

A Patient's Viewpoint of Cataract and Detached Retina Surgeries

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ABSTRACT

Aims: The purpose of this paper is to (1) describe the changing details of a complex medical example allowing the reader to continually diagnose complications resulting from cataract and detached retina surgeries, (2) explain good and bad aspects of communications between patients, optometrists, ophthalmologists and systems engineers, and (3) show a patient's view while a retina is detaching.

Methodology: This paper was written from the patient's point of view of the interactions between the patient, the optometrist and the ophthalmologists during a dozen eye surgeries for cataracts and detached retinæ. It was excerpted from the patient's notes (including test results, charts and images), hospital reports, letters to the doctors and their referral reports. This paper was written in the first person singular and in chronological order: which should allow the reader to see changes in the interactions of the symptoms and treatments from ocular surgeries in a complex medical example.

Results: This paper has documented malposition of an intraocular lens, ignoring patient's complaints of pain, lack of explanation of what the subject should expect after retinal detachment surgery (such as strabismus, diplopia, pain, wrinkled retina, and dynamic visual changes due to bubble changes), lack of explanation for the subject's potential visual acuity defects and color deficiencies, poor communication between patient care specialists about these defects, lack of knowledge of technicians using ophthalmological instruments, lack of documented processes for using these instruments (which means different technicians used the instruments differently), lack of proper medical care due to physician overload (i.e. scheduling more than 60 patients per day per physician), and ignoring the patient's complaints of pain. While reading this paper, the reader should accept or challenge each of these assertions.

Conclusions: Pain is hard to diagnose, measure, quantify and treat, making it frustrating for both the patient and the physician: in this case there were many causes of the pain, which caused confusion. For the last six years, this patient complained about ten specific symptoms, which were treated individually: treating this case as a system of interacting

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problems led to a better understanding and resolution.

Keywords: cataract surgery; scleral buckle, communication; complications; detached retina; detaching retina; ocular pain; quality of life; retina surgery; lessons learned;

1. INTRODUCTION

1.1 Who Should Read This Paper And Why Should They Read It?

1.1.1 Ophthalmologists

Ophthalmologists can read this paper and diagnose the patient's medical problems. The symptoms and people interactions have been laid out in chronological order. These are the facts that were thought to be true at the time, but some of them might prove to be wrong in the end. The appendix provides useful but possibly irrelevant statistics that he or she might want to consider. Hopefully, the ophthalmologist can learn a little about the patient's viewpoint of ocular surgeries. The ophthalmologist could learn about the types of pain that can result from ocular surgeries. Then he or she could write brochures that describe potential postoperative pain and explain treatments that would be used to resolve those pains. Finally the ophthalmologist can decide if he/she would have done better than these dozen ophthalmologists.

1.1.2 Optometrists

Optometrists can expand their horizons and find their place in ocular surgeries. In 1977, Larry Stark et al. [1] described many nontraditional optometry tasks that professionals were performing in his Neuro-optometry Clinic at Berkeley (UC) and San Francisco (UCSF). This paper suggests another nontraditional task: assisting patients with detaching retinas. Detached retinas seem to be in the purview of ophthalmologists. However, this paper explains ways that an optometrist was involved in (1) diagnosing a detaching retina, (2) tracking the specialties and equipment of local ophthalmologists, (3) acting as a primary visual care provider, (4) understanding and explaining to the patient what lies in store for him during and after the surgery, (5) diagnosing and perhaps solving postoperative complications {such as (a) postoperative diplopia, which (in this case) was ameliorated with prism spectacles, (b) the iris being trapped by the intraocular lens, which was solved by a lens replacement, (c) inflammation, in this case due to the suture securing the scleral buckle and (d) helping with pain diagnosis and remediation,} and (6) explaining the relationships between fundus photos, visual field diagrams and ocular coherence tomography images. Also the American Optometric Association has an extensive set of recommendations for optometrists dealing with retinal detachments [2] [Jones].

1.1.3 Students of Ophthalmology and Optometry

Students of Ophthalmology and Optometry can augment their diagnostic skills by practicing on this real-life case study. They can also learn about a topic that does not get much attention in the curriculum, pain.

1.1.4 Intelligent layman

Intelligent laymen and patient advocates can learn about complications and interactions between cataract and detached retina surgeries, such as the following. Pain is hard to diagnose, measure, quantify and treat, making it frustrating for both the patient and the physician: in this case there were many causes of the pain, which caused confusion. There was no face-to-face communication between the dozen doctors that were involved in this case: furthermore, many times the written communications were not received, read or understood. In complicated procedures involving many physicians and many physical systems, perhaps there should be a patient's advocate, who knows the system and is interested only in the patients' best interests. A useful metric for choosing a doctor is the amount of time that he or she schedules for each appointment or operation. A better understanding and resolution for a medical problem may be treating the symptoms, the doctors, the patients and the procedures as a whole system instead of a group of specific entities to be treated individually.

1.1.5 Families and friends

Families and friends of patients who have or will undergo ocular surgeries can understand what the patient is experiencing and what signs and symptoms should be reported to the ophthalmologist. When a new clue surfaces a very difficult decision is always, Should I call the doctor? Should I go to the emergency room? Should I take more narcotic pain pills? Reading this paper should help with these decisions.

2. HISTORY/METHODS/RESULTS

A. Terry Bahill (ATB) has had a dozen eye surgeries over the last half-dozen years. He has been examined and treated by an optometrist and ten ophthalmologists. The following report is his description of the interactions between these vision care specialists. This paper describes (1) cataract and detached retina surgeries and their after effects (including many images from the patient's viewpoint, which have never before been presented in the literature), and (2) quality of life measures.

This section was written by ATB about his dozen eye surgeries. Other patients will have different numbers and details, but the overall processes should be about the same. This section is written from the patient's point of view of the interactions between the patient, the optometrist and the ophthalmologists during a dozen eye surgeries for cataracts and detached retina. Therefore, this section is written in the first person singular. It was excerpted from my notes, hospital reports, my letters to the doctors, and their referral reports. Nothing was retrospectively edited. So it is possible that at one time I wrote something in my journal that was different than something that I had written at another time: I did not edit out these contradictions. Oscillations in my health and mood may be apparent. This case is multifaceted with many complications. The ten ophthalmologists are identified as "Ophthalmologist-1" to "Ophthalmologist-10."

May 24, 2007, First Cataract Operation

It all started on a beautiful May morning in Tucson. Ophthalmologist-1, his wife (the anesthesiologist) and a surgical nurse performed a cataract extraction and lens implant on my left eye. It was a quiet relaxed atmosphere where they were describing to the nurse their upcoming vacation to Italy. Ophthalmologist-1 was doing hydrodissection in the membrane capsule, when he suddenly said, "Whoops. What was that?" He wrote in his hospital report, "the posterior capsule had torn as a result of the hydrodissection... It was elected to insert an [available] MA60AC lens rather than the [selected] one-piece acrylic lens." That evening, the next morning and the next afternoon, I told his staff that I was in pain.

May 25, 2007, Follow-up Exam

The next morning I told Ophthalmologist-1 that the eye hurt and that I was seeing lots of floaters. As he was examining the operated eye, he said that in order to compensate for the ruptured posterior capsule, he removed some of the vitreous [which pulled on the retina], placed the lens (a square edged, 3-piece posterior chamber intraocular lens, Alcon model MA60AC) more anterior than planned (in the ciliary sulcus), and put a stitch in the cornea. Later he said that rupture of the posterior membrane capsule was a rare event, happening to only one of his other patients 17 years ago. [See the appendix for statistics from the literature.](#)

May 26, 2007, Pain in the Eye

My left eye hurt. It was tearing and bloodshot. Ophthalmologist-1 was on vacation in Italy. I called a friend, Ophthalmologist-2, and told him that my eye hurt and I could not contact Ophthalmologist-1 or his backup. He said that pain after a cataract operation most certainly means infection. He advised me to go to the emergency room. Ophthalmologist-3 (who by coincidence was the backup in Ophthalmologist-1's practice and also the ER ophthalmologist on duty) gave me a prescription for Vicodin (hydrocodone). It did not relieve the pain. I saw him another four times in the next two weeks. He said that he did not know why there was severe pain. For the next four years at every medical exam with my ten ophthalmologists, I complained about pain in the front of the eye. Table 1 shows that nothing relived the pain.

**Table 1. Since 2008, at various times, ATB has taken the following anti-pain drugs.
None relieved the pain in the brain.**

Generic Name	Strength	Brand Name	Dosage
Ibuprofen	200 mg	Motrin®	16 pills per day
Hydrocodone/APAP	5/500 mg	Vicodin®	6 pills per day
Oxycodone/APAP	5/325 mg	Percocet®	6 pills per day
APAP is an abbreviation for acetaminophen.		Tylenol®	

May 8, 2008, One Year Later

I saw a static, 100-degree diameter¹, ¾ ring (two degrees thick) of bluish light for maybe a half minute in left eye with the eye open. It looked like Figure 1 (top-left). The dark green (or gray) disk represents the subject's field of view. That event was probably caused by the vitreous (the jelly in the eyeball) detaching from the retina. Please note that this is the visual experience of one subject. The literature more often describes the detaching vitreous with spider webs and lightning bolts.

