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Breaking news – when it's bad ...

COMMUNICATION SKILLS PART 7 COURSE CODE C-18047 O

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27/01/12 CET

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In this final article of the series, attention turns to how best to align with a patient for whom the eye examination outcome may not be good. Not all visual problems can be improved with a simple change in prescription. There are several scenarios to consider when outlining a potentially negative result for a patient, and these are discussed to provide a framework on how best to respond to such situations.

Is the patient expecting bad news?

One of the first questions asked of the patient is the main reason for their visit. Not only does this elicit the direction that the consultation takes, but it also provides hints about how aware the patient may or may not be of the potential findings of the examination. Of course, the optometrist also does not know the exact nature of the pathological findings to come, and it is this element of the working day that carries the greatest burden.

How long is it since they were last seen?

The interval from the previous examination to the present day, and whether or not the patient has been seen before at the practice, plays a role. Clearly an optometrist seeing a patient with previously recorded early-stage dry age-related macular degeneration (AMD) (Figure 1) is slightly more likely to know the possible outcome from the examination compared to if the patient were new to the practice. Preparation for this can be made when asking questions at the start of the examination, having made thorough reference to the previous records. A change in vision is generally

described by a patient in terms of their perceived need for a new pair of glasses. In situations where their symptoms do not align with refractive changes, the optometrist knows there is work to be done in educating the patient in this regard. In some instances, the patient may have already seen another optometrist and is seeking a second opinion. The support staff play a vital role when screening the patient for the appointment. The last examination date is important when handling this scenario, as the patient who has lost vision may be having difficulties accepting this. It is easy to be offended by a patient who appears to be questioning the opinion of their previous optometrist. However, due consideration of their circumstances and appreciating the process of how the patient comes to terms with their loss of vision, no matter how slight, should be viewed from the patient's perspective. Providing the patient with another opportunity to learn about their condition can also serve to restore confidence in their previous practitioner when confirming the findings.

The eye care professional's role

Patients don't know what they don't know, and whilst simple elements of ocular anatomy may be considered to be in the

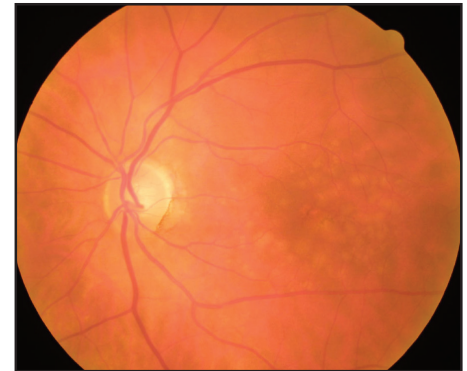


Figure 1

Dry age-related macular degeneration (AMD)

everyday vocabulary of the layman, confusion of what exactly is the 'iris' and the 'pupil', for example, remains. From this standpoint, the optometrist must ensure that their explanations can be understood.

There are many conditions where patient understanding of their condition greatly impacts on their ongoing care and compliance with treatment and management. Often, the optometrist is their most accessible eye health professional, and being able to telephone the practice or email the optometrist direct can help allay any initial fears. Additionally, when first explaining a condition or the need for referral to a patient, they may think of questions after leaving the practice. Providing them with the opportunity to get in touch with the optometrist is appreciated and may differentiate the practice from the competition. Retaining information from a health professional can be difficult when the patient is struggling to take on board the results and potentially serious findings of the examination. In some cases, a patient attends with their partner or a member of their family. If the accompanying person has not been in the consulting room during the examination, asking the patient to invite them back into the room for the discussion can be invaluable. It is helpful when advice is given in written form too, eg, leaflets that explain common pathological conditions.



What if there's no cure?

Much of an optometrists' time is spent optimising vision for patients and it is a great frustration to both the patient and the optometrist when no improvement can be made. This is especially the case with AMD. Some patients may be aware of 'treatment' for AMD but do not know that it is appropriate only for a minority of cases who suffer from the wet type. The optometrist knows that AMD affects only a small yet important area of the retina. However, a patient who has experienced devastating vision loss affecting their ability to function is often fearful of where their vision loss will end. They may wrongly assume that they will become totally blind and as such optometrists should reassure patients in the contrary. Imparting such a small fact can provide significant relief to the patient, who may be reluctant to verbalise their fear for the risk of being told something they may not want to hear.

Dealing with visual loss

When health professionals have to manage a patient who is dying, knowledge of the grieving process has been shown to affect the attitudes of health professionals caring for such patients.¹ Not every patient responds in the same way, although in the case of vision loss, it has been compared with the grieving process for which there is an established model, first described by Kübler-Ross,² which is summarised below.

