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COMMENTARY

A Patient Perspective on Quality of Life with wAMD: A Podcast

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ABSTRACT

Wet age-related macular degeneration (wAMD) is an advanced stage of AMD characterised by the rapid onset of acute vision loss. Vision loss limits daily activities, such as reading and driving, and therefore has a notable impact on quality of life. However, there is insufficient research focusing on the patient perspective on wAMD and its effect on quality of life. In this podcast article, a person with wAMD and an expert physician discuss the patient experience of wAMD diagnosis, disease progression and treatment, and the most important aspects of quality of life that should be preserved or improved. wAMD can progress extremely quickly, but diagnostic guidelines vary by region, so the words 'macular degeneration' are not heard by some patients until long after vision has been lost, if at all. The potential impact of wAMD on a person's life may never be explained, leading some people to rely on their own research. Therefore, patients may be unprepared for the subsequent effect on their lives and careers. The support of family is critical for maintaining quality of life. Working with a physician who understands an individual's communication preferences is also important for ensuring treatment adherence and maintaining good mental health; treatment for wAMD is typically administered via intravitreal injection, which may be alarming to patients who have not been informed well by healthcare professionals. Adapting to vision loss is key to maintaining quality of life, and magnification is especially useful for patients with wAMD. Furthermore, modern technology, such as smart phones and smart watches, greatly improves the accessibility of daily tasks. However, what is most important to patients is access to information about their disease—whether via an advocate, self-led research or a healthcare professional. Crucially, physicians must ensure that they speak to their patients in an informative but accessible manner.

Keywords: Age-related macular degeneration; Ophthalmology; Patient perspective; Retina; wAMD

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PODCAST TRANSCRIPT

Introduction to wAMD from a Physician and a Patient

Alexander Foss: Hello. I'm Alexander Foss, and I'm a consultant ophthalmologist at the Queen's Medical Centre, Nottingham, in the United Kingdom. I'm joined here today by Jill Adelman, a person with wet age-related macular degeneration, commonly known as wet AMD.

Jill Adelman: Hello, I'm Jill Adelman, and I have wet age-related macular degeneration. I was diagnosed approximately 7 years ago, and I live in Turnersville, New Jersey, in the United States.

Alexander Foss: As a brief overview of macular degeneration: it is a disease in people over the age of 50, with loss of one's central vision (central vision is very small, it's about the size of one's thumbnail, arm outstretched) but leaves one's peripheral vision intact [1, 2]. It interferes with such activities as faces, reading, watching television—and therefore has a big effect on one's quality of life [3]. It's subdivided into two major types, loosely called wet and dry; the dry form being a loss of cells to atrophy while the wet form is due to new blood vessel growth. Each patient will have their own experience of wet macular degeneration: Jill is here to provide her personal perspective on living with wet macular degeneration. Jill, when did you start noticing problems with your eyesight?

Jill Adelman: I had first found difficulty seeing, driving at night, and I knew something was wrong or different just through daily activity. It was approximately 8 years ago. I did go and have a general eye examination, and there was no mention of macular degeneration in any form to me at that time. The topper was, I was a registered nurse in a very busy trauma centre in this major city and I was documenting on a patient (we have all electronic records here in the United States) and I typed a whole paragraph about why a patient was in the emergency department—and I could not see it to read it back to proof it to myself. It was a very acute change. At that point, I went further with trying to find the right physician to evaluate and find out what was going on with me.

Alexander Foss: How long did that process take?

Jill Adelman: I started with a general optician's office, got an evaluation—they said nothing to me, but told me that I should be evaluated by a retina doctor. Here in the United States, my insurance had me go through to a certain office, so it took a couple of weeks until I was able to get an appointment. Once I saw him, he still said nothing to me using the words of 'macular degeneration' in any form. He did tell me I had drusen and said we would watch it. So it did take a little bit of time—follow-up in 6 months.

Alexander Foss: When did you convert to wet macular degeneration?

Jill Adelman: Six months later I did my follow-up, right on the 6-month point, and he said everything was stable—and 100 days later, I was in the car doing errands with my grandson, and knew I was coming to an intersection with a traffic light, and I could not see the traffic light. So, it was 100 days after my second evaluation by a retina doctor.

