would be paying approximately $700 per month (for a 30-day supply) for these drops. It is worth mentioning that she pays for the most expensive health insurance plan there is. She described the approval process as intense, disappointing, and debilitating. To obtain approval, she had to call her insurance company every day, wait for long hours, and explain the situation over and over again to every new agent that took her call. Her optometrist sent multiple letters explaining why the patient required this medication, but despite all the optometrist's efforts and all the hours that the patient invested in reaching out to the insurance company, it still took almost 2 months to obtain what she needed.

Unfortunately, this is a complicated reality that most of our patients must deal with after leaving our clinics with a prescription for a new medication. Most doctors are not even aware of the obstacles that patients encounter to get affordable access to the medications they require. Obtaining insurance approval for medications to treat this disease may be a lot harder than for other pathologic conditions, as even its name, "dry eye disease," can be a misnomer: most people think of dry eye disease as a very mild, harmless condition, but the truth is that it has a huge impact on patients' quality of life [2].

## GATHERING MORE INFORMATION ABOUT HER CONDITION

In December of 2021, Diana traveled to Medellin, Colombia. She scheduled an appointment with a well-renowned ophthalmologist. He performed a thorough examination of her eyes and told her that her tears evaporated very fast, and therefore she had "evaporative dry eye," possibly associated to Sjogren's syndrome. Since she was staying in Medellin for only a few more days and he would not be able to follow up, he advised her to see a cornea specialist in Miami, at the Bascom Palmer Eye Institute. As soon as she got back to Miami in January 2022, she started contacting Bascom Palmer to get an appointment. She sent her ophthalmologist's report that showed that she already had an established dry eye disease diagnosis (which was a requirement to see a cornea specialist in this extremely busy center) and got an appointment to see Dr. Sabater in March.

## STRATEGIES FOR THE MANAGEMENT OF CHRONIC DRY EYE DISEASE BY A CORNEA SPECIALIST

At this point, before meeting with Dr. Sabater, Diana's symptoms were at their worst. The discomfort, tearing, and soreness, which before only came after a long day of work, were now showing up early in the morning. Close to noon she would have to literally stop working, as staring at her computer screens produced excessive, uncontrollable tearing and a severe burning sensation.

Dr. Sabater diagnosed her with meibomian gland dysfunction (MGD), which is known to be a leading cause of evaporative dry eye [3]. He evaluated her tear production via Schirmer's test [4], which was normal (> 20 mm in each eye), and then assessed the anatomical integrity of her meibomian glands by performing a Lipiview® infrared scan [5] and the glands' functionality by performing manual expressions [6]. Diana recalls him saying that the meibum came out opaque and "as thick as toothpaste." She had a very short tear break-up time (< 3 s in each eye) and moderate corneal staining. She also had some inflammation on the ocular surface, as evidenced by testing positive on the Inflammadry®, a point-of-care test that detects the presence of the inflammatory molecule matrix metalloproteinase-9 (MMP-9) [7].

Everything pointed towards a diagnosis of evaporative dry eye, coinciding with what her Colombian ophthalmologist told her. Therefore, Dr. Sabater started targeting this condition.

First, they discussed general and environmental measures that can be taken in conjunction with the medications. These include drinking abundant amounts of water daily, removing fans and getting a humidifier for her workplace and home, avoiding retinoic acid creams, and performing daily lid hygiene with tea tree oil shampoo. He also advised her to change the microwaveable warm compresses for electric ones, as she would be able to control and adjust their temperature. Second, she would have to continue using topical cyclosporine A 0.05% to address the inflammatory component on her ocular surface. Third, he recommended using an agent to try to improve the functioning of her meibomian glands. Two antibiotics, doxycycline and azithromycin, have been shown to increase tear film stability by improving the quality and quantity of the lipid layer [8, 9]. Therefore, she first tried oral doxycycline 50 mg daily, but stopped it because of gastrointestinal side effects and then topical azithromycin (three times per day for 3 days and then repeating this cycle once a month for three months).

