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COMMENTARY

Blinded by Stress: A Patient and Physician Perspective on Central Serous Chorioretinopathy

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ABSTRACT

This commentary is co-authored by a patient with central serous chorioretinopathy (CSC), which is the fourth most common exudative maculopathy. The patient, a young and profiled member of the Danish Parliament, kindly shares his experience living with stress, onset of symptoms, and the experience of being diagnosed with CSC and receiving photodynamic treatment. The experiences of the patient are put into perspective by an ophthalmologist.

PLAIN LANGUAGE SUMMARY

In this patient–physician perspective, a patient with central serous chorioretinopathy shares his experience. Central serous chorioretinopathy mainly affects men aged 30–50, is associated with stress, and the main symptom is blurring of central vision. The patient describes his life and work as member of the Danish Parliament, living with stress, being diagnosed with central serous chorioretinopathy, receiving treatment, and finally adapting to a new life in which work–life balance is prioritized to avoid excessive stress.

Keywords: Central serous chorioretinopathy; Stress; Visual symptoms

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Key Summary Points

Stress can lead to central serous chorioretinopathy, which leads to symptoms from central vision.

Vision loss is invisible to bystanders but constantly present for the patient—the psychological impact of vision loss can be tremendous.

Understanding the patient's perspective can potentially improve patient care.

This patient perspective provides insight into real-life onset, diagnosis, management, and prognosis of central serous chorioretinopathy.

PATIENT PERSPECTIVE

I ran for city council in Køge municipality when I was 18 years old and was elected as one of the youngest city counselors in Danish history. After that I lived a life with politics as one great part of my life and being young, heartbroken, drunk, partying, travelling, studying as the other. I said yes to everything because life was great.

Later, I ran for the Danish general election in 2015, while also doing my university degree. I was elected—once again as one of the youngest ever. My life has always been a mix between wanting to say yes, pushing my own limits, living my life to the fullest, doing impossible things, while also feeling an internal, sometimes unhealthy, uncertainty. I wanted to show the world that I was good enough. The only problem, I was not sure if I was good enough.

But through hard work, I could see results, which made me seek even more work. Looking back, I realize that I had developed an unhealthy and overtly ambitious image of what it meant to be a good politician, a good son, a good friend, and a good person—and I tried to live up to my own image by working as hard as possible and saying yes to all opportunities. For years, I lived in this stress, gaining more and more political success after the election in 2019 where I was one of the politicians in Denmark with most voters behind me. But in 2020 my lifestyle culminated with lower work satisfaction, social exhaustion, physical and mental breakdown, and increasing anxiety attacks.

I ignored these symptoms of stress, at least until October 2021. I realized that my vision was beginning to deteriorate, and I booked an appointment at my general practitioner, who then referred me to an optician. My expectation was that I needed spectacles. The optician measured my vision to less than 30% and referred me to an ophthalmologist. My right eye was slightly worse than my left eye, but both were poor. The ophthalmologist told me that I had central serous chorioretinopathy (CSC), also known as *stress-eye* (translation from the Danish term *stress-øje*) which is a more generally used term in Denmark. I was told that CSC often disappears without any treatment, but that around 5% remain chronic, which may need laser treatment. The ophthalmologist also told me that this was stress-related and that I needed to take a break from my work. For me, this was the final straw and I realized that I needed to take control of my stress. I cancelled all my political appointments immediately and asked my political leader for leave of absence. I was number two in the party, so it was not an easy choice.

Being home and focusing on not being stressed was in itself a very stressful experience. I was thinking, what will I do? Will I ever be able to work with politics again? Should I consider another job? In which case, which sort of job would I be able to do? I was constantly thinking about my future, filled with uncertainty. Will I become blind after this? With all these thoughts in mind, it felt very difficult to relax and avoid stress. I felt that in periods where I was better able to relax, my vision would improve. My vision fluctuated with the number of thoughts and stress, but never normalized.