Alexander Foss: In the United Kingdom, the National Institute for Health and Care Excellence (NICE) provides a set of guidelines for diagnosis of patients with wet AMD [4]. In brief, patients are classified here into early and late, and late between wet and dry. Early macular degeneration, as you describe, is with drusen, that normally does not affect one's eyesight, and normally in the United Kingdom would not require routine hospital review. Suspected cases of wet macular degeneration, because of high risk of visual loss, the guideline is that treatment should start within 2 weeks of the referral letter; treatment takes the form of injection of anti-VEGFs (vascular endothelial growth factor [therapies]), and it stops blood vessels growing, and that should commence as stated within

2 weeks of referral. Now, the guidelines for handling patients with eye disease vary both by region and by country. For example, Jill is based in the USA, and I believe the guidelines in America are somewhat different [5]. Is that correct?

Jill Adelman: It seems as though. I would like to interject, though, that when I had that acute visual change, and I called a well-known retinal organisation that I was familiar with, they did give me an emergency appointment for the next morning.

Alexander Foss: That sounds terrific, that sounds very good.

The Impact of wAMD on Quality of Life

Alexander Foss: Well, as a physician, I think the important point, of course, in diagnosing patients with wet macular degeneration goes really beyond just making a diagnosis but also needs to include a full explanation of the disease and how it affects people's lives. Jill, what effect has macular degeneration had on your daily life?

Jill Adelman: Well, the biggest effect it had for me was—I was a registered nurse, in a very busy level 1 trauma centre in a major city, and when this happened it became very apparent that I could no longer safely care for patients at the bedside. The first thing that came into my mind is: what am I going to do about my career? My career was a second career, I was 40 years old when I went and became a nurse, and I loved what I did. Here, it was going to take something very important away from me. Unfortunately, in the beginning, I really thought that I would get a couple of injections—so maybe I would only be out of work for a few months. They would give me medication, get a couple of injections, and life would go back to normal. It was never explained to me clearly what to expect or what we could possibly expect. And I use the word 'possibly' because everyone is different, and we never know. It took quite a few months for my own education, self-searching, to have a better idea of really what life was going to be like.

Alexander Foss: And how did it impact on activities of daily living—household chores, or travel, things like that—or your hobbies?

Jill Adelman: Fortunately, every day is a new adventure, and I learned early on how to do things. Magnifying glasses were my best friend. I have magnifiers all over my house: wherever there could possibly be something I needed to do, there is a magnifying glass. I have an electronic magnifying glass that goes with me everywhere, and it has become a major tool. I've learnt to adjust to everything that needs to be done on a daily basis. I know that I'm much slower at doing things, so I have to allow for a lot more time. I know that I become very frustrated when I can't see things clearly enough to follow instructions easily, so I have to take a step back, take a deep breath, and practice before things needs to be actually done many times. I do still cook; I still do clean. The one positive—bittersweet as it is—as this world got crazy with COVID, because I was no longer able to work, I was able to help and take care of my grandchildren. Mentally, my grandchildren kept me stable. Otherwise, I would have probably had many more issues. I think, mentally, this ocular disease is very debilitating.

Alexander Foss: Well, that raises a huge number of issues we could touch on there. I'm not quite sure where to begin. I'm guessing, one of the things I was going to ask you about was the impact on your relationships with others—but from the sounds of it, it's been positive with your grandchildren.

Jill Adelman: Kids are great. Three of them were born the year that this really got bad and completely took away my normal independent function. But I was safe enough to be able to help with their care. And then of course, when COVID hit I was the main caregiver. That's why I say bittersweet—because I could safely take care of the children, yet it took away my independence from doing what I thought my life structure was going to be. Kids are very resilient—as they got older, I'm always dropping things. All I have to do is say to the kids, 'sorry, memom dropped something', and they are on the floor looking for what I dropped, and they usually find things very quickly for me. It's just a normal part of life for them. So, it's become a

normal routine for me—accepting the little ones to be helpful to me.