Three months later she saw Dr. Sabater again for follow-up. Even though she was having fewer "bad days" with all the interventions, her symptoms were still "not good enough." Dr. Sabater recommended an adyuvant therapy: LipiFlow®, an FDA-approved treatment for MGD that works by heating and massaging the inside of the eyelids to improve the oil production in the meibomian glands [10]. Of note, this procedure is not covered by insurances, and patients have to pay around $700 out of pocket for each session. After this procedure, Dr. Sabater referred the patient to Dr. Stephanie Frankel, an optometrist with whom he shares many of his patients with severe, chronic dry eye disease who require more frequent follow-ups and/or evaluation for one of the last-resource treatments used for addressing this condition: scleral lenses.

## DOCTOR SABATER'S COMMENTS ON LIPIFLOW®

"Results with LipiFlow® are variable. A randomized clinical trial showed that a single 12-minute LipiFlow® session can alleviate symptoms and improve meibomian gland lipid secretion lasting for at least three months [11] but in my clinic, I've noticed that the duration of the effect and even the benefit in general differs a lot amongst patients. Also, it is very important to evaluate the anatomy and function of the meibomian glands prior to doing this procedure, as the absence of meibomian glands on an infrared scan meibography or absent secretions on manual expressions predict no benefit from this procedure. In Diana's case, she felt some benefit only for a few weeks after the LipiFlow®."

## DR. FRANKEL'S APPROACH

Dr. Frankel started seeing Diana in August 2022. By then, subjectively, Diana was having more good days than bad days, and objectively she had less significant corneal staining. When expressing her meibomian glands, the meibum came out easier and less opaque than before. Dr. Frankel performed the scleral lenses fitting trial, but the patient, who had never worn contact lenses, did not tolerate them. Scleral lenses are usually very well tolerated, especially in cases of severe, refractory dry eye [12], but the reality is that having to wear contacts on a daily basis is not an easy task for anyone, especially for a patient that has never worn contacts before. Dr. Frankel thus decided to reinsert collagen punctal plugs, maintain topical cyclosporine A 0.05%, and do other short-term steroid (loteprednol) and antibiotic (azithromycin) cycles. Because the patient started complaining of mouth and skin dryness, and her ophthalmologist in Colombia had mentioned that she might have Sjogren's syndrome, Dr. Frankel ordered a blood analysis for early and late Sjogren's markers, all of which came back negative, ruling it out.

In September, Dr. Frankel received a free medical sample of varenicline nasal spray

0.03 mg. This medication's use has recently been approved in the US by the FDA for the treatment of dry eye disease. It is a highly selective nicotinic acetylcholine receptor agonist that binds to these receptors in the nasal mucosa, activating the parasympathetic trigeminal pathway and resulting in an increased basal tear film production [13, 14]. It has been demonstrated to work in both pre- and post-menopausal women [15], so Dr. Frankel thought that it might be a good fit for Diana. She used it twice a day for 1 month until she finished the spray bottle. Diana asserted: "Since I started this pathway 10 years ago, I never felt as good as I did when I was using that nasal spray." Therefore, of course she would like to continue using it.

Here comes the painful part of the story again: despite doing a free 1-month trial and proving that Diana benefits from the drug, her insurance company is denying coverage of it. They claim that this drug will not be covered if the patient is using topical cyclosporine A. From a scientific point of view, this makes no sense. Both medications have completely different mechanisms of action. One is an anti-inflammatory agent, and the other increases basal tear production. In fact, they have a powerful synergistic effect, and there is no contraindication to using them concurrently. Both, Dr. Frankel and Diana are now fighting to get access to the medication. Frustrated, the patient has offered to pay for it out of pocket, but not even with that offer has she been able to obtain the medication yet.

## DR FRANKEL'S COMMENTS ON SCLERAL LENSES

Scleral lenses are large-diameter, fluid-filled, hard contact lenses that are custom designed to align with the patient's sclera, vault over their cornea and provide lubrication to the tissues underneath it, all day. This is generally used as a "last resource" because, as with all inserted medical devices, it increases the patient's risk of infectious keratitis; although the increase is low (estimated microbial keratitis incidence in scleral lens wearers is 45 cases per 10,000 wearers per year [16]), it is still an increase. Therefore, you want to weight your risk to benefit before initiating this therapy. You should also consider physiologic, psychologic, and financial components as well before recommending this treatment. For example, elderly patients with rheumatologic co-morbidities may present is deformities in their digits, making insertion and removal of the device a challenge. Patients that are unmotivated to incorporate contact lens wear into their daily regimen often times abort the fitting process, as it can require upwards of several months to fit the lens properly. Many times these lenses are not covered by insurance and can range in price from $1000–$7500 each, so there may be financial constraints as well.