Note added in 2013: Both moving the lens forward and removing some of the vitreous gel would move the gel forward, and pull on the retina. This sequence can lead to a retinal tear and a detachment, especially during the first year after surgery. "if the cataract surgery is complicated with a capsular rupture, the risk increase for [retinal detachment] RD is ten-folded. It is a shame that I did not know that in 2007.

May 12, 2008, First Detached Retina Operation

The optometrist saw a half-dozen retinal tears (like tears in a fabric, not like tears when a person is crying) and referred me to a retina specialist, Ophthalmologist-4. He told me that the operation had a 92% chance of success and if it did fail there was a second operation that he could do that had a 50% chance for success. For more statistics like these the reader should go to the appendix. He scheduled an operation for that evening. During that operation, he put a sclera buckle around the eyeball, removed the vitreous humor (vitrectomy), repaired the retinal tears with freezing (cryopexy) and with an endolaser, and inserted a bubble of perfluoropropane (C₃F₈) gas (also called octafluoropropane), a procedure known as pneumatic retinoplexy. My double vision (diplopia) started after this surgery. The next day, and on other visits, I complained about inflammation, a blood shot eye, foreign body sensation (like an eyelash trapped under the eyelid), pain in the front of the eye and now pain behind the eye.

Explanations of Technical Terms

I had a rhegmatogenous (rhegma = rent or rupture) retinal detachment, which means tears (like tears in a fabric, not like tears when a person is crying) in my retina allowed fluid to leak underneath the retina, thus detaching it from the choroid (the vascular layer of the eye lying between the retina and the sclera). The tears were probably caused by the detaching vitreous (the jelly in the eyeball). Ophthalmologist-4 decided to simultaneously use all common retinal repair techniques: scleral buckling, vitrectomy, laser photocoagulation and pneumatic retinoplexy. Simplistically, a scleral buckle is a band of silicone that is sutured around the eyeball under the extra ocular muscles. It buckles the eyeball pushing certain regions closer to the retina. In vitrectomy, the jelly-like vitreous humor is removed. Pars plana vitrectomy describes a particular pathway (pars plana) that the surgeon uses to remove the vitreous. In pneumatic retinoplexy the surgeon, inserts a bubble of about 15% perfluoropropane (C₃F₈) gas (the other 85% is just air) into the vitreous chamber of the eye (the big part of the eye between the lens in front and the retina in back). This bubble prevents fluid in the eye from passing through the tear and under the retina. This allows the choroid to pump the fluid out of the subretinal space allowing the retina to reattach to the choroid. You cannot fly in an airplane (or do anything else that will rapidly change the pressure around you) with a gas bubble in your eye.

Typically, an ophthalmic laser for retina photocoagulation uses a diode-pumped solid-state green argon laser with a wavelength of 532 nm (a yellow 586 nm laser is another possibility), a power of 50 to 2000 mW, a pulse duration of 0.01 to 4.0 seconds with a 635 nm red laser aiming beam. The visual field comprises the images that the subject can see with the eye looking straight-ahead (primary position): typically, this is 90° temporal, 60° nasal, 60° up and 75° down.

Concerning cataract operations, the human intraocular lens is enclosed in a capsule. This is sometimes referred to as the membrane capsule, a capsular bag, or a lens capsule. The front and backsides are referred to respectively as the anterior capsule and the posterior capsule.

Throughout May and June, my vision was improving. However, I was surprised by the tropia: when at rest, my left-eye images were about ten degrees up and ten degrees to the left of the right-eye images, and I could not fuse the right and left eye images. Ophthalmologist-4 did not prepare me for this.

June 29, 2008, Gas Bubble Disappears

Ophthalmologist-4 had told my wife and me to expect that if we lasted six weeks, or until the gas bubble disappeared, then we would be out of the woods for further complications. On this Sunday, we were in high spirits, because this was six weeks after the operation and the gas bubble was completely absorbed.

¹ In this paper, the size of the visual angle will be given in degrees of arc or angular size, because it is easy to estimate. For example, at arm's length, a typical thumb is two degrees wide and a fist is a little less than ten degrees wide. For comparison, the sun and the moon are ½ degree in diameter.

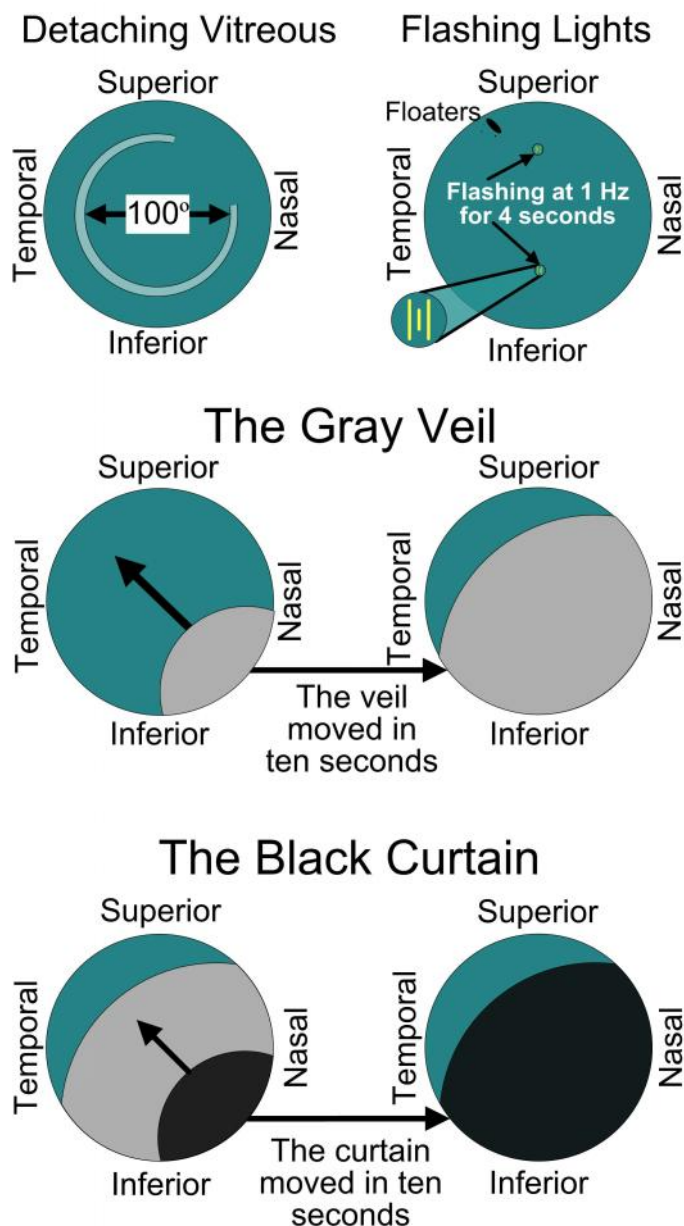


FIG 1. Temporal sequence from the patient's viewpoint of the left eye's retina detaching. Top-left: the vitreous detaching. The dark green (or gray) disk represents the subject's field of view. Top-right: floaters and flashing lights caused by the retina detaching. Middle: the gray veil started in the lower-right visual field and progressed to the upper-left. Bottom: the black curtain followed the same path as the gray veil.

At 10:00 AM, Ophthalmologist-4 saw a small hole in the retina, as well as a scab on the retina. He scheduled an operation for 3 PM the next day. Four hours later, I saw vertical yellow lines about two degrees long and one degree apart: three on top of my field of view and three on the bottom. See Figure 1 (top-right). They flashed at one hertz for a dozen seconds. Later I saw big black floaters². Then a convex gray veil (with a radius of curvature of around 40°) moved from the lower-right to the upper-left across my field of vision as

² Floaters are small clumps of cells, pigment or gel that "float" inside the vitreous. They have a wide variety of sizes and shapes. For me they are often black circles tenths of a degree in diameter. Sometimes they move, seemingly like a house fly. Floaters may appear as small specks, hair-like objects, clouds, strings, streaks, dots, dust, or spider webs moving in front of a person's field of vision. They are especially apparent when looking at a plain white background or a blue sky.

shown in Figure 1 (middle row): this took around ten seconds. Then, a few minutes later, a convex black curtain moved across my retina and eclipsed 80% of my field of vision, Figure 1 (bottom row). I called Ophthalmologist-4 and he confirmed that my macula of my retina had detached and we would do the operation the next day. I was not a happy puppy: since the operation, they would not let me drink beer, work on the computer for more than 15 minutes at a time, or go out of the house for more than an hour a day. I had to lie on my side for most of the day. My primary care physician had prescribed Sertraline for my depression.

Note: this is the visual experience of one subject. The literature most often describes the detaching retina with spider webs, flashing lights, lightning bolts, sparkling dots, fireflies, fireworks or sparks. I did not take measurements of the recovery from this first retinal detachment operation, because I had no idea of what to expect. So I could not plan an experiment.

July 1, 2008, Second Detached Retina Operation

Ophthalmologist-4 pushed the macula back into place, zapped the retina with his laser and inserted another gas bubble. A gas bubble occludes the retinal tear, permitting the choroid to remove subretinal fluid, and then the bubble presses the retina against the choroid, sheltering the edge of the tear until a choroid-retinal scar is formed, sealing the break. A bubble of perfluoropropane (C_3F_8) gas will gradually be absorbed into the blood stream and will be replaced by aqueous fluid, which is continually produced by the ciliary body. This process will take six to eight weeks depending on how big the bubble is and a bunch of other things. The first objects that I saw as the gas was absorbed were stars in the sky as shown in Figure 2. Obviously, I was outdoors looking straight ahead.