My husband is my sole support, he is right there with me all the time, and that's very important because he's in a position where he can change his schedule around and take me where I need to go, doctor's appointments, things like that—so I'm lucky. Friends adapt easily as well, and they'll be like: 'Hey Jill, do you need help? Can we get you down the steps? Do you see that?'—and because they're friends, they're comfortable enough to say to me, 'Hey, can you see that, do you need any help?'—so I'm lucky there. They always pick me up, they know that I can't get out the door at night. My night-time life has completely changed because I'm not independent at all at night. As for travelling, my husband's goal is that, while I can see the big picture, he's trying to take me to as many places as he possibly can for me to see the world. And this is his goal. I can still see the big picture, so that's a good thing. And I learn how to adjust, to adapt to the surroundings where the little pictures are involved.

Alexander Foss: Well again, a significant number of positives there. I imagine a huge negative has been the impact on your career. I take it you lost your job and you've not been able to find another job—so your career is ended, is that correct?

Jill Adelman: My career as a trauma nurse in an emergency department has ended, that is correct.

Alexander Foss: And the emotional impact of that?

Jill Adelman: Emotionally, it destroyed me. That was probably the most difficult part of this that I had to accept and had to learn how to accept. There was nothing I could do about it, and I wasn't going to be foolish enough to fake it—because patient care, and my patient care, was too important to me. I knew I could no longer safely practise nursing.

Alexander Foss: It sounds like you get a lot of support from your family and from your friends—how about from the medical services?

Jill Adelman: Medical services here in the United States—I'm very lucky, I have excellent healthcare insurance, so I can go anywhere at any time. Sometimes it's hard to get appointments—I've never had to deal with that. Like I said, when I had this acute visual change, I had an appointment within 24 h. I don't think, as a caregiver who advocated for patients on a daily basis, I don't know that there's enough patient advocacy for patients with macular degeneration in the United States. I've been to doctors' offices that are like what I call 'cattle chutes'—there's no doctor time, if you have questions, you write them down and then you get one-word answers. That didn't work for me; because of being a professional in the medical field, I needed communication, I needed dialogue.

So, wherein I continued treatment, I also continued looking for a retina doctor that could understand what I needed, in that vein. And I did find a doctor that explains so much more to me and was willing to say to me: 'We don't know why this happens, but we're working on it', or 'We can try this, these would be the ramifications'. He gave me a broad spectrum. There was always communication. He never short-changed me for time, and that was very important. Unfortunately, he became ill, and I did have to seek another physician—whose practice was not bad in any way, shape or form, but it didn't work for me. So as a patient for my own advocacy, I knew that I needed to continue my treatment. But I also knew that I would need to find another doctor.

I've actually been to now my fourth retina specialist in this seven and a half years. But it's because of unfortunate situations like a physician becoming ill, or just knowing that our personalities didn't mesh, and I think that's important because you have to be able to have a discussion. This is such an unknown disease in so many ways, and people have so many questions—and, whether they can be answered completely or not, a patient still deserves an answer.

Alexander Foss: I have to totally agree with that. Certainly, I think it's fair to say—first, mental health issues are very common. Anxiety and depression are well-recognised features of the disease [6–8]. Again, I think it's safe to say that many ophthalmologists don't pay a huge amount of attention to that. It's something that the NICE guidelines did bring attention to [4].

In the UK I think we're really quite lucky, we have something called eye clinic liaison officers (we call them ECLOs) [9]—one of their jobs is to take the time to explain to patients what's going on and to be a point of contact at times of crisis. They're also trained to give some emotional support and to be aware what help is available in the community. Because the second thing that is done not brilliantly, I think, in many places, is rehabilitation, and good access to good-quality low vision aids [10, 11]. Again, in this country, the UK Care Act of 2014 states, and I can quote here [12]: 'Local authorities must: carry out an assessment of anyone who appears to require care and support, regardless of their likely eligibility for state-funded care. Focus the assessment on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve'. And that is given to some social workers—we call them ROVIs (rehabilitation officers for the visually impaired)—who are meant to visit and assess needs. I have to state that it's a fairly new system, and it's under huge pressure. I believe in Nottingham the wait at the moment to see one is over a year, so it's very much a work in progress.

I believe in America, about 30 million people under the age of 65 actually have no healthcare coverage [13]. The likelihood of developing AMD increases with age, but onset can be as early as 50 [14, 15], meaning that a substantial number of patients in the USA may not receive treatment in this critical early period. I believe also some healthcare packages exclude eye care. It seems a very different system to the one I'm used to working in.