In some instances, patients that are experiencing concurrent pain or discomfort from their dry eye and/or neuropathic pain may have difficulty with insertion and removal as their ocular surface is very inflamed. Usually, with consistent practice, they can overcome this hurdle and overcome their challenge with handling the lenses. As it pertains to dry eye and scleral lenses, in my experience, they generally work best when the patient presents with a category of aqueous deficient dry eye syndrome and have a 50/50 success rate when they are evaporative.

## OTHER INNOVATIVE OPTIONS

Blood-derived products were introduced into ophthalmology almost 50 years ago [17]. Due to their high concentrations of growth factors, products like autologous serum tears [18], umbilical cord serum [19], and plasma rich in growth factors [20] have demonstrated great efficacy in the treatment of severe refractory dry eye disease as well as many other abnormal ocular surface conditions (i.e., epithelial defects, ocular graft versus host disease, cicatrizing conjunctivitis, limbal stem cell deficiency, etc.).

## IMPORTANT CONCURRENT CONDITIONS: LOOK BEYOND THE EYES!

It is important to remember that the environment, other systemic physiologic or pathologic conditions, and even medications may have a detrimental effect on the tear film. First, Diana mentioned that her symptoms got dramatically worse in 2020 when COVID-19 struck and changed the world forever. Yes, she had stared at computer screens for work her whole life, but with COVID-19 meetings that were supposed to be in person were being hosted virtually, increasing the amount of time she spent on the computer. Second, she mentioned that she went into menopause and was diagnosed with uterine fibromas in December 2021, so her gynecologist put her on hormone replacement therapy (HRT) with estrogen patches and oral progesterone. It is known that HRT, especially with estrogen, can cause or worsen dry eye symptoms [21]. After reading about it and discussing it with her gynecologist, Diana stopped using estrogen patches and doubled the dose of progesterone she was taking. She feels like eliminating estrogens contributed to the improvement of her dry eye symptoms. Finally, she recognizes that if her job did not involve being in front of computer screens all day, every day, her eye health would probably not be as affected as it is now.

## IMPACT ON HER QUALITY OF LIFE

"When my symptoms were at their worst, my productivity in work decreased significantly because I couldn't stare at computer screens for too long before I had to stop because I got blurry vision and excessive tearing. I love reading but doing it for too long would cause an extremely annoying burning sensation in my eyes. When I traveled to cities where humidity levels were lower than Miami's—basically any other city in the world!—my symptoms worsened tremendously, so I was never able to fully enjoy my trips. Even now that I have more good days than bad days I must set up alarms to remind me to use my drops. I still find the hardest time at night, when my eyes are so sore that even instilling the cyclosporine A drops burns and makes it hard for me to go to sleep—another reason why I would prefer to use the varenicline nasal spray. It is very frustrating and limiting to have all these eye issues, and additionally having to hurdle so many barriers to get access to the medications I need."

## DR. ANAT GALOR'S COMMENTS

"Dry eye is an umbrella term. Don't forget that there is a subset of patients with normal tear metrics and ocular surface parameters who still complain of 'dryness, discomfort, and/or burning pain.' They may use many different words to describe what they feel in their eyes. If the noxious stimuli at the level of the ocular surface, also known as nociceptive sources of pain (e.g., ocular surface inflammation, tear deficiency, meibomian gland dysfunction, anterior blepharitis) have been addressed and the patient's symptoms do not improve, or there are no signs of ocular surface disease, it is important to consider neuropathic sources of pain. Often, a pain specialist can help in the management of the neuropathic components of pain."

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***Compliance with Ethics Guidelines.*** Informed consent to record the interview and later publish the patient's story was obtained.

***Data Availability.*** Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.



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