I tried to seek information online. I needed to understand what was happening in my eyes. But it was extremely difficult to find any information addressed to me as a patient. A lot of the

information was too medical for me. I was often left with patient information for age-related macular degeneration or other retinal diseases, which made me worry a lot. For those diseases, there was a recommendation of treatment with injections into the eye. It made me worry whether I needed to get injections, and why I was never informed about those. And I read somewhere that cortisone hormone was linked to both this disease and stress, and I thought, what if I buy a lot of cortisone tests and test myself every day? And then plan my day according to my stress hormone? Fortunately, I was able to get answers to all these questions through my ophthalmologist, but when not speaking to a specialist, you are left with whatever you can find on the Internet.

In April 2022, I was referred to an eye department at my local hospital for treatment. The fluid in my right eye had disappeared, so I was treated in my left eye only. Confident of an improvement and control of the situation, I returned to work. But my right eye readily relapsed. After some time, I received treatment again, and in both eyes. Meanwhile, there was a global shortage of the medication for laser treatment, which meant that I and others with this condition were told that we needed treatment, but that we had to wait for the medication to arrive—for an unknown amount of time. We would be contacted when the department had medication for us. Imagine, being ill is one thing, but being ill and the medication is not available! That is another level.

Today, my vision is around 80% in both eyes. I can drive my car, read, and see whatever I need to see. I experience some issues with contrasts and colors, for example, my right eye sees colors less bright compared to my left eye. But overall, I am happy that the condition is under control. I am very grateful for our health system, and I have received good information and treatment everywhere I have been.

I have also changed my approach to my work and my activities to better control the amount of stress. Before, I packed my day with political activities, always checked my mail, and was always available. Now, I actively plan periods of rest. I am also aware that I can have days or weeks with a lot of activities, but now such periods are followed by rest and restitution. In some strange way, I am grateful for this disease, as I am not sure if I would have acted as promptly on my stress symptoms if it had not affected my eyes. At least that's what I'm trying to tell myself. The truth is that I am scared and sometimes frustrated. Many days I don't think about it. But there are also many days where I feel like there is a big axe hanging just above my head—as a warning. Because today, I am very aware as I know that if the stress wins, I might become blind one day.

PHYSICIAN PERSPECTIVE

I am grateful that Mr. Jacob Mark shares his experience with CSC with the readers of this journal. The patient perspective as outlined by Mr. Jacob Mark clearly highlights that CSC goes beyond just "fluid in the retina." The lives of our patients are impacted in many ways by their eye disease.

CSC is the fourth most common exudative maculopathy, after neovascular age-related macular degeneration, diabetic macular edema, and retinal vein occlusion [1]. It is 3–6 times more common in men and typically onsets between the ages of 30 and 50, although it may occur as early as in pediatric cases up to individuals aged 80 years or older [2–5]. The condition was first described in 1866 by von Graefe and later associated with stress by Bennett in 1955 [6, 7]. Exogenous and endogenous sources of corticosteroids are the most important risk factor [8, 9]. In this case, Mr. Jacob Mark is a young adult male with unremarkable medical history, but with a long history of psychological stress.

Although psychological stress can be an important endogenous source of corticosteroids, the exact pathophysiological link between male gender, stress, corticosteroids, and CSC remains incompletely understood [9–12]. However, important clinical features of CSC have allowed certain pathophysiological mechanisms to be well characterized. The choroid in CSC is thick and exhibits hyperpermeability on indocyanine green angiography (ICGA) [11–13]. This may represent choroidal

congestion, which has been associated with thickened sclera and arteriovenous anastomoses [11, 12]. Pathophysiologically, these congestion changes in the choroid may lead to an increased force of fluid pressure that elevates the retinal pigment epithelium (RPE) from the Bruch's membrane, and when the pumping function of RPE no longer can withstand the fluid pressure force from the choroid, decompensation leads to subretinal fluid [11, 12]. Presence of subretinal fluid (SRF) defines the onset of CSC. The SRF in CSC can wax and wane [1], which in some cases may reflect fluctuations in psychological stress (CSC) [14]. Interestingly, some studies also find seasonal fluctuations in the incidence of CSC that are hypothesized to be associated with the seasonal fluctuations of either psychological stress or baseline corticosteroid levels [15, 16]. In the case of Mr. Jacob Mark, there is a clear fluctuation in the visual symptoms that is related to the subjective experience of psychological stress.