Jill Adelman: That is absolutely correct. Fortunately for myself, I had eye care—but I had to go to a very specific place for eye care. Once I got the diagnosis of age-related macular degeneration, then the coverage changes in the United States, and it reverts specifically to the medical coverage that you have. So it removes itself completely from an eye package. Unfortunately, a lot of people—youngsters through 40s, 50s—when you really do start to see possibly ocular changes, they don't bother going to an eye doctor for just a general evaluation because they don't have eye coverage. Sometimes they just can't afford an ophthalmologist's or an optician's fee. It's an unfortunate situation here in the United States, where vision is concerned.

Alexander Foss: So in that situation, do I take it that they simply get no care?

Jill Adelman: That is correct. Until you have a major diagnosis, where the medical coverage picks it up. So just going to a general eye doctor is where there's a break in the coverages, depending on what you have or what you don't have. If you have no insurance at all then you have no coverage, and there would be no care.

Alexander Foss: Gosh.

The Patient Experience of Treatment for wAMD

Alexander Foss: Well, given the impact of wAMD on patients, clearly an effective and practical treatment plan is very important. The standard practice in this country is that you'll get three injections 4 weeks apart, a loading phase, and then there are a number of regimens in this country [16]. NICE reviewed them all and showed them all to be very similar in efficacy—from watch and treat as required, or treat and extend, or just regular treatment [4]. One has to state that some patients appear resistant to anti-VEGFs and have a poor response. My understanding is about one-third will get visual improvement and two-thirds hold it steady—at least for a significant period of time—but the treatment fails in approximately one person in 20 [16, 17]. Research suggests that having treatment on time is helpful [18, 19]. That's me again on the technical stuff—Jill, what was your experience of having the injections?

Jill Adelman: The very first day when the doctor said to me: 'You're going to be OK, we're going to give you medication in your eyes to see if we can get you some of your vision back, and we'll continue with treatment, and it'll just be an injection…'—I looked at him, and of course at this point I don't hear very much of anything because all I'm hearing is, 'get your vision back' and 'medication in my eye'—well, how are we doing this? Do we go to a hospital? Do I go to the surgical centre? How is this done? And he

proceeded to say, 'No, you're going to sit right in the chair that you're at, we'll numb your eye, and we're going to do it right here'. And I wanted to know if my husband could hold my hand down, because I was afraid that I would grab him—all of the things that, this is all that I could think of. So I sat on my hands, and my husband talked to me—he was allowed to stay in the room.

His nurse just held a flashlight and I just followed his instructions. Fortunately, I find I'm a good patient—so I'm going to follow anything a doctor is going to tell me, as long as I understand why, where and when. Obviously he did the injection and after the fact it was like, 'OK, well that's not bad'. But I don't know how many people understand that beforehand. They hear me say 'needles in my eyes' and they're like, 'What, are you crazy?'. I did get improvement in one eye. One eye in the hundred days was totally scarred. Why I scarred so quickly, they have no idea. So the central vision in that eye is gone. But the other eye, I was able to regain some vision and keep me safe.

I do get injections, I am a person who does need to have injections every 28 days—or I can actually sense the return of fluid at around day 25, I start to have more difficulty doing things for the last few days. But it's just my course of disease. So the injections have become a part of life, and I have found I have no pain, I have no difficulty with the betadine [bacitracin zinc–polymyxin b]—I hear a lot of people having problems with the betadine, but it's very important to understand that the betadine keeps it clean and safe.

Alexander Foss: I can emphasise the importance of that actually, it reduces infection. So from your point of view, the injections have been well tolerated, but when you discuss with other patients, some of them struggle—is that correct?

Jill Adelman: Yes. Most of the struggle I hear is from the betadine, and research on my own, one time I had a bad experience. But if you're numb enough before they put the betadine in, that can help. Some doctors believe in rinsing, some physicians believe in hydrating the eyes before and after—so if you're somebody that uses irrigation drops, keep your eyes nice and moist before you even get to the eye doctor. The numbing takes effect, then they do the betadine, you don't have that much difficulty. But I do say to people that the side effects of the betadine are a lot less difficult to deal with than an infection.

Alexander Foss: Do you feel that your physician told you enough about the effects of the treatment, how it was delivered—or was it a bit of an adventure into the unknown?