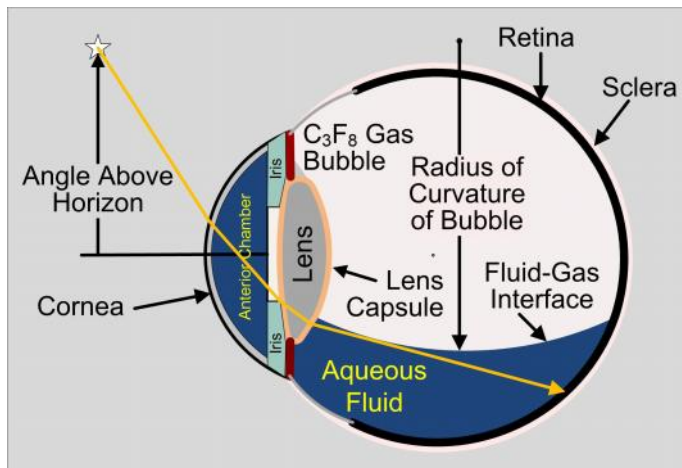


Fig. 2. Schematic drawing of the eye showing the path of the first light that the patient saw after the detached retina operations that used perfluoropropane gas.

Because of the difference in the index of refraction of liquid and gas, light rays that go through the gas bubble diffuse before they reach the retina. Only rays going through the aqueous fluid can reach the retina in focus, as shown in Figure 2. As a patient, this came as a surprise to me. Next, as the gas was being absorbed into the blood via the retina, choroid and aqueous fluid, the bubble changed its size and shape.

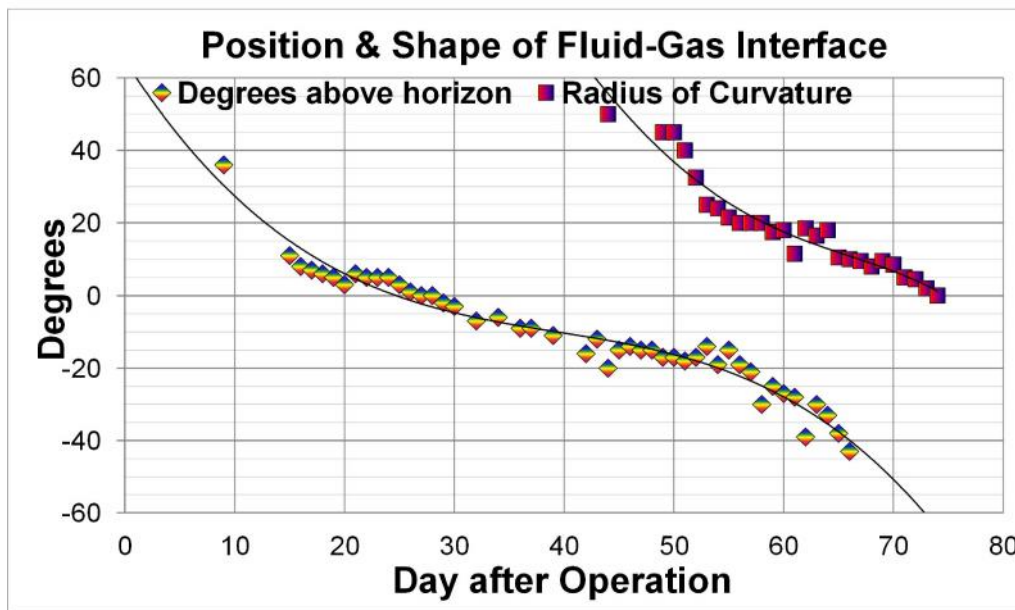
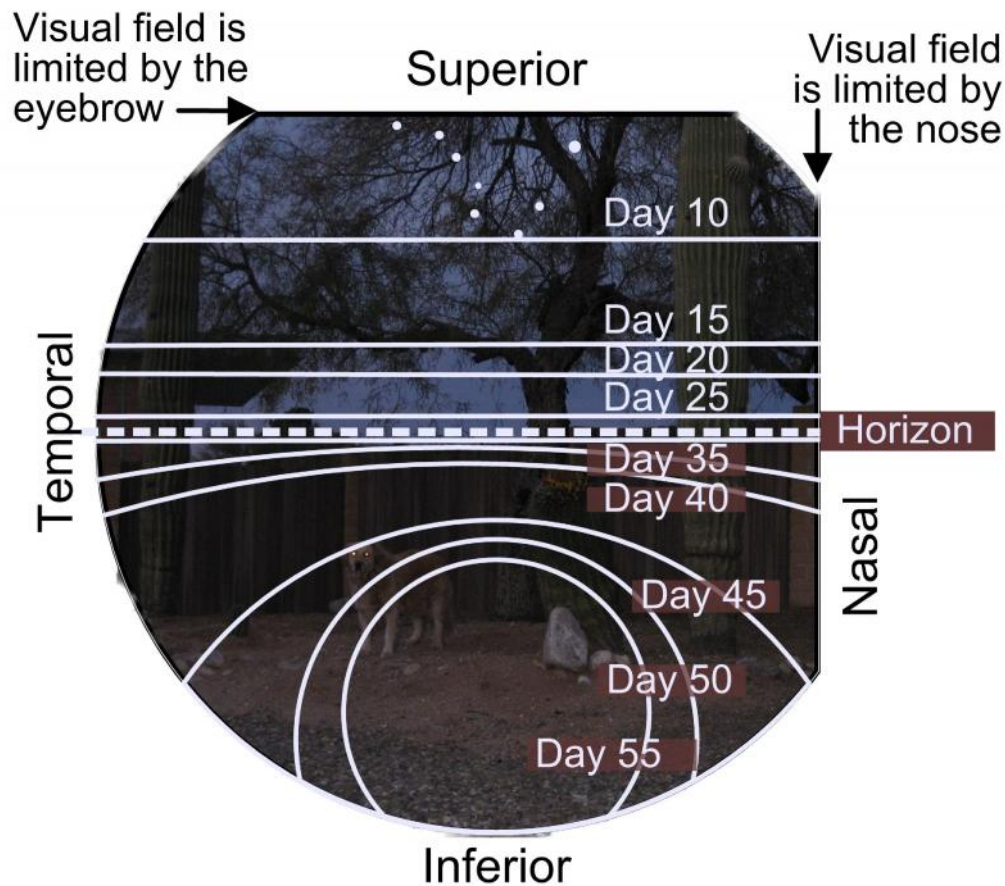


Fig. 3. The patient's viewpoint of the time sequence of the gas bubble being absorbed and replaced with aqueous fluid.

Figure 3 shows my viewpoint of the time sequence of the gas bubble being absorbed and replaced with aqueous fluid. I could only see what was above the white line for that day. For, example, on day ten I could only see the stars. When the fluid-gas interface dropped below the horizon, it stopped being a straight line and seemed to have curvature, eventually turning into a circle. The bottom of Figure 3 shows quantitative data from my viewpoint of the temporal disappearance of the C_3F_8 bubble. It seemed to disappear from the top down starting about the 10th day after the operation. On the 60th day, the bubble broke up into one big bubble and lots of little ones: the numbers in this figure are for the big bubble.

In the first few days after the operation, the bubble always increases in size, but I could not detect this. I could only see white with shadows and bright objects like windows. Around day 10, I was surprised to see the bottom of the gas bubble. It was in my upper field of view (remember that the lens inverts the image before it is focused on the retina). In Figure 3, this gas-fluid interface looked horizontal, so I measured how far it was above the horizon. I saw lots of very strange reflections off of this gas-fluid interface. Later at about day 40 the bubble started to look more like a circle and less like a line. So I started measuring the radius of curvature of the bubble. The ophthalmological literature emphasizes the *volume* of the bubble Woon, et al. [3], which may be scientifically more relevant. But as the patient I did not care about the volume. I only cared about what was happening in my visual field. Figure 3 is for one patient only, with C₃F₈ gas only and in only one operation, although after the other two operations the bubble behaved the same way.

August 3, 2008

Since the implant of the scleral buckle, my eyes were misaligned (strabismus and diplopia). On this date I was finally able to align the left and right eye images, albeit with difficulty and not for long.

September 11, 2008, Distorted Vision

The gas bubble from the second detached retina operation was gone after 10 weeks. The left eye retinal image had become wrinkled. The width of the image of the left eye was around $\frac{3}{4}$ the size of the right eye. See Figure 4. With the left eye, everyone looked like a pinhead, or a person in an El Greco painting. The scotoma in the lower-left quadrant resulted from peeling the inner limiting membrane (ILM). The ophthalmologists' had no instruments that could produce a figure like this. The misalignment of the left eye had become smaller and I was able align the two eyes. Thus the tropia had become a phoria.

