PERSPECTIVE OF A LOW VISION PATIENT

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AIMS

This module aims to outline the impact that low vision can have by reviewing an individual case and developing an:

- Appreciation of low vision
- Understanding of the social and psychological impacts of low vision

LEARNING OUTCOMES

After completing this module, students should be able to:

- Describe the symptoms of low vision
- Appreciate the social impact of low vision
- Discuss the relationship between low vision and educational and employment opportunities
- Describe the ways and means to overcome the barriers presented by having low vision

INTRODUCTION

This case study discusses a type of juvenile macular dystrophy (Stargardt's Disease) from the perspective of the patient:

"I have a type of juvenile macular dystrophy called *Stargardt's Disease,* which is an inherited form of macular degeneration.

When I was almost 24 years old, I noticed that something was wrong with my eyesight, and that things were starting to disappear in my central field of vision. I remember staring at a crumb on the kitchen counter, and seeing it 'disappear', only to 'reappear' again in my peripheral vision. The same thing would happen if I focused on numbers on a clock, or letters on a page.

I had worn glasses to correct my short-sightedness since I was fifteen, and had always had routine eye examinations. However, the main visual symptom I was experiencing - the absence at the centre of my vision - was unusual and alarming. Wearing my glasses or taking them off did not change the symptom, and I realised this indicated something more serious in nature. I knew this time my eye examination would be anything but routine, and at the examination my mind raced. Was this a brain tumour, or something growing along the optic pathway?

The eye specialist remarked on the 'beaten copper' appearance of my retina, a hallmark of this type of macular dystrophy. It was a shock to learn that I had a retinal disease, and that there was no cure. Until this diagnosis, I did not knew nothing about inheritable eye disease, and I had no idea that there was anything like this in my family history. To hear that there was no cure was just as astonishing. I remember thinking how ridiculous it was that technological advances had enabled men to land on the moon, but no one could save a few retinal cells in my eyes.

Even more shocking to me was the fact that no one could tell me how quickly my vision would deteriorate, or to what extent. It seemed that impending blindness, its rate of progression, or the extent to which such diseases might affect people's lives, was of little interest to anyone except the patient.

Blindness seemed absolute, untreatable, and irrevocable; it was just plain bad luck for those with such a diagnosis.

Because there was nothing that could be done for me, I resolved to get on with my life as best as I could, at least grateful that I experienced no pain, and that this was not a terminable disease. I had to be philosophical - there were no options.

In the early stages of my diagnosis, there was only a minor area of central vision loss, but it was particularly noticeable when I was looking at fine detail. The scotoma must have been quite small, and I could still drive, read, and recognise faces.

However, within six months, my vision had deteriorated rapidly, to the point of legal blindness.

The scotoma had become larger, and I could no longer drive. I could not see the cars in front of me on the road, or identify street signs.

I was now entering into a phase of more profound vision loss, with no idea of how rapidly things would deteriorate, or if and when this accelerating change in my vision would come to an end. There was very little information on this disease: ophthalmologists could tell me little more than I already knew, there was no discussion in the media about vision loss, and certainly no role models who I could look to for guidance. I felt very isolated by this disease, and the sense of profound isolation was only amplified by a lack of understanding from family, friends and society. No one understood how vision loss looked to me. My disease was invisible to them.

Reading became much more difficult. I taught myself to read peripherally, by finding a position where I could place my eyes above the written lines on the page. I also needed stronger magnifiers, and I had to hold the page much closer, in order to read.

Over the years, as the disease progressed, its impact became more deeply felt, and wide reaching. Simple daily activities like cooking, cleaning, reading books, labels or price tags, going shopping, recognizing family or friends, and

getting around, all became more challenging. A significant point is that, as my eyesight deteriorated over time, I had to adapt to both changing levels of visual acuity, and changing life circumstances.

Vision loss as a younger person was different to coping with vision loss as a student, homemaker or mother, and new challenges will have to be faced with increasing age. Each life stage brings different needs that must be accommodated for, as a result of vision loss.

SYMPTOMS

Central vision loss does not always mean that people see a static black spot at the centre of their vision. It is much more complex than that, and there are many symptoms that can arise as a result of this disease. As a consequence of its dynamic nature, the experience of central vision loss is very hard to describe.

For me, the predominant symptoms of *Stargardt's Disease* are very much about the experience of an *absence* of vision, which is especially pronounced in the central field. Much of the time, things appear invisible when I look at them, and this area of 'invisibility' has grown significantly over the years. I understand that the 'filling in' phenomenon plays a large part in the symptoms I perceive, as my brain tries to fill in the missing bits of my vision with whatever is dominant in my surroundings, or is in my conscious awareness.