Denial

It is quite natural for a patient with vision loss to disbelieve that there is no treatment or cure. Most experienced optometrists have encountered patients with cataract/AMD who are convinced that their spectacles simply need to be made a 'little bit stronger' in order to improve their vision. This is a classic example of the denial stage.

Anger

This stage in the process is probably the most important for any health professional to be aware of and recognise. The patient may be very difficult to handle during this time, and may even attempt to apportion blame on the optometrist as they seek for a cause for their loss. Perhaps they are angry that if their condition had been detected sooner, the vision loss wouldn't have occurred.

Bargaining

The next stage may involve the patient asking for 'therapies' that are futile. For example, they may suggest changing their spectacles to a very expensive lens type in the vain hope that this will be the solution. A patient may also suggest that if they 'use their eyes less' or 'do eye exercises' that this will help to 'preserve' their vision. This stage provides the opportunity to educate the patient about the most appropriate course of action. Whilst they may not be ready to take that advice yet, outlining it at this stage in the process gives the patient the necessary information to refer to later. The optometrist saying 'I have the details of a website/organisation which provides great advice for people who are experiencing similar vision changes to you' allows the patient the chance to ask for this when they are ready to do so.

Depression

Clearly, significant visual loss impacts negatively on a patient in terms of their social interaction with others, their ability to continue working or maintaining key hobbies and interests, whether or not they can drive, and their overall independent living. Whilst to a young optometrist a patient may be 'elderly', this in no way means that vision loss will be accepted as a normal consequence of ageing. There may be a period of withdrawal as the patient moves through this stage towards accepting the changes that have happened to them. With the patient's

consent, informing the GP about their vision can be valuable as the patient may consult their GP during this difficult time.

Acceptance

Eventually, the patient comes to terms with their vision and from this stage they are better placed to look for adaptation solutions. In the case of a patient with AMD, it is at this point that the patient is most receptive to advice on low vision aids (LVA) and seeking help with converting everyday equipment around the home (e.g. cooker knobs and telephone buttons). Those practitioners who have felt dejected after giving excellent LVA advice may realise afterwards that the patient was not quite at the stage of accepting their condition. Of course, keeping the door open for the patient to return, when they are ready, is very important.

The approach

Vision loss is the top-rated fear of the ageing process aligned with paralysis.³ Furthermore, the impact of delivering such news cannot be underestimated. Several factors must be taken into consideration during a consultation when bad news must be delivered:

Environment:

- is the patient listening (eg, not distracted by the time limit of the parking meter)
- is there sufficient time to explain
- keep the consultation interruption-free

The message:

- be brief, simple and direct
- discuss ways forward, a treatment/referral plan where appropriate
- give hope when there is hope
- explain when no treatment is possible and include lifestyle adjustments
- ask the patient if they have any questions
- arrange another visit for further discussion if necessary

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- provide contact details (eg, telephone number, email address)
- supply information on sources of help and advice
- don't understate the condition to make it easier (this is misleading and dishonest)

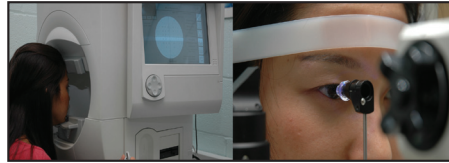


Figure 2

Certain tests, such as visual fields (left) or contact tonometry (right), may need to be repeated and careful explanation of this to the patient is required

'situation'. The patient may be offered a tissue and given time to compose him/herself whilst the practitioner makes some notes in the records. It can be tempting to provide reassurance bordering on false hope but the patient must continue to see their practitioner as the source of help and advice. Knowing that they can return at a later date for follow-up provides some degree of comfort even if they may not yet be ready for the proposed plan of action.

Other considerations

Some practitioners believe that the patient should be told the diagnosis by the next healthcare professional that manages their condition. Indeed, not all cases of visual loss have an obvious cause at the time of examination, although the optometrist is often well-placed to provide a tentative diagnosis. The patient may have already researched their symptoms on the Internet and could be harbouring significant concerns. Asking the patient whether they have done this helps the optometrist to establish the patient's current understanding and then to educate and advise the patient appropriately about their findings.

Scenarios and what to say

When concluding an eye examination, there is a clearer starting point to explain the findings if there are presenting symptoms. However, some potentially serious findings may not have associated symptoms and so careful explanation to the patient is important. It may even be necessary to bring the patient back to repeat

or perform additional tests eg, contact tonometry or visual fields (Figure 2), to decide on the need for referral. The following template can be used to explain the examination outcome for most situations: Optometrist: *"You came to see me today for a routine check/because you've noticed What I have found is This means that we need to bring you back for some additional tests/seek further medical opinion on these findings. Let me explain why I recommend this."*