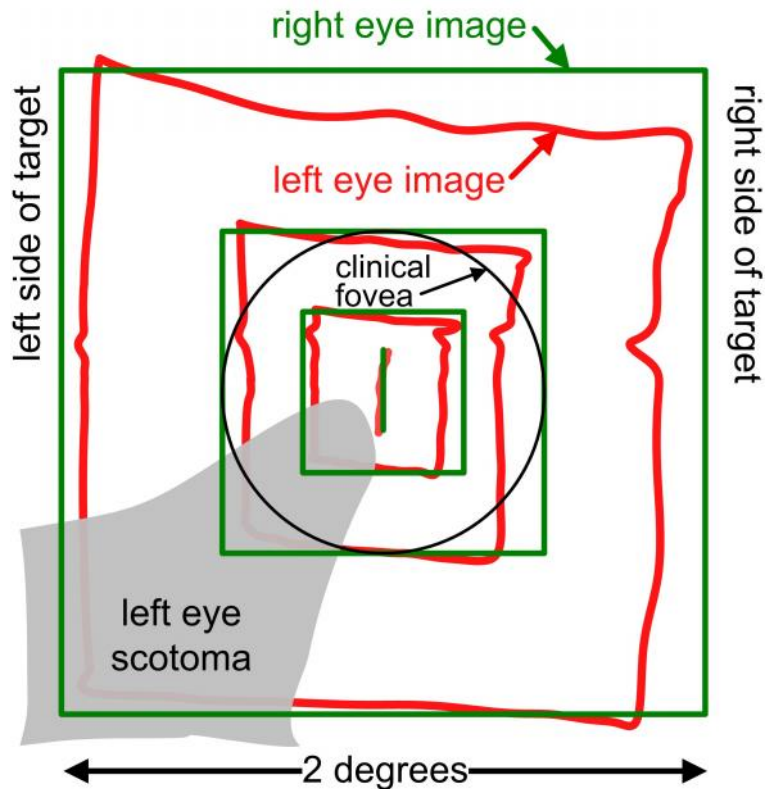


Fig. 4. The patient's viewpoint of binocular viewing of a small target. The right eye's image (green) is the same as the visual target. The left eye's image (red) shows the distortion due to a wrinkled retina or macular pucker.

September 12, 2008, Third Bubble

During a routine office visit, Ophthalmologist-4 found a new tear in my retina. He repaired it with 60 pulses of a head mounted laser. He inserted a cryopexy probe on top of the eyeball near the scleral buckle to freeze (cryopexy) the area of the retina above the tear. He removed some fluid from the eyeball and inserted a new

243 bubble of C₃F₈. But he was doing these procedures while he was seeing other regularly scheduled patients.
244 So he finally gave up and asked me to come back the next day.

245 September 13, 2008, Many Laser Pulses

246 Saturday morning we returned at 8 AM. Ophthalmologist-4 administered 567 laser pulses. Ophthalmologist-4
247 said, "I know you want to ask, why? The answer is bad luck." Over the next few months, there were varying
248 degrees of vertical, horizontal and cyclorotational disparities between the two eyes due to the misdirection
249 (phoria) of the left eye. The pain on the back of eye and the double vision (diplopia) started with the first
250 surgery on May 12, 2008. But the phoria might have been exacerbated by the cryopexy freezing on
251 September 12, 2008. At this time, with the left eye, everyone looked like Don Quixote, tall and skinny.

252 At this time, my symptoms were (1) inflammation and pain in the front of the left eye, (2) pain behind the left
253 eye, (3) pain in the brain, (4) double vision, (5) lack of depth perception, (6) poor visual acuity in the left eye
254 due to a wrinkled retina, and (7) poor vision in the *right* eye due to a cataract.

255 October 29, 2008, Macular Edema was Noticed

256 Using a Heidelberg Engineering OCT instrument, Ophthalmologist-4 noted cystoid edema in the macular
257 area. He also noted that the retina was reattached.

258 March 9, 2009, Attempts to Eliminate Edema

259 The image of the left eye was about ¾ the size of the image of the right eye. The left eye's image was
260 wrinkled. Ophthalmologist-4 had been recommending use of cortical steroids (drops and injections) for five
261 months trying to flatten the macula. There was fluid behind the retina. At various times he called it
262 inflammation, swelling, fluid, a cyst and cystoid macular edema: for the rest of this paper I will refer to this as
263 macular edema. Ophthalmologist-4 noted that the inner limiting membrane (ILM) was not thickened. He
264 injected corticosteroids (Kenalog) directly into my eyeball. I probably had a reaction to the carrier or the
265 preservative (benzyl alcohol), because the Kenalog turned into white crystals and I was blind in that eye for a
266 week. The intraocular pressure shot up to 30 mm Hg. Thirty-six drops of three different eye medicines per
267 day (spaced at least ten minutes apart) brought everything back to "normal."

268 June 1, 2009, The Right Eye

269 A small inconvenience was caused by the cataract in my right eye. I had intended to have it removed soon
270 after the cataract in the left eye. But when the left retina started falling off, the doctors suggested that nothing
271 be done to the right eye until the left eye stabilized. For about a year, I did not drive my car. Ophthalmologist-
272 5 removed the cataract in the *right* eye and replaced it with a 13 diopter artificial intraocular lens. Although
273 the right eye was *her* eye, she spent a good deal of time examining and tracking the progress of the left eye.

274 July 10, 2009, Kenalog

275 Ophthalmologist-4 injected *preservative-free* Kenalog into the left eyeball. It did not react adversely. It did
276 help with the fluid behind the retina.

277 September 4, 2009, Summary of Symptoms

278 The left eye's image was smaller than the right eye's image, it was wrinkled, it was about eight degrees up,
279 four degrees to the right and was rotated about three degrees clockwise. I had a (possible) aniseikonia
280 headache. I had no depth perception for near objects: therefore, threading a needle, tying a hook on a fishing
281 line or pounding in a nail was difficult, or near impossible.

282 I wore a black patch over my left eye to see if that would reduce the pain in the brain. That helped, but
283 Ophthalmologist-4 asked me to stop doing that, because he was afraid the brain would shut down that eye if
284 I stopped using it. So for about six months, I wore a black patch over my left eye when reading or working on
285 the computer and I wore a black patch on my right eye when I was teaching, riding in a car or watching
286 television. This reduced the pain in the brain.

287 October 16, 2009, Planning the Seventh Retinal Surgery

288 At a routine appointment, Ophthalmologist-4 worried about the macular edema and scheduled surgery for
289 October 20. He said that he will go in with his microscope, look, see what is there and try to remove it. He
290 said, "I *think* this will work."

291 October 20, 2009, Peeling the ILM

292 Ophthalmologist-4 peeled the inner limiting membrane (ILM) over the macula. The normal inner limiting
293 membrane is a diffusion barrier between the vitreous and the ganglion cells of the retina. It is about two

microns thick. He removed an area about one mm in diameter. He did this manually, quite a feat! Then he injected Kenalog into the eyeball (fresh hospital Kenalog is preservative free). Note added in 2013: The purpose of peeling the ILM was to reduce the edema, not to improve visual acuity [4] [Nadal], because visual acuity seldom improves after a macula-off detachment. Peeling of the ILM is used to repair macular holes. However, it has side effects. Tadayoni et al. [5] wrote "ILM peeling may reduce retinal sensitivity, and significantly increase the incidence of microscotomas.... We found that mean retinal sensitivity was significantly lower ... in eyes that underwent peeling than in those that did not. Postoperative microscotomas were also significantly more frequent in eyes that had undergone peeling...."

October 21, 2009, Follow-up Exam

The day after the surgery, he said, "That will be your last operation on that eye: that eye can't take any more surgery: it was hard to get the membranes back together." Ophthalmologist-4's practice schedules a patient every ten minutes. Well on that day he said, "They're trying to kill me. Today they have scheduled 89 patients for me."

November 2, 2009, No Progress

I told Ophthalmologist-4 that peripheral vision in the left eye was good: but the left eye's image was still smaller than the right eye's image. Since the operation, the left eye's image had a two-degree diameter gray-brown cloud over the fovea. He looked and said that it was a hemorrhage and that was not unusual: it will probably go away.

For the last year and a half I have reported to Ophthalmologist-4 that I have had the following symptoms: (1) pain in the front of the left eye, (2) pain behind the left eye, (3) pain in my brain, (4) double vision (diplopia) due to left eye phoria, (5) lack of depth perception (stereopsis), and (6) poor visual acuity in the left eye due to a wrinkled retina and, since peeling the ILM, a scotoma (an area in the field of vision where the subject sees nothing) in the inferior temporal macula as shown in Figure 4.

June 23, 2010

I visited Ophthalmologist-4. Vision in the left eye has been about 20/60 for the last seven months. I could obtain this only by scanning across the letters and recognizing them with peripheral vision. There was tremendous variability in this measure. Peeling the inner limiting membrane (ILM) over the macula has made the vision worse. At this time, we lost confidence in Ophthalmologist-4 and switched to Ophthalmologist-6.

July 27, 2010, New Ophthalmologist

I asked if it would help if we removed the scleral buckle. Ophthalmologist-6 suggested *not* removing the sclera buckle. His optical coherence tomography (OCT) confirmed fluid behind the retina.

At this point my symptoms (and possible known causes) were (1) pain in the front of the left eye and light sensitivity (perhaps caused by the haptics of the artificial lens interfering with the iris), (2) inflammation and intermittent pain behind the left eye (perhaps caused by the sclera buckle or damage to the superior rectus and superior oblique muscles), (3) pain in the brain. [Surely, this had many causes. It could be a continual retinally induced aniseikonia headache (asthenopia). The MRI's did not reveal a cause. A neurologist found no reason for them. They are not migraine or cluster headaches.] (4) left eye phoria [When looking straight ahead, the left eye's image was rotated about three degrees right, two degrees up and five degrees clockwise. (This may have been caused by the sclera buckle or damage to the superior rectus and superior oblique muscles)], (5) diplopia and lack of stereopsis (caused by the phoria and the wrinkled retina), (6) poor visual acuity (caused by a wrinkled retina and a scotoma in the inferior temporal macula).