This 'filling in' of the absence at the centre of my vision causes me to see things which I know are not there, such as patterns, colours, or other phenomena, not unlike what is experienced by those with Charles Bonnet Syndrome. For example, if I am talking to someone who is wearing a bright floral shirt, I will 'see' the patterns of their shirt superimposed over their face, which I cannot see because of the scotoma. My peripheral vision seems to 'draw in' what is predominant in the surrounding area to fill in the absence at the centre of my vision.

In addition to these symptoms, there is a pulsating light that seems to emanate from the area of the scotoma, which is always visible, even in darkness. My peripheral vision is also affected – blurriness of vision, the difficulty in adapting to changing light, and the constant interplay between environmental, or physiological factors, and the diseased photoreceptors, mean that my visual symptoms are always changing.

In recent years I have also begun to get blurred, wavy, or jagged lines in the peripheral field, particularly if I am tired. These symptoms are most noticeable after reading on the computer or iPad (I can barely read any print, even with the strongest hand held magnifiers).

Sometimes the words will appear to be smeared, like someone has taken a small q-tip and run oil all over the page, and at other times the letters are broken and jagged, as if written on a mirror that has been smashed into fragments.

Another aspect people sometimes don't think about, is how exhausting vision loss can be. Visual fatigue is a constant problem, particularly when steady focus is required. It is hard work to fix a gaze on someone's face, when all you can see is the pulsating scotoma (and patterns or colours) in front of you. The alternative is to look to one side, or the other, while engaged in conversation, but this can also be equally demanding, and disconcerting, for both parties.

SOCIAL FACTORS

There are many factors that come into play between central vision loss and social situations, and I have mentioned only a few of them here.

Because this disability is invisible to others, it sometimes seems that there is nothing 'wrong' with my vision. This may contribute to misunderstandings in social contexts, as I cannot recognise people when they pass by, or I may not realise they are addressing me specifically because I haven't made eye contact with them. Sometimes people look over their shoulders to see who I am looking at, not realizing that that is where I have to fix my gaze in order to see them better. When I am shopping, travelling, or dealing with others in a work or study environment, such difficulties are always there, and it makes every day social activities more difficult to negotiate.

It becomes even more confusing when I cannot see the person I am talking to, yet I can see the movement of an object somewhere in my periphery. Because people do not understand the role peripheral vision plays in central vision

loss, they sometimes think I do not have central vision loss at all. They ask me, "How come you can't see me, but you saw that plane in the sky?"

A long conversation with people requires prolonged eye contact and concentration, and this creates more visual fatigue. To see people better, I have to either look over their shoulder, which is disconcerting for both parties, or stand very, very close to them, which can also be unsettling.

Very often, I ignore my scotoma and the other phenomena at play, and 'pretend' that I am making eye contact during conversations with people, in an attempt to not call attention to my vision problems. In these instances too, people may think I am looking directly at them and that there is no 'problem' with my vision, when in actual fact all I really see is pulsating light and colour.

Another implication of central vision loss is the inability to drive. In a car-dependent society, this too has had an impact on my sense of social connection.

Travelling to meet friends or family for social occasions can be all the more difficult, no matter how good public transport systems are.

It can be even more socially isolating if those with vision loss do not have adequate social support networks. Travelling to meet for special occasions, meeting up with social groups in the community, or participating in events, all prove problematic.

As a woman with low vision, travelling at night by public transport, or even by taxi, carries difficulty and risk. My vision loss is worse at night, and I feel even more vulnerable. I am often dependent on others to drive for me on such occasions.

Because of my experiences in social situations as a result of vision loss, (some of them humorous), I have found myself avoiding such situations more often than not. This is not a helpful coping strategy, and only compounds the sense of isolation and frustration that I feel as a result of vision loss.

EMPLOYMENT OPPORTUNITIES

Perhaps a further contributor to feelings of isolation is that some people with low vision find it difficult to obtain employment, which can be a source of satisfaction, pride and belonging, as well as a means to financial independence.

Employment opportunities are far more limited for low vision job seekers, where factors such as driving, making eye contact with customers or clients, and being able to quickly read detailed data or financial figures, all play a large role in most jobs. When I am in a shop, I find it enormously difficult to identify the sales staff, browse products for sale, or read the information labels or prices on items. To work in this capacity would be impossible for me, as would many other professional jobs.

My own experience in the work force has been fraught with issues. If I disclosed my disability to a prospective employer, it could mean a polite rejection. I had to face the choice of disclosing my vision loss, or not, in order to gain employment. On the other hand, there were many jobs I cannot do as a result of my vision loss. I always looked for jobs that didn't require such a reliance on good visual acuity. Needless to say, these jobs were few and far between, and I saw my options narrowing in alignment with my diminishing vision.
As a result of my eyesight, employment has been scarce and sporadic over the years.