A diagnosis of CSC requires anatomical insight into the macula and the choroid. To that end, optical coherence tomography (OCT) provides detailed structural insight that allows visualization of RPE detachments and SRF. Fluorescein angiography (FA) and ICGA may visualize point of leakage, RPE atrophy, choroidal hyperpermeability, and choroidal arteriovenous anastomoses. A complicating phenomenon can be the development of macular neovascularization (MNV), which can be visualized using FA, ICGA, or OCT-angiography [17]. Onset of MNV requires another approach to treatment, as timely treatment using intravitreal anti-vascular endothelium growth factor is needed to limit the neovascularization process and development of subretinal fibrosis [1, 18]. Acute CSC can be observed, as studies show that the SRF resolves spontaneously in approximately two out of three cases within 3–6 months of onset [18], although treatment at this stage is shown to lead to excellent outcomes [19]. Recurrent or chronic cases may exhibit waxing and waning of the SRF but need treatment to achieve complete and persisting resolution of the SRF [1], as prolonged SRF may cause irreversible damage to photoreceptors [20]. A comparative efficacy network meta-analysis determined that the greatest effect on the SRF resolution in chronic CSC was achieved through focal laser photocoagulation treatment or half-dose photodynamic treatment (PDT) [21]. However, focal laser photocoagulation treatment does not address the choroidal pathophysiology and is not a feasible option for leakage points near the fovea. Thus, half-dose PDT remains the preferred choice of treatment [21]. For recurrent cases, re-treatment with half-dose PDT can be performed [22]. Long-term outcomes after half-dose PDT for chronic CSC show relative preservation of best-corrected visual acuity and central retinal sensitivity [23] and thus most patients often have a good long-term prognosis after half-dose PDT [23]. The patient journey of Mr. Jacob Mark illustrates the routine approach of initial observation and then progression to treatment using half-dose PDT for chronic CSC. The global shortage of verteporfin proved a challenge for treatment-demanding cases of chronic CSC and left patients with CSC and ophthalmologists with great frustrations [24].

Unlike the ophthalmologist, the Internet is readily available. Seeking health information online is easy and practical but requires relevant and approachable information. One Danish study reported that when the information online misaligned with the information from the doctor, the patients were dissatisfied with the consultation [25]. Information online is not necessarily developed by clinical experts, which potentially puts patients at risk of inaccurate or even dangerous information [26–30]. For example, ChatGPT provides accurate information on CSC when it comes to pathophysiology, prevention, and prognosis but potentially dangerous information for questions related to treatment [31]. One complicating factor in this topic is that even peer-reviewed literature may be harmful when not seen in relevant context or not viewed critically considering its evidence level. For example, case reports or advice can be found on the use of topical NSAIDs for CSC, although best evidence does not recommend their use [32]. Thus, accurate and relevant patient information needs to be accessible, and different strategies may be required in different settings. However, as illustrated by Mr. Jacob Mark's patient journey, we as ophthalmologists

need to be aware of the information to which the patients are exposed, to better understand the thoughts and concerns of our patients.

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I am very grateful that Mr. Jacob Mark participated in this publication and allowed me to provide a clinical and scientific perspective on his disease. Perhaps more importantly, I commend Jacob Mark for speaking publicly about having a disease whilst in the position of being a public figure, as it illustrates to others that they are not alone.

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Declarations

Conflict of Interest. Jacob Mark and Yousif Subhi declare that they have no competing interests.

Ethical Approval. This article is based on personal experiences and previously conducted studies and does not contain any studies with human participants or animals performed by any of the authors.

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