At this time, Optical Coherence Tomography (OCT) images were the cat's meow of ophthalmology. The OCT instrument scans the retina with a laser beam. It stores this information in a computer as a three dimensional model of the eye. The OCT images of my eye showed fluid under the retina, so the doctors tried to get rid of that fluid. That fluid caused an elevated thickness at two places in the retina. They were about five degrees left and right of the fovea. Visual field analysis does not have the resolution to show such defects. In fact, when I looked for evidence of such defects I could not find any. So the OCT images showed a new type of pathology and my ophthalmological treatments over the last two years were directed to reduce these fluids and those potential defects.

At most of my eye exams since May 2007, before dilation, someone would measure the pupillary reflexes. The right eye was normal; the left eye was non-circular and non-responsive (tonic). I presumed that these test results were entered into my records and read by the doctor: but no ophthalmologist ever commented about this anisocoria.

347 November 5, 2010, Letter to Ophthalmologist-6

348 Visual acuity in the left eye is about 20/70. However, viewing a Snellen chart is a primitive indicator of vision.
349 For example, it does not disclose the important additional information that the brain has shut down vision of
350 the left eye by about 1.5 log units. That is, if I want to see a target equally with both eyes in the same
351 illumination, then I must put a 1.5 log unit neutral density filter in front of the right eye to equalize the
352 perceptual disparity between the eyes. It also fails to disclose retina wrinkles and scotomas as shown in
353 Figure 4. It does not reveal lack of stereopsis or color vision deficiencies. Given time, I would saccade across
354 the proper letter of the Snellen chart and recognize it with off-foveal vision.

355 December 3 and 8, 2010, MRIs

356 MRIs of the brain and left eye orbit showed no cause for the pain in the brain. This pain seems to be
357 localized in a cylinder two inches in diameter stretching between the temples.

358 December 10, 2010, Diagnosis of Phoria

359 The optometrist measured the misalignment of the eyes. This was the first time that anyone had measured it.
360 He suggested that the pain in the back of the eye and the vertical, horizontal and cyclorotational disparities
361 between the two eyes were due to the sclera buckle and the effects of the surgery on the superior rectus and
362 perhaps the superior oblique muscles. He prescribed new spectacles with horizontal and vertical prisms for
363 both eyes. These spectacles got rid of some of the pain in the back of the eye and attenuated the pain in the
364 brain. Since the first retina operation, when looking straight ahead (eyes in primary position), my left-eye
365 image was $5.7^\circ \pm 1.5^\circ$ right, $3.6^\circ \pm 2.3^\circ$ up and $4.5^\circ \pm 1^\circ$ clockwise. The optometrist recommended spectacles
366 with horizontal prisms of 1 Δ base-in for both eyes, and 2 Δ base-down for the OD and 2 Δ base-up for the
367 OS. Although it is only the left eye that is misaligned, half of the needed prism correction is put into each
368 spectacle lens. Note added in 2013: alternative words that describe my eye position at rest are that the left
369 eye was abducted 5.7° , depressed 3.6° and excyclorotated 4.5° .

370

371 December 29, 2010, Diagnosis of Tonic Pupil

372 The optometrist told me that the right eye pupillary response was normal, but the left pupil was dilated,
373 oblong shaped, with the pulling point at 11 o'clock, and was nonresponsive (tonic). The optometrist wanted
374 to run an experiment to see if the origin of the tonic pupil was mechanical or neural. One possible neural
375 cause of the tonic pupil was an injury (during the surgeries) to the axons in the short ciliary nerve between
376 the ciliary ganglion and the ciliary muscles. So he called a retina specialist distantly involved with my case,
377 Ophthalmologist-8. Together they decided that pilocarpine (a pupil constrictor) might help and would not hurt.
378 The pilocarpine did not cause the pupil to constrict; therefore the tonic pupil was due to mechanical not
379 neural restraints. The pilocarpine was then discontinued. This experiment led us to think that perhaps the
380 haptics were hooked into the iris. However, we did not have an instrument that could image the haptics. Note
381 added later: This situation led to the lens replacement surgery of July 21, 2011.

382 January 24, 2011, Confirmation of Tonic Pupil

383 Ophthalmologist-7 noted that the left pupil was an oblique oval with a diameter of 5 mm. Prism cover testing
384 showed 5 prism diopters.

385 January 31, 2011, Summary of Symptoms

386 I gave the optometrist the following summary of my symptoms: (1) inflammation and pain in the front of the
387 eyeball. I described it as a scratchy, blood-shot irritation of the eyeball. This pain was intermittent. It came on
388 a half-dozen times a day and lasted 10 or 20 minutes. The left eye was light sensitive. After walking the dog
389 in the sun for a half-hour, the eyelid was almost closed and the eye hurt. (2) Pain in the back of the eyeball:
390 an intermittent localized pain, sometimes sharp, sometimes dull. It felt like a foreign body was trapped in the
391 orbit. I attributed it to the sclera buckle or to inflammation around the buckle. This pain had been there for
392 two years. (3) Pain in the brain. A continual periphery-induced aniseikonia headache (asthenopia). My brain
393 hurt when I got up in the morning: it got worse as the day went on. I had put a black patch on the left eye for
394 close vision like reading on a computer screen and on the right eye for distance vision like when watching TV
395 or being outside. That helped, but Ophthalmologist-4 asked me to stop doing that. So I put a small (one
396 degree) dot on the left lens. This blocked the distorted left eye image and caused the left eye to use
397 peripheral not foveal vision. I had hoped that this would ameliorate the static aniseikonia. The optometrist's
398 prism spectacles did help with the pain. Roughly, the pain seemed to be localized to a region between the
399 temples. If I rubbed the temples, it helped. This pain got worse a half-dozen times a day. These episodes
400 lasted a half hour. However, the MRIs found nothing and my neurologist found nothing wrong. (4) If I bent

401 over and to pick up something from the floor the left eye hurt. About once a day, I lose my balance and
402 almost fall.

403 I wrote that Ophthalmologist-7's report said that all four of these pains were consistent with the eight
404 operations that were done on that eye. He offered nothing to relieve the pains.

405 Spring 2011, Finding a Specialist

406 Now the biggest difficulty was finding an ophthalmologist who had the experience and instruments to handle
407 this one-in-a-million problem. Finally, Ophthalmologist-5 recommended Ophthalmologist-9, with whom she
408 had done a fellowship, at the UCLA Medical School. Ophthalmologist-9 was a professor of ophthalmology
409 specializing in the anterior chamber (cataracts and refractory surgery).

410 May 6, 2011, First visit to Ophthalmologist-9

411 Ophthalmologist-9 and two of his Fellows spent over an hour examining me. He wrote in his report, "Ocular
412 Motility... With Distance Fixation cc: 6 prism diopter left exotropia and 4 prism diopter left hypertropia, Left
413 incyclotortion persists after horizontal and vertical deviations are neutralized.... The left pupil was 3×4 mm,
414 oval, and peaked at the 11 o'clock position... posterior synechiae [meaning places where the iris adheres to
415 lens] at the superonasal optic-haptic junction... A single posterior synechia is noted at the 11 o'clock
416 position. The iris is stuck to the optic-haptic junction at this location... The quality of the central vision in his
417 left eye is poor. He must scan over letters to read them, and even when he does, his acuity is not very good."

418 June 17, 2011, Preoperative Visit

419 Ophthalmologist-9 noted, "2 permanent sutures that are attached to the scleral buckle tent up, but do not
420 pierce the conjunctiva."

421 July 21, 2011, Lens Exchange Operation

422 Ophthalmologist-9 noted significant posterior synechia superonasally, an eccentric pupil, and a chafe
423 between the iris and the square edge of the intraocular lens. He performed refractive cataract surgery with
424 peripheral corneal relaxing incisions. He removed the artificial lens in the left eye and replaced it with a type
425 of lens that was designed to be placed in the ciliary sulcus (Starr Surgical AQ20110V). In two months the
426 pain in the iris was gone, but the pupil was still noncircular and nonresponsive (tonic).

427 Ophthalmologist-9's reports were excellent: they were clear, specific and detailed and he made sure that
428 copies were sent to all seven of my previous principal doctors. Evidentially the optometrist and the eight
429 ophthalmologists that had examined me before had never seen this particular cluster of symptoms. So, I was
430 a rare patient. I think that doctors in medical schools are more experienced in dealing with rare cases. So, in
431 retrospect, when I realized that my case was so rare and I found Ophthalmologist-9 at a medical school that
432 solved my major problem, perhaps I should have stayed with him, even though it would have meant frequent
433 trips between Tucson and Los Angeles and a more expensive medical insurance plan.

434 January 25, 2012, Revisiting the Pain Behind the Eye

435 The optometrist notes inflammation of the sclera and of the anterior chamber. He prescribed Bromday and
436 Pred Forte. This prompted Ophthalmologist-6 to inspect the suture securing the scleral buckle.