This has had profound economic effects.

Attitudes towards those with a disability are changing, but I feel that the lack of understanding of how vision loss affects an individual, and their capabilities to adapt in the work place, still prove a significant barrier to gainful employment.

EDUCATION

Access to education for low vision students is vital, and can also increase employability in a competitive job market.

I was fortunate enough to have completed both secondary and some tertiary level education before I noticed the effects of my vision loss. Things may have been different if my eye disease had manifested in my early teens. I did however, continue on with tertiary studies in my later years, and even though I found it very difficult to keep up in class situations, where seeing the white board or lecture screen was difficult, I was sometimes fortunate to have specially printed material made for me by teachers and lecturers.

Computers have improved my access to educational opportunities, as more courses, reading material, and lectures come into the digital arena. Large screen computers, both at home, and at university, have made it easier for me to read and access content. I also use text to speech software to help me read faster, and I use dictation software to assist with typing. Printed material is far more difficult for me to see, and I rely on textbooks in e-book format on my iPad, although not all material is available in this form.

PSYCHOLOGICAL FACTORS

There are many psychological factors to consider in vision loss, and as a person with low vision, I realise these factors are deeply intertwined with social and economic circumstances.

The social implications of living with low vision have affected my sense of independence, increased feelings of isolation, and reduced my ability to participate in many activities. Of course, these have psychological consequences. Moreover, difficulties in gaining steady employment, the types of jobs I am able to apply for, and even the locality of available jobs, have all impacted my economic security and financial independence, and again, these factors have a psychological consequence.

On a daily basis I deal with the implications of my vision loss in a myriad of ways - sometimes, I am able to get on with things and don't even notice my vision disability, and at other times, the symptoms intrude on my consciousness, interrupt my ability to complete tasks and get things done. At these times I am extremely conscious of my symptoms.

When travelling, my symptoms of vision loss become very apparent to me, and feelings of frustration and embarrassment are not uncommon. Sometimes I board the wrong tram, bus or train and end up somewhere I didn’t intend to be. When I end up in these unfamiliar surroundings, it is even more difficult to find signage, landmarks, transport routes, or help. To prevent such problems, I have to ask the person standing next to me what the approaching tram or bus number is, even though it is prominently displayed on the front of the approaching vehicle. At times like these, I feel very embarrassed to ask such questions, and these situations also contribute to feelings of frustration.

As a mother, it is also difficult to meet the requirements of dependent children, who need to be taken to and from school, meet their friends, or participate in extra-curricular activities. It is also difficult when they are sick, and need to be collected from school and taken to the doctor. I have felt that my children have been greatly impacted by my vision loss, and this has contributed to feelings of guilt, disappointment and concern that they have missed out on a more 'normal' childhood.

In all these circumstances, the sense of isolation, loss, frustration and a feeling that people with vision loss are not adequately accommodated for, add to the psychological impacts of vision loss. These factors prove as challenging to me as the physical manifestations of my disease.

OVERCOMING BARRIERS

When first diagnosed, I had no idea of the impact vision loss would bring. The social, psychological and economic consequences were enormous and profound, reaching into all areas of my life. Overcoming some barriers has been more achievable than others.

As my vision has deteriorated over time, I have had to find ways to adapt and accommodate this loss by using means other than vision. I find it surprising how much can be achieved *without* full vision, utilizing memory, sound, touch, orientation cues, and vision aids.

Familiar surroundings help me through the activities of daily life. Memory and touch help me locate where things are at home, so that I don't need to rely on my vision so much.

When preparing food in the kitchen, I make sure my fingers are tucked right underneath my knuckles, so that I don't cut them by accident. Good lighting is also essential.

On my large screen computer I can easily zoom text to a comfortable size. Text to speech software helps me read, and alleviates fatigue and eyestrain, while dictation software helps when I need to use the keyboard for stretches at a time.

My iPad is not only indispensable for reading text, but also in accessing information, whether I am at home, or out and about. I use it as a navigating device. Again the ease of zooming text on the iPad means I can access information such as travel routes, street maps and destinations, easily and quickly via mobile Internet. I can also discreetly read my emails, books and website pages in large text while travelling in public, without having to pull out a magnifying glass.

All these strategies have been a way to overcome some of the physical barriers that are encountered in my everyday life as a person with vision loss.

Despite my ability to cope and adapt much of the time, there are still further barriers that need to be overcome, including social, educational, employment and psychological factors.

Perhaps the greatest barrier though, is the one that calls for cultural change towards those with vision loss. This is the barrier of *understanding*.

Because macular degeneration is a disease that is invisible to others, it is very difficult for people to understand how the world looks from a low vision perspective.

I have found that when people better understand how vision loss actually *looks* to me, then they begin to recognize some of the challenges that I have had to face every day.