If, for example, the examination reveals an increase in IOP, leading to a suspicion of borderline glaucoma, the optometrist can confer these findings to the patient in the following manner: *"What I notice today is that the pressures of your eyes are slightly higher than the levels we like to see. It is not excessively high but this can sometimes, though not always, be associated with a condition called glaucoma. Glaucoma is treatable and the worst case scenario is that you may need to use eye drops every day to keep the pressures lower. If we do nothing, and you did have glaucoma, you could lose some of your vision. It's important to me that we err on the side of caution and get this checked out. If indeed you have this condition, it isn't likely to change dramatically over the next few months, so we're certainly seeing this at a very early stage."*

Key phrases to use include:

- *"sometimes, not always, be associated with..."*
- *"the measurements are a little large/small/high/low/narrow ..."*
- *"many people with this do not have..."*
- *"it is better to be cautious and thorough..."*
- *"it's important to do the tests/to involve your GP in following this up/ to seek expert advice from a specialist who sees cases like this every day..."*

Summary

When dealing with a situation of potential

Bad news is bad news

There is no easy way to tell a patient that they have had a sinister occurrence (eg, central retinal vein occlusion, retinal detachment) or that their deeply amblyopic eye cannot recover vision at the age of 25 years. Whatever the scenario, the patient wants to hear that their vision can be restored, and this is not always possible. Explaining this to a patient cannot be rushed, and the delivery of the information must be appropriately paced so that the patient understands what is being said. Of course, there are medical words that sound terrible to the ears of a patient, which can be changed to make the news more palatable. Using the word 'condition' as opposed to 'disease' is preferable. Describing the vision 'loss' as a 'change in vision' is also softer. Most importantly though a patient cannot be told that everything will be ok when this is clearly not going to be the case. Giving the patient the worst case scenario can be in their best interests, as patients can worry that they will go blind overnight if they have not been furnished with the exact nature of their visual prognosis. Worry is best controlled by considering the very worst-case scenario, accepting this, and then considering the better options from there onwards.⁴

The crying patient

Giving bad news can have an extremely emotional impact and response. If the patient and practitioner have not met before, this can be embarrassing for the patient. The practitioner must empathise with the patient with responses such as 'I appreciate that this is upsetting' or 'this is a perfectly natural response to this difficult



conflict, it is useful to view this from the patient's perspective. How might they feel? What impact is this going to have on their life? Delivering bad news is never easy, and is probably the most challenging aspect of optometric practice. In most cases, informed consent means that the patient has the right to know what their eye/vision problem is, and this may prove to be essential if they are to take referral and further treatment seriously. For some, it is important to know what they stand to lose if they do nothing, and this can be reinforced by

explaining what they also stand to gain (if anything) too. A minority of patients do not want to know and will make this clear, whilst for others, the information may even be harmful. Discretion is the key. Honesty and compassion need to be at the forefront of the practitioner's mind, whilst paying careful attention during the exchange of advice and information. Giving the patient the permission to ask questions both during as well as after the consultation has finished is probably the most helpful and most appreciated level of ongoing care a patient could wish for.

About the author

Sarah Morgan is an optometrist with expertise in effective communication. She teaches at the University of Manchester across all three years of the optometry programme where she holds the post of visiting scientist. She is author of *Up Front - a practice knowledge guide* and *The Complete Optometric Assistant*.

References and further reading

See <http://www.optometry.co.uk/clinical/index>. Click on the article title and then download "references".

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1. When starting the examination:

- a) check if the patient is of a nervous or anxious disposition
- b) explain to all those over 60 years of age that there will be expected vision loss
- c) discover the patient's symptoms and expectations of the outcome
- d) explain that the spectacle prescription is as strong as it can be

2. If a patient with irreversible wet AMD has been seen elsewhere within three months:

- a) consider that the patient may be going through the denial stage
- b) explain the limitations of the NHS eye examination
- c) refuse to see the patient as they are not manageable
- d) recommend that the patient consults their GP first

3. When a patient has early visual loss related to dry AMD:

- a) reassure them that they won't go completely blind
- b) explain that nothing can be done to help them
- c) refer them for registration as severely sight impaired
- d) refer them urgently for treatment with Lucentis

4. If a patient seems angry about their poor vision:

- a) explain that the practice does not accept liability
- b) ensure an extra member of staff is present during the consultation
- c) ask them to return when they are calmer
- d) show empathy and concern for their frustration of their loss

5. If a patient wishes to try a slightly stronger spectacle prescription:

- a) determine whether the patient will be able to afford this first
- b) consider the stages of grieving and decipher if this is appropriate
- c) explain the limitations of new ophthalmic lens technology
- d) tell them that it is at their own risk and there are no guarantees

6. When there is clinical concern about raised IOPs:

- a) discuss in full the normal diurnal variations with the patient
- b) explain that visual field testing determines whether treatment is required
- c) tell the patient that if left untreated, blindness is a certainty
- d) explain that in some cases, treatment with eye drops is required



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