Jill Adelman: The very first doctor tried to make light of it. He was a very kind, soft-spoken man. But my head was spinning so I don't know that an independent person would have got much out of that visit after hearing the diagnosis anyway. My husband was with me and he asked more questions than I did, because me as a patient, again, my head was spinning. As time went on and I had questions that I wanted answered—that physician, he didn't have time for his patients. Nor did they have someone in the office to advocate or to have these discussions with me. That was a bad blend for me. Then the next group that I went to, that doctor explained a whole lot more to me. We also talked about low vision specialists, and he was more willing to answer all kinds of questions and was OK to say to me, 'We don't have an answer for this yet, we are working on it—but we don't know why this happens. There's nothing you can do to not have it happen, and if you read a lot it's not going to make it worse, if you watch TV it's not going to make it worse'. He was very specific and deliberate, and I think patients need—for want of a better term—to dumb it down.

Adaptations to Life with wAMD

Alexander Foss: Clearly, loss of vision is associated with adverse effects on quality of life and can cause a handicap. I personally quite like the framework of impairment (my eyesight is affected) giving rise to disability (I can't see letters) causing a handicap (I can't read books). The handicap aspect is potentially amenable to rehabilitation. That's what rehabilitation is all about, trying to prevent a disability turning into a handicap. So, how have you adapted, how

have you adapted to disability so that you can still function?

Jill Adelman: Everything is big! Everything is big. I'm sitting in front of a 56-inch computer screen. A few years back, iPhone became very involved here in the US with the Americans with Disabilities Act (ADA) [20], and they put a whole accessibility part on their phones. So, my husband would sit next to me—because I have to do it—and I use all the accessibilities. Somebody sitting behind me in a movie theatre can read my phone if I happen to have it on because that's how big my font is. But that's where I'm comfortable. I wasn't able to wear a watch for years—when, I think, the fourth or fifth generation of the Apple Watch came out, they also put the accessibilities on it. So I can actually see my own watch because it's an Apple Watch. My watch also tells me sunrise and sunset. So in daylight saving time—which I hate—I know what time I have to be in the house. If I happen to be out, I know that I have to be in the house 15 min before my watch is telling me sundown is. The contrast on the Apple Watch also makes it where I can see it. So I do a lot with reverse of contrast, and everything is big. Everything has to be big. My magnifying glasses—I have a really big purse, because, between three or four different pairs of glasses and my magnifiers, I need a big purse. That's how I mostly adapt.

Alexander Foss: I have to say, modern technology really has come to the rescue for a number of people. It's been terrific.

Jill Adelman: Absolutely.

Alexander Foss: The iPhone has been described, I heard it described as the best low visual aid there is at the moment. I believe also there are some very interesting apps that can convert text into speech, so it can read things for you—like the Seeing Eye GPS™ phone app is available in the USA and Canada [21], and the Be My Eyes app is a European application [22], which I think people find very helpful for both for navigation and identification of surroundings, and helps reading menus, finding street names.

Jill Adelman: I have heard that—but I'm not to that point. I'm still, where I'm fighting for the central [vision]. The small stuff is where I'm still fighting. So the big stuff, I'm not too familiar with those devices.

Conclusion

Alexander Foss: Well I think we're coming to the end. Just to summarise, what to you is the most important thing about all this?

Jill Adelman: From a patient standpoint, I think, number one, every patient has the right to an advocate. You must advocate for yourself, to get the information that you need. Unfortunately, in this day and age I have found that people are so afraid to ask questions, or they don't know what questions to ask. So they need to be guided, so that they understand exactly what they need to do for themselves, what they can't do for themselves and how to get the information that they need. I think there just needs to be more basic information. Unfortunately I think a lot of the retina specialists, they know how to talk clinical, they know how to talk medical, but they don't know how to talk to a patient.

Alexander Foss: Guilty as charged.

Jill Adelman: Maybe because of the position that I was in before this happened to me, where I very often had to step in and explain to the patient what the doctor just told them, that was a part of my advocacy for my patients, and that's why it's important to me in this vein, because it was important to me in a career that I loved. Patients have to understand, and they have to be aware of all the good things that are going on, and all the things you can do to continue your life almost as normal as possible, with just learning how to adjust on an everyday basis.

Alexander Foss: Well, thank you very much indeed Jill, for sharing your experiences. It's been great—thank you.

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