ORIGINAL ARTICLE

STUDY OF EXPERIENCE OF LIVING IN PATIENTS WITH GLAUCOMA

Jayantilal Shah

Associate Professor, Department of Ophthalmology, Gujarat Adani Institute of Medical Science, Bhuj, Gujarat

ABSTRACT:
Introduction: Glaucoma has been called the "silent thief of sight" because the loss of vision often occurs gradually over a long period of time, and symptoms only occur when the disease is quite advanced.Worldwide, glaucoma is the second-leading cause of blindness after cataracts. It is also the leading cause of blindness among African Americans. **Materials & Methods:** Participants were recruited via advertisements placed newsletter. Participants were required to have a diagnosis of Glaucoma or ongoing treatment of glaucoma this criteria helped to ensure that participants had sufficient experience of living with glaucoma and receiving treatment and follow-up care. **Results & Conclusion:** Glaucoma can impact on a person's life across multiple domains. This study confirms the highly variable between-person responses to living with glaucoma but also serves to highlight strategies adopted by patients. Active strategies, such as making use of practical support or consciously making head and eye movements towards areas of vision loss, were noteworthy in this sample of patients. This study offers a better understanding of what it is like to live with glaucoma
Keywords: Glaucoma, Living experience, Eye problems

Corresponding author: Dr. Jayantilal Shah, Associate Professor, Department of Ophthalmology, Gujarat Adani Institute of Medical Science, Bhuj, Gujarat

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INTRODUCTION

Glaucoma is a group of eye diseases which result in damage to the optic nerve and vision loss. A major risk factor is increased pressure in the eye.The disorders can be roughly divided into two main categories: "open-angle" and "closed-angle" (or "angle closure") glaucoma.[1] Open-angle chronic glaucoma is painless, tends to develop slowly over time and often has no symptoms until the disease has progressed significantly. Closed angle glaucoma is usually chronic and asymptomatic but can present all of a sudden as well. This involves sudden eye pain, blurred vision, mid-dilated pupil, redness, nausea and vomiting, resulting from a sudden spike in intraocular pressure from iridotrabecular contact.[1, 2] Glaucoma can permanently damage vision in the affected eye, first by decreasing peripheral vision (reducing the visual field), and then potentially leading to blindness if left untreated.[3]

Glaucoma has been called the "silent thief of sight" because the loss of vision often occurs gradually over a long period of time, and symptoms only occur when the disease is quite advanced.[4] Worldwide, glaucoma is the second-leading cause of blindness after cataracts. It is also the leading cause of blindness among African Americans.Although the term "glaucoma" has a history relating to disorders of the eye going back to ancient Greece, in English the word was not commonly used until after 1850, when the development of the ophthalmoscope permitted visualization of the optic nerve damage caused by glaucoma.[5]

The primary division in categorizing different types of glaucoma is open-angle and closed angle (or angle-closure) glaucoma.[6] The open angle refers to the angle where the iris meets the cornea being as wide and open as it should be, allowing the fluid from inside the eye to drain, thus relieving the internal pressure. Where this angle is narrowed or

closed, pressure can build up, and eventually damage the optic nerve leading to loss of vision.[7]

It is well recognized that glaucoma affects daily life through visual deterioration which subsequently brings reduced quality of life, and results in high healthcare costs. Despite the large amount of time and resource spent on treatment trials, there are still few effective treatments and limited intervention to help reduce the incidence or progression of glaucoma. However, the importance of involving patient's experiences during the management of vision impairment was well recognized.

Previous studies do have reported that people value with their vision more highly than physicians realize. Other findings have indicated that clinical diagnosis of vision loss is not reflected in the glaucoma patient's own assessments of visual disability. Spaeth et al. reviewed the available literature to present a concise summary of how glaucoma patient's quality of life has been operationalized into quantitative measures.[8] They organized a growing literature that can be difficult to synthesize into an approach that is straightforward for the clinician to understand and apply to their interactions with the patients. Spaeth et al. highlighted the need for continued efforts to improve the methods for collecting and analysing data to further the understanding of the impact of glaucoma.[9] Therefore, it is imperative that such appreciation be fully explored so that the patient's expectations can be better addressed for greater satisfaction. The aim of the study was to explore the life experiences of those living with glaucoma and describe their strategies to deal with the consequences of this disorder.

MATERIAL & METHOD

Participants were recruited via advertisements placed newsletter. Interested parties contacted the research team via email or telephone to receive the full information booklet for the study. A suitable time was then arranged for those still interested to take part in the study. Participants were required to have a diagnosis of Glaucoma or ongoing treatment of glaucoma this criteria helped to ensure that participants had sufficient experience of living with glaucoma and receiving treatment and follow-up care. Volunteers were excluded if they had an ocular condition other than glaucoma (i.e. age related macular degeneration or diabetic retinopathy) or cortical visual impairment. Potential participants were also excluded if they had dementia or another isolated cognitive impairment. Participants were required to provide their own informed written consent.

In this study, we collected data using in-depth 1-on-1 interviews and focus groups. Consequently, 30 patients did approach; all of them consented to participate. Among the sample, 20 participants were selected for 1-on-1 interviews, and the other ten were divided evenly into two focus group. On average, the 1-on-1 interviews took 30 minutes, and the focus groups, 50 minutes, and both were audio-taped and transcribed verbatim after the permission was taken from the patients. The field notes were completed immediately upon each encounter to allow a reflection on such issues as setting, context and potential bias. The transcripts and reflective comments were formed as the raw data. In addition, several participants provided written notes on their experiences, which were also included in the data.