437 May 8, 2012, Ophthalmologist-6 is Optimistic

438 In his consultation report Ophthalmologist-6 wrote, "Bahill was in again with his remarkable scientific
439 knowledge and his scientific analysis of what is happening in his left eye. ... Summary: The only treatable
440 condition here is the macula edema."

441 June 4, 2012, Old Suture Removed

442 For four years, my sclera was inflamed, blood-shot and it hurt. Bromday seemed to be helping. But on June
443 4, in an in-office operation, Ophthalmologist-6 removed an exposed Dacron suture in the sclera from the
444 original scleral buckle operation of May 12, 2008. The pain dropped by 40%. But then he noted a 2 mm
445 fistula in the conjunctiva over the scleral buckle. He consulted with his partner, Ophthalmologist-10, and then
446 suggested an operation in the hospital.

447 July 18, 2012, Fistula Sutured

448 Ophthalmologist-6 sutured a conjunctiva fistula in the sclera over the scleral buckle. The operation went well,
449 except that the area became infected. Ophthalmologist-6 and Ophthalmologist-10 treated the infection with
450 Ofloxacin and Neo/Poly/Gram.

451 November 6, 2012, Large Macular Edema

452 The optometrist noted that his OCT instrument showed an overall retinal thickening with a maximum
453 thickness near 500 microns in the area centered five degrees temporal of the macula. The optometrist
454 recommended that I accelerate my next visit with Ophthalmologist-6 and sent a consultation letter to him.

455 November 26, 2012, Treatment of Macular Edema

456 Ophthalmologist-6's OCT instrument replicated this macular edema with a thickness of 427 microns in the
457 area centered five degrees temporal of the macula. He recommended reapplication of cortical steroids
458 (Durezol) four times a day. Table 2 summarizes the eye drops that I have taken.

459

460 **Table 2. Over the last six years, ATB has used the following eye drops.**

Category, Purpose	Generic Name	Brand Name
Corticosteroid, Anti-inflammatory	Difluprednate 0.05%	Durezol® emulsion
	Prednisolone acetate 1%	Omnipred®
	Prednisolone acetate 1%	Pred Forte®
	Triamcinolone acetonide	Kenalog® (by injection)
NSAID, Anti-inflammatory	Bromfenac 0.08%	Xibrom™
	Bromfenac 0.09%	Bromday™
	Ketorolac 0.4%	Acular®
Vasoconstrictor, Antihistamine, Anti-inflammatory	Naphazoline HCl, Pheiramine Maleate	Naphcon A®
Intra-ocular pressure reduction		
alpha agonist	Brimonidine tartrate 0.15%	Alphagan®
beta-adrenergic blocker	Levobunolol HCl 0.5%	Betagan®
cholinergic agonist	Pilocarpine HCl 1.0%	
Antibiotic	Gatifloxacin 0.3%	Zymar®
	Gatifloxacin 0.5%	Zymaxid™
	Moxifloxacin HCl 0.5%	Vigamox® Solution
	Neo/Poly/Gram	Neosporin®
	Ofloxacin 0.3%	Ocuflox®
Artificial Tears and Lubricants	Propylene glycol	Systane®
HCl means hydrochloride		

461 December 27, 2012, Miraculous Cure

462 The macular edema had started in 2008. It was detected and measured with OCT scans. It was treated with
463 corticosteroid eye drops Omnipred® and Pred Forte®, injections of Kenalog®, peeling of the inner limiting
464 membrane (ILM) over the macula, and eye drops of Xibrom™, Bromday™, Acular® and finally Durezol® four
465 times a day. By Christmas, in one of the most successful treatments (or coincidences) for my eye in four
466 years, the swelling of the retina had nearly disappeared. The area of concern had thinned by 160 microns; it
467 was now thinner than the right eye retina! Ophthalmologist-6 recommended continuing Durezol but only once
468 a day. On March 9, 2013, a small amount of macular edema had returned. We increased Durezol to twice a
469 day and by March 27 most of the macular edema had gone away. On July 11 the edema was almost
470 completely gone. Unfortunately, this did not cure visual acuity deficit.

471 December 29, 2012, More Mysteries

472 If there was only one object in my visual field and it was a small green dot of light, then it appeared green to
473 my right eye and bluish-white to my left eye. This was repeatable in intraocular pressure tests (glaucoma air-
474 puff test, Reichert AT555 non-contact tonometer). Several times, a white dot in a Goldman visual fields test
475 appeared green. Also the left eye did not show negative color after images. I had mentioned these
476 peculiarities for two years, but I did not have experiments to explain them.

477 March 27, 2013, Color Blindness

478 The fovea of the left eye is color blind. When a small (0.07 degree diameter) green dot of laser light was
479 positioned on my fovea, it appears green to the right eye and bluish-white to the left eye. This was
480 repeatable in intraocular pressure tests and with lasers in my laboratory. These effects would be consistent
481 with destruction of retinal ganglion cells [6] [Kolb] while peeling the inner limiting membrane (ILM) of my left
482 eye. It might also be consistent with the brain shutting down the left eye by one or two log units. With the left
483 eye viewing through a 10-degree field of view, the Ishihara test for color blindness [7] [Flück] indicated I
484 perceived 2 of the 22 test plates correctly, indicating color blindness, but not *red-green* color blindness.
485 <http://www.colour-blindness.com/colour-blindness-tests/ishihara-colour-test-plates/>. On the X-Rite color IQ
486 test, a simplified on-line version of a Farnsworth-Munsell 100 Hue Test,
487 http://xritephoto.com/ph_toolframe.aspx?action=coloriq,
488 my right eye scored 16, which is low and therefore good. My left eye scored 182, which is poor and in the
489 99th percentile. This is an unusual example of a color anomaly that is not based a defective gene responsible
490 for producing the green photo-pigment (deuteranopia). It could be based on destruction of retinal ganglion
491 cells.

492 3. DISCUSSION

493 Table 3. Summary of ATB's ocular status October 2013

Description (name)	Probable cause	Primary solution	Present condition, 100% is best
Pain on the front of the left eye and light sensitivity	The iris was stuck to the square edge of the intraocular lens or to the haptics, thereby immobilizing the iris.	Replacement of the intraocular lens	90%, the pupil is still tonic
Pain behind the left eye	Sclera buckle, its sutures and damage to the superior rectus and superior oblique muscles	Removing exposed suture & suturing conjunctiva fistula over the scleral buckle	80%, the muscles are still damaged
General pain in the left eye	Inflammation of the sclera and in the anterior chamber	Corticosteroid eye drops	50%
Pain in the brain	Different images from the two eyes and something else	Reducing dynamic aniseikonia	60%
Poor visual acuity in left eye	Scotoma in the macula, wrinkled retina, macular edema, color deficiency	Corticosteroid eye drops	60%
Size and shape of the images are different in the left and right eyes (static aniseikonia)	Macula-off detached retina, peeling the ILM, subretinal edema and disruption of retinal pigment epithelium	Corticosteroid anti-inflammatory eye drops	10%
Double vision. At rest, the left eye's image drifts up and to the right of the right eye's image. (dynamic aniseikonia, phoria, diplopia)	Damage to or interference with the superior rectus and superior oblique extra ocular muscles	Prisms in spectacles	70%
Lack of depth perception for objects within ten feet. (lack of stereopsis)	Static and dynamic aniseikonia	None	0%
Color blindness in left fovea	Peeling the ILM	None	20%
Poor vision in the right eye	Cataract	Replaced natural lens	100%

494

495 3.1 Quality of Life

496 Because the images in my two eyes are of different sizes and shapes, it is difficult, error prone and time
 497 consuming to read. homework (I often misperceive or skip words), grade exams, read textbooks, grade tests
 498 and read project reports. I do not recognize student faces as well as I used to. My ability to read lips is
 499 diminished, so my hearing impediment is exacerbated. The lack of stereopsis (depth perception for objects
 500 within 10 feet due to the difference in the images of the two eyes) makes it dangerous to climb stairs or even
 501 walk on a sidewalk. I lose my balance daily, but fortunately, I have only fallen few times, once I broke my
 502 fibula. This lack of depth perception makes it difficult to tighten a small screw, zip up a jacket, pound in a nail,
 503 put a nut on a bolt, or twist a wire around a receptacle screw terminal.

