

Glaucoma patients report a wide range of emotional and psychological changes

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Fear of the unknown is one of the greatest issues facing patients with glaucoma - the second leading cause of blindness worldwide after cataracts - according to research in the April issue of the *Journal of Advanced Nursing*. People also worry about how the eye disease, which can be hereditary, will affect other members of their family.

Researchers spoke to 24 people with [glaucoma](#), which can lead to severe restriction of the visual field and irreversible blindness if it is not detected early enough and successfully treated.

It's estimated that 4.5 million people worldwide are blind due to glaucoma, with more than a third of them living in China, where the study – carried out by Fudan University in Shanghai – took place.

"Despite the large amount of research time and resources that have been spent on glaucoma, there are still few effective treatments and limited interventions to reduce the incidence or progression of the disease" says co-author Shu-Xin Xi from the Department of Nursing at the University.

The researchers recruited patients from a specialist eye hospital to find out how glaucoma affected their daily lives and their quality of life, carrying out a combination of in-depth interviews and focus groups. The ten men and 14 women were aged between 23 and 86, with an average age of 43 years. Time from diagnosis ranged from one month to 12 years.

"Although glaucoma is one of the leading causes of blindness in China, all the participants knew little about it prior to diagnosis" says Shu-Xin. "However, once they were diagnosed most of them were eager to seek information and educate themselves as much as possible."

Key findings and comments included:

- Patients worried about going blind and how effective their medication was. And they felt powerless when their intraocular pressure became high and impossible to manage. "There is no light at the end of the tunnel. You don't know what is going to happen to you. Maybe you will go blind tomorrow and the whole world is dark."
- They also worried about their families developing glaucoma. "My mother was diagnosed with glaucoma at the age of 50 and went blind some years later. It occurred to me at the age of 30. What worries me is my only son. I hope the tragedy won't happen again."
- The internet, reading material and radio health programmes were popular sources of information on glaucoma, but they often provided contradictory information and patients questioned their credibility. Internet information was often too complex to understand and hard to read with declining vision.
- Peer support was very important as it gave the patients a sense of belonging. Talking to people about how they managed their glaucoma was useful and more practical than the advice they received from their doctors. "Some of them have a long period of time managing this disorder, so they can tell me how to deal with it."

- There was a lot of confusion among patients about how to administer their eye drops. Most did it incorrectly and were upset that they had not been shown the right way to do it.
- Others felt that they did not have enough information about the pros and cons of important treatment, such as laser eye surgery. "I want to know the exact advantages and disadvantages...before I make a decision."
- Most found comfort in their religion and felt it helped them to cope better. Religion played a greater role when people suffered sudden pain, such as when their intraocular pressure became very high. "The prayer will make me feel good."
- Patients and their families had found practical ways to cope with daily tasks, such as improving lighting. "My wife arranged the furniture so that my moving route is straightforward."
- Some used traditional Chinese herbs like Wolfberry and Ginseng and the martial art of Tai Chi to help manage their condition. Others avoided spicy food to keep their condition stable. "Some food will get you into trouble like seafood and leek. They contain too much Yang, which can do harm to the eyes."
- Managing their condition was a way of maintaining their independence and not being a burden to their family. Loss of independence was associated with feelings of helplessness, guilt and fear of going blind. "Dependence is the worst, so I try to manage my daily activities."

"The glaucoma patients in our study experienced a wide range of emotional and psychological changes and found a number of practical

ways to manage their disease and cope with daily tasks" says Shu-Xin.

"One interesting finding is how Chinese culture can help patients to maintain a healthy lifestyle. More research is needed to find out how healthcare professionals can support patients with glaucoma in China, together with patients from other diverse ethnic, cultural and religious backgrounds around the world."

More information: Patients' experiences of living with glaucoma: a phenomenological study. Wu et al. Journal of Advanced Nursing. 67.4, pp800-810. [DOI: 10.1111/j.1365-2648.2010.05541.x](https://doi.org/10.1111/j.1365-2648.2010.05541.x)

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