RESULTS:

Although glaucoma is one of the leading causes of blindness, all the participants knew little about it prior to diagnosis. Upon its diagnosis, however, most of them were eager to seek information and educate themselves as much as possible. It was clear from the interviews that they sought, processed and acquired many different opinions.

The most frequently identified sources of information about glaucoma were found to be radio programs, reading materials and the Internet. However, they identified many shortcomings associated with these sources, including an overwhelming amount of contradictory opinions which they questioned for credibility. And, sometimes, they had difficulty obtaining information. They frequently complained about the Internet which provided information too complicated to understand, and had difficulty reading prints because of their vision impairment.

Speaking of credibility, most participants highly valued contacting the same patients, which was viewed by some as an effective way to seek peer support and feel a sense of belonging: I do like being with them, having a chat. It is useful. Some of them have a long period of time managing this disorder, so they can tell me how to deal with it. It is practical, not as the same as the doctor' order.

In some cases, the information they had obtained was incorrect and could be misleading. One patient stated that she was told to have 10-minute intervals between drops to allow each enough time to work,

which others disagreed with. Meanwhile, some patients were extremely confused. Unfortunately, the problem was that few patients had received proper guidance on drop application in the hospital. Therefore, the participants were upset when they learned about different methods of eye drop instillation for the first time during the discussions. Some participants reported needing sufficient information at critical points, such as deciding whether or not to go ahead with laser surgery for glaucoma.

One man mentioned that he preferred listening to the radio to watching TV because TV lighting stimulated the pupil dilation causing higher eye pressure. Even though his statement is not entirely accurate, it is important to acknowledge that watching TV or movies in the dark for a long time can be problematic. In the focus groups, the participants talked about their strategies to preserve independent mobility and to manage daily activities, and exchanged ideas in terms of symptom management and regimen application.

Glaucoma imposing an emotional impact on the patient' health and well-being, all the participants felt uncertain about their future after their deterioration of vision function despite hospitalizations. Even the interviewees who currently experienced no visual difficulties spoke of worries about the future, such as movement restrictions and possible blindness. The patients could still remember feeling confident at the diagnosis that their treatment would be successful.

The altered ability due to visual impairment affected employment, domestic and social activities; however, the salience of the difficulties was rooted in their particular social circumstances. For women, the efficiency of home management and childcare was compromised, thus leading to feelings of self-worth loss.

DISCUSSION

Glaucoma is a condition that causes damage to your eye's optic nerve and gets worse over time. It's often associated with a buildup of pressure inside the eye. Glaucoma tends to be inherited and may not show up until later in life.[10] The increased pressure, called intraocular pressure, can damage the optic nerve, which transmits images to the brain. If damage to the optic nerve from high eye pressure continues, glaucoma will cause permanent loss of vision.[11] Without treatment, glaucoma can cause total permanent blindness within a few years. Because most people with glaucoma have no early symptoms or pain from this increased pressure, it is important to see your eye doctor regularly so that glaucoma can be diagnosed and treated before long-term visual loss occurs.

Glaucoma usually occurs when pressure in your eye increases. This can happen when eye fluid isn't circulating normally in the front part of the eye. Normally, this fluid, called aqueous humor, flows out of the eye through a mesh-like channel.[12] If this channel becomes blocked, fluid builds up, causing glaucoma. The direct cause of this blockage is unknown, but doctors do know that it can be inherited, meaning it is passed from parents to children. Some people with glaucoma have "low vision." Low vision means there may be problems doing daily, routine things even if using glasses or contact lenses. With glaucoma, this can include loss of contrast sensitivity, problems with glare, light sensitivity, and reduced visual acuity. A variety of products and resources are available to help people who have low vision.[13]

This is not the first study to interview patients with glaucoma about their experiences: prior research studies have also endorsed the use of qualitative methods for improving understanding into the impact of glaucoma from the patient's perspective.[14] For example, previous research has asked patients to describe what vision loss "looks like", challenging simple depictions of the visual symptoms of the disease. Studies have used focus groups to explore patients' viewpoints about reasons for late diagnosis, aspects of their follow-up care, and perceived barriers to treatment adherence. One similar study, conducted over a decade ago, conducted individual and group interviews with patients with glaucoma about what it is like to live with glaucoma. Patients reported that they experienced few negative effects of glaucoma initially, but had to learn to live with the condition as it worsened over time.

The limitation of the study is that the participants were selected only in one tertiary specialized hospital. Moreover, the fact that the severity of glaucoma was not assesses and primary glaucoma sub-groups in our patients could be a limitation. This paper provides an insight into the living experiences of the patients with glaucoma using 1-on-1 and focus-group interviews. As expected, the group interviews proved useful, as many experiences were only identified as related to glaucoma when the participants could share their experiences each other, i.e. drop instillation method, self-management skills

and new perspectives, which might not have been heard in the in-depth interviews. By its very nature, a focus group involves a group discussion in which participants focus collectively on a specific issue, and further, allow for interviewees to elaborate on and share issues raised.

CONCLUSION

Glaucoma can impact on a person's life across multiple domains. This study confirms the highly variable between-person responses to living with glaucoma but also serves to highlight strategies adopted by patients. Active strategies, such as making use of practical support or consciously making head and eye movements towards areas of vision loss, were noteworthy in this sample of patients. This study offers a better understanding of what it is like to live with glaucoma. As inferred from the interviewees' quotes in the study, they experienced a wide range of emotional and psychological changes and used a variety of behaviors to manage their disease so that they developed a range of self-management strategies for coping with daily tasks. Our findings suggest that patients with glaucoma need professional, effective and appropriate support and attention.

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