504 ~~When delivering a lecture, intermittent pain in the left eye breaks my concentration and I have to restart a~~
 505 ~~derivation from the beginning. Because of the constant headaches, I cannot think quickly, this makes~~
 506 ~~teaching ineffective.~~

507 ~~The scleral pain often interrupts me in mid-sentence. Sometimes I can resume my sentence and sometimes I~~
 508 ~~cannot. Sometimes the pain interrupts me in the middle of the other person's sentence. All I can do is turn~~
 509 ~~away, wait a while, apologize and then ask them to restart their train of thought. These pains occur a few~~
 510 ~~dozen times a day: they last for about 10 minutes.~~

511 The pain in my brain varies (on a scale of 0 to 10) from 1 to 4. It spikes about a dozen times a day and these
 512 episodes last about 15 minutes, but sometimes they last for hours. This pain prevents me from working on a
 513 computer for extended periods. Sharp occurrences of pain make it impossible to maintain a continuous long
 514 chain of thought. Therefore, I cannot write papers or proposals. ~~This pain peaks in the afternoon.~~

515 ~~After walking in the sun for a half-hour, working on a computer terminal for two hours, driving at night for one-~~
 516 ~~quarter-hour or after 9 PM my left eye has closed itself.~~

517 ~~A few years ago when people asked me when I planned to retire, I would answer, "Between one and ten~~
 518 ~~years from now: I'll work until some administer pisses me off." But my disability finally caused me to~~
 519 ~~"voluntarily relinquish [my] employment, tenure, and/or continuing status at the university" in May 2011.~~

520 3.1 The Systems Approach

521 Starting in 2007, I continually complained of these symptoms (1) inflammation and pain in the front of the left
 522 eye, (2) pain behind the left eye, (3) pain in the brain, (4) left eye misalignment (phoria), (5) double vision
 523 (diplopia), (6) lack of depth perception (no stereopsis), (7) poor visual acuity, (8) foveal color blindness, (9)
 524 light sensitivity and (10) a non-circular and non-responsive pupil. These ten complaints seemed like ten
 525 different problems. This is like the story of seven blind men describing an elephant: each saw a different
 526 aspect. But now we can see the relationships between these problems. We can understand this medical
 527 history as a system, instead of ten isolated events. As shown in figure 5, it can be seen how treating one
 528 symptom affected other symptoms.

529

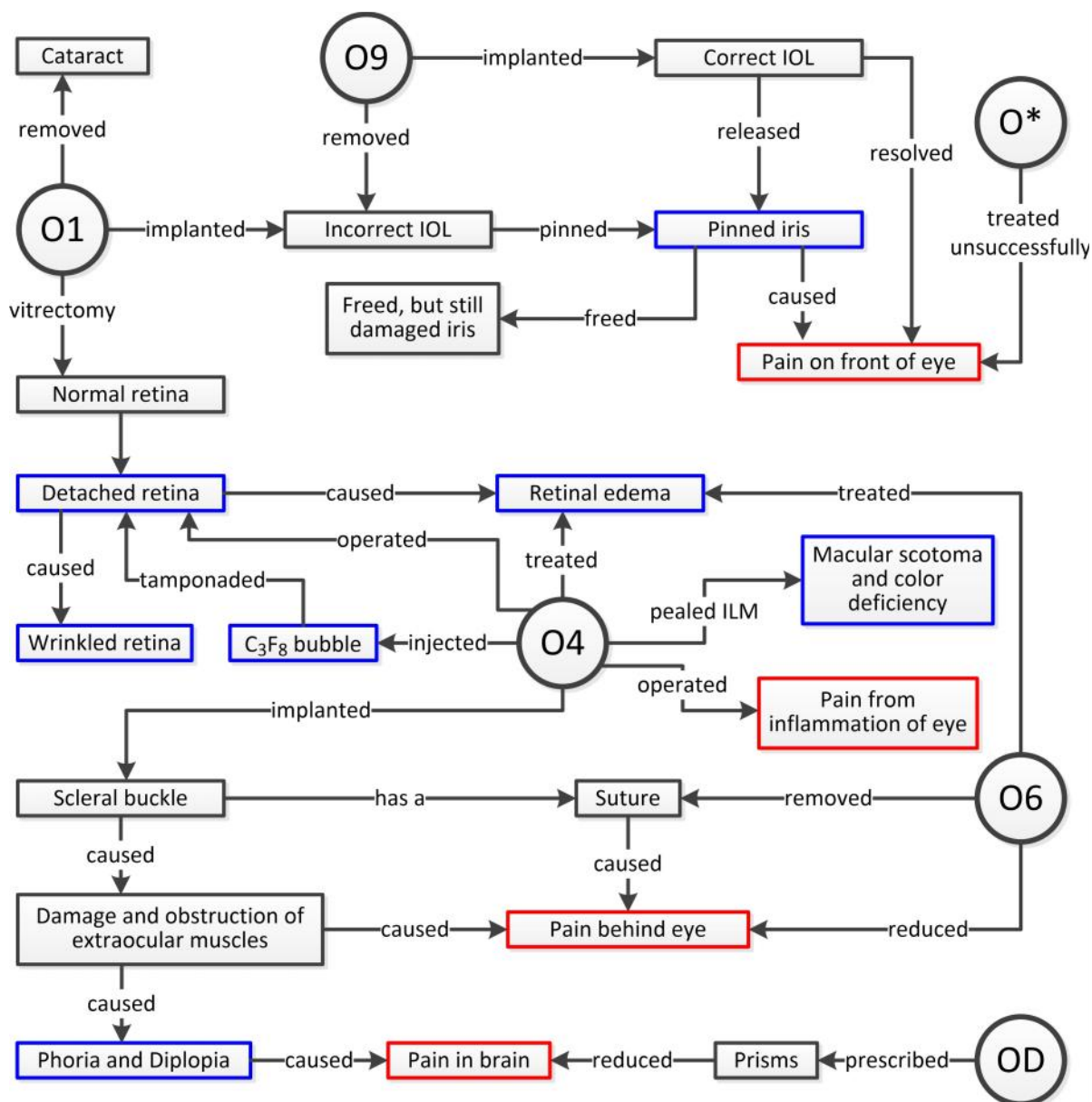


Fig. 5. Ocular history of ATB's left eye represented with objects and their relationships. O1 to O10 represent the ten Ophthalmologists, with O* meaning many. OD represents the Optometrist. IOL stands for intraocular lens. ILM means inner limiting membrane. Boxes with thick blue borders are states with reduced quality of vision. Boxes with thick red borders are states associated with pain.

For years, I had a dozen doctors and a dozen symptoms: each doctor treated his most familiar symptoms, one at a time. This shows the need for face-to-face communication between the ophthalmologists and optometrists. If we had understood this system years ago, my treatment surely would have been different.

4. LESSONS LEARNED

4.1 Pain

Medical doctors have difficulty successfully treating pain, even if it is in their realm of study and experience. Pain is hard to diagnose, measure, quantify and treat, making it frustrating for both the patient and the physician. If the cause is not visually obvious (either to the naked eye, in photos, CAT scans or MRIs), then many times it is not successfully treated. In this particular case, for the last five years most ophthalmologists did not think that they could resolve my complaints about pain.

In fact, Ophthalmologist-6 wrote in his May 8, 2012 consultation report, "Bahill was in again with his remarkable scientific knowledge and his scientific analysis of what is happening in his left eye. He still complains of bi-temporal headaches, which I do not believe are related to his eye disease. If there is any

connection it is purely stress or depression related as a result of his concern for his left eye. ... Summary: The only treatable condition here is the macula edema. Hopefully successful treatment will improve the acuity and bring him back to where he was." But on June 4, in an in-office operation, Ophthalmologist-6 removed an exposed Dacron suture in the sclera from the original scleral buckle operation. The pain that had bedeviled me for six years dropped by 40%. On July 18, in an in-hospital operation, he sutured a conjunctiva fistula in the sclera over the scleral buckle. The pain dropped by 20%. In summary, in May he said that the only improvement that could be made was reducing the macular edema: but in June and July he performed operations that substantially reduced the pain. It is hard to predict pain resolution.

Before each of my operations the ophthalmologist discussed the likely outcomes and the risks of the operation. However, none of them mentioned the risk of potential postoperative pain. We believe that the ophthalmologist should know about the types of pain that could result from each type of ocular surgery. They should describe (ideally with a brochure) what the pain would be like. They should tell the patient what to do if such pain occurs. And then they should explain what they will do to alleviate the pain and correct the operation.

4.2 Communications

From this case, we have learned a little bit about the medical profession. I was not simply jumping around trying to find a doctor that could cure my problems. Instead, most of these doctors were working together to help me. Certainly, they exchanged referral reports. One pair talked on the telephone, and another pair talked in person about this case. Perhaps it would have been better if there were more face-to-face communications, but that would have required extra time, money and recourses.

Most of their communications were implemented by low quality FAX. Their referral reports varied in quality: some were incomprehensible because the doctor used a canned report generation program, some were superficial, some were mere boilerplate, but the reports of one doctor were truly excellent. It is important that the patient and the doctors ensure that all relevant parties (including the patient, when appropriate) get copies of the reports. In my experiences, most of the times this link failed.

4.3 Selecting a Doctor

I have found that searching the Internet and asking friends for recommendations about good ophthalmologists was not useful. People tend to make recommendations based on only a few data points. Searching the Internet to find specific procedures that I wanted the doctors to use was futile. My best results came from asking doctors that I trusted for referrals and then trusting the judgments of these doctors [although this process was also fallible]. In the future, I will ask what the ophthalmologist's patient load is. I will not recommend ophthalmologists who schedule six or more patients per hour nor the cataract surgeons who schedule four operations per hour.

However, an anonymous reviewer of this paper wrote, "a retina surgeon seeing 6 patients per hour is the norm and most in private practice see up to 10 per hour. That's the reality of being a small businessman.... Likewise face-to-face communication for each patient is impossible with physicians seeing 500+ patients per week and none in the same location"

In the last five years, I have had ten eye operations and 130 doctor's visits. I estimate that, on average, (a) the ophthalmologists scheduled a patient every 20 minutes with a standard deviation (SD) of 10 and a range of 10 to 60, (b) on each visit, the ophthalmologists or their staff spent 30 minutes with me with a SD of 15 and a range of 10 to 90, (c) Each operation lasted 65 minutes with a SD of 15 and a range of 30 to 90.

