

Trauma of diagnosis stays with eye disease patients

July 22 2022



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The way in which a patient is told they have serious eye disease can impact their psychological health and ability to cope with their condition in the long-term, according to new research published in the open-access journal *BMJ Open*.

A research team led by Dr. Jasleen Jolly, of Anglia Ruskin University (ARU) interviewed patients across a range of ages who had been diagnosed with eye disease in England over the course of several decades, and assessed the psychological impact of the way their [diagnosis](#) was communicated.

Interviewees had been diagnosed with a variety of conditions, including [diabetic retinopathy](#), [macular degeneration](#), Stargardt disease and [retinitis pigmentosa](#), all of which can cause significant vision loss.

The interviews showed four themes; the convoluted process of being diagnosed; the impact of clinicians' words; the search for information; and reflections on what could be improved.

Researchers found that patients often vividly remembered the way they were told they had their condition, and the manner of the medical professional that delivered the news. This impacted on how they saw their [vision loss](#) and themselves, as well as their interactions with other people.

One patient described the news as "like being hit with a brick". Another said: "It was very brief, very clinical. They literally told me that I had this and in time was slowly going blind. There was no cure."

Some had waited months or years for diagnosis from initially being aware of a problem, creating a sense of frustration and anxiety. One younger patient said: "You're told 'something is wrong, you're going to have an appointment in 14 weeks to have this test done, you need to wait five or six months for the results.' Five or six months is a long time when you're waking up every day, worried, and you're not sleeping well. And it's affecting relationships with other people, potentially your job."

Some patients felt the need to trawl the internet to find out more, coming across misinformation and "scare stories" online and increasing their anxiety about their condition.

Dr. Jolly, Associate Professor at Anglia Ruskin University's Vision and Eye Research Institute (VERI), said: "Being given a diagnosis of eye disease can be unexpected and devastating. The moment of diagnosis is

emotionally charged and interactions with clinicians can have a lasting impact on how a patient comes to terms with their visual impairment. If patients don't feel they have received enough information, this can lead to them feeling lost and often searching for details from less reliable sources.

"This is one of the first studies to examine how the communication of a diagnosis impacts psychologically on a patient in the long-term, and we found that the words and demeanour of medical professionals affected a patient's ability to come to terms with their condition.

"Clinicians should carefully consider how they communicate a diagnosis to patients, how and when they offer information about diagnosis or prognosis, and signpost them to appropriate charities, [support systems](#) or counselling services as soon as possible. Hospitals need to put in place better support mechanisms, such as more Eye Care Liaison Officers, to provide information and support to patients, as well as more training on empathetic communication."

More information: 'It was like being hit with a brick': a qualitative study on the effect of clinicians' delivery of a diagnosis of eye disease for patients in primary and secondary care, *BMJ Open* (2022). [DOI: 10.1136/bmjopen-2021-059970](https://doi.org/10.1136/bmjopen-2021-059970)

Provided by Anglia Ruskin University

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