4.4 Invisible Gorilla

When people focus on a task that demands their attention, they often fail to notice unexpected objects and events that occur in full view. This phenomenon is known as *inattention blindness*, because people typically do not consciously perceive aspects of their world that fall outside of the focus of their attention [8] [Chabris and Simons]. Medical doctors are just like the rest of us: they suffer from *inattention blindness*; they only see what they expect to see.

From the very first surgery until today, I have complained about pain in the eye. In retrospect it seems that initially the pain was caused by the iris being trapped by the edge of the original intraocular lens: but it was difficult to figure this out, because people do not see what they do not expect to see.

On December 29, 2010, the optometrist broke the mold and gave me a through exam lasting 1.5 hours. He looked for unusual things. Finally, he told me that the right-eye pupillary response was normal, but the left pupil was dilated, oblong shaped with the pulling point at 11 o'clock, and was nonresponsive (tonic). This was the needed breakthrough. He had looked at the iris, which no one else had done.

Ophthalmologist-1 was looking for evidence of the success of his surgery; therefore, he only looked at visual acuity. He did not look at the iris. Ophthalmologist-3 was trained to look at the cornea; therefore, he did not look at the iris. Ophthalmologist-4 was trained to look at the retina; so he did not look at the iris. Ophthalmologist-5 was trained to look at the lens; so **she** did not look at the iris. Ophthalmologist-6 was trained to look at the retina; so he did not look at the iris. Ophthalmologist-7 was a neuro-ophthalmologist trained to look for neurological problems. He noted the tonic pupil, but did nothing about it. Ophthalmologist-9 was trained to look at the anterior chamber; so he did not look at the sclera on the back of the eye.

Before every exam, a technician would measure intraocular pressures, Snellen acuity and pupillary reflexes. The ophthalmologists usually commented about the pressures and the acuity, but none ever mentioned the abnormal pupil.

4.5 Process

In complicated procedures involving many physicians and many physical systems, it can be unclear who is in charge of the overall system. Some hospital rules force them to “work on only one body part at a time.” In addition, there is usually no patient’s advocate, who knows the system and is particularly interested in only the patients’ best interests. Perhaps both of these roles are played by the patient or a member of the patient’s family.

For every visit, the patient should have a written letter listing symptoms and questions to ask the doctor. It is the patient’s responsibility to make sure that the doctor reads the letter. Often he/she does not. Also, I guess that it is the patient’s responsibility to make sure that tests and measurements (such as intraocular pressure, visual acuity and pupil reflexes) made by technicians are read by the doctor, because the process does not.

The medical profession does not seem to have a strong culture of using feedback from the patients and other physicians. Often they do not even checkup on their own work. For example, ophthalmologist-1 never looked for possible complications of cataract surgery such as a trapped iris, cystoid macular edema, intraocular infection or signs of potential retinal detachment. Ophthalmologist-4 did not look for possible complications of retina surgery such as strabismus and diplopia and he did not look for possible complications of peeling the inner limiting membrane such as central scotomas.

4.6 Miscellaneous

Be sure to shake eye drops before use, because some are suspensions, not solutions or emulsions. In suspensions, the solids will eventually fall to the bottom. Try to use preservative free eye drops.

There is a journal article that might have a patient’s description of his visual images during the first month after a detached retina operation [14]. However, it is in French and I could not obtain a copy.

Professors in medical schools are probably more experienced in dealing with rare cases. When I realized that my case was rare and I found an ophthalmologist at a medical school that solved my major problem, maybe I should have stayed with him, even though it would have meant frequent trips between Los Angeles and Tucson.

Finally, my advice **to you** is, do not accept an appointment for surgery right before the surgeon is scheduled for vacation! The surgeon may be distracted and you will miss out on follow-up care.

5. CONCLUSION

(1) Pain is hard to diagnose, measure, quantify and treat, making it frustrating for both the patient and the physician: in my case there were many causes of pain, which caused confusion. (2) There was no face-to-face communication between the dozen doctors that were involved in this case: furthermore, many times the written communications were not received, read or understood. (3) In complicated procedures involving many physicians and many physical systems, perhaps there should be a patient’s advocate, who knows the system and is interested only in the patients’ best interests. (4) I found the best metric for choosing a doctor was the amount of time that he or she scheduled for each appointment or operation. (5) For the last six years, I complained about ten specific symptoms, which were treated individually: treating this case as a system of interacting problems led to a better understanding and resolution.

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653 **COMPETING INTERESTS**

654 Neither author has any conflicts of interest with regards to this paper: furthermore, we believe that there is
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656 **AUTHORS' CONTRIBUTIONS**

657 Bahill designed the study, performed the statistical analysis, wrote the protocol, and wrote the first draft of
658 the manuscript. Barry provided the medical instruments, measurements, clinical images, and medical
659 expertise.

660 **CONSENT**

661 The patient has given his informed consent for this report to be published.

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699 **APPENDIX: SUCCESS RATE**

What is the success rate for medical procedures? That is a hard question to answer, because it depends on the patient, the surgeon, the year, the operating equipment and conditions, and the definition of success. This appendix will examine published success rate examples for cataract and detached retinal operations. The percentages do not total to 100% because each study had different numbers of patients and different definitions for the outcomes, which were not mutually exclusive. There is a lot of variability in these numbers as is demonstrated by the large standard deviations.

A.1 Cataract Surgery Success Rate

According to the American Society of Cataract and Refractive Surgery, three million Americans undergo cataract surgery each year, with an overall success rate of 98 percent. I presume this success rate was defined as the biological lens with the cataract was removed and an artificial intraocular lens was inserted. Papers published in the last decade have documented that 97% of cataract operations are completed successfully ($\bar{x} = 96.7$, $\sigma = 3.6$, $n = 11$) the numbers in parenthesis are (average, standard deviation, number of reports), while 0.8% had posterior capsule rupture [9][Lee], 1% caused cystoid macular edema that produced visual acuity less than 20/40 ($\bar{x} = 1.4$, $\sigma = 0.6$, $n = 8$), 12% produced cystoid macular edema that could be detected with fluorescein angiography or optical coherent tomography ($\bar{x} = 12$, $\sigma = 6.1$, $n = 6$), 0.7% caused intraocular infection ($\bar{x} = 0.7$, $\sigma = 0.4$, $n = 11$), which is called endophthalmitis, and 1% were followed by retinal detachment within a year [10] [Haug] and [11] [Clark]. In order to compute the expected success rate when there are multiple not mutually exclusive outcomes, we must recast all of these numbers as success rates not failure rates.

ATB had cataract surgery which has a 0.97 success rate, posterior capsule rupture 0.992, cystoid macular edema 0.99, intraocular infection 0.993, and retinal detachment within a year 0.99. This example is of one event with multiple not independent outcomes. Therefore, if we multiply these numbers together, we approximate the overall expected cataract surgery success rate of 0.95.

A.2 Detached Retina Surgery Success Rate

Of retinal detachment surgeries, about 90% are successfully repaired with a single operation. In the remaining cases, the retina detaches again and needs another operation that has a 50% success rate, which yields an overall success rate of 95%.

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Retinal_detachment.

One retinal detachment operation failure is ocular misalignment after surgery. Among 821 patients who underwent scleral buckle surgery 1.5% of the patients developed strabismus and diplopia <http://www.ncbi.nlm.nih.gov/pubmed/17978674>. Another study reported that among of 1030 patients who underwent scleral buckle surgery 3.8% developed strabismus and diplopia <http://www.ncbi.nlm.nih.gov/pubmed/22466475>. A third study reported that among of 750 patients who underwent scleral buckle surgery 3.3% developed strabismus and diplopia <http://80.36.73.149/almacen/medicina/ofthalmologia/enciclopedias/duane/pages/v6/v6c059.html>

The average for these three review papers is ($\bar{x} = 2.9$, $\sigma = 1.2$, $n = 3$).

Bensen [12] found that 55% of their patients who had scleral buckles implanted had cystoid macular edema a. k. a. subretinal fluid ($\bar{x} = 42$, $\sigma = 37$, $n = 9$). Less than 1% caused intraocular infection ($\bar{x} = 0.7$, $\sigma = 0.4$, $n = 11$).

ATB had at least two retinal surgeries with 0.95 success rate, developed strabismus and diplopia with 0.962, had intraocular infection 0.99, and had cystoid macular edema 0.58. The product of these numbers is 0.52. Multiplying this by the expected success of cataract surgery of 0.95 yields an overall expected success rate so far of 0.50.

A.3 Interlimiting Membrane Peeling Success Rate

Macular holes in the retina are commonly treated by peeling off the inner limiting membrane. This operation is effective in closing macular holes. However, ILM peeling has complications: 39% caused central scotomas [13] ($\bar{x} = 39$, $\sigma = 15$, $n = 5$), 0.1% resulted with infection, 1% produced retinal detachment and 75% created a need for cataract removal within one year: however, ATB already had that lens replaced so that number is omitted.

749 ATB had his inner limiting membrane peeled which has complications of central scotomas with a 0.61
750 success rate, infection 0.999 and retinal detachment 0.99. So, if we multiply these numbers together, we get
751 an overall expected ILM peeling success rate of 0.60.

752 Now we will state that the expected success rate for ATB's cataract surgeries, detached retina surgeries and
753 inner limiting membrane peeling is 0.3. This is a small success rate.

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