# Patients' barrier to adherence with glaucoma therapy experience: a qualitative research study

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**Purpose:** To explore the experiences of therapeutic glaucoma adherence in patients with glaucoma regarding the obstructive factors to adherence and its importance to health outcomes.

**Methods:** This qualitative study, purposive sampling, was used to recruit ten glaucoma patients. Data were collected from the outpatient ophthalmology clinic at Thammasat University Hospital between January and June 2017 using in-depth interviews along with observation and field records. Data were analyzed using content analysis.

**Results:** The main findings illustrated that adherence barriers with glaucoma therapy in patients with glaucoma were 1) lacking essential knowledge and 2) forgetfulness. Adherence is crucial to the overall general health of glaucoma patients because it helps them able to proper healthcare, resulting in better therapeutic outcomes and able to independent living.

**Conclusion:** The results present an understanding of specific obstacles to adherence to anti-glaucomatous therapy. Future research should focus on investigating methods by which primary education related glaucoma and nursing management should be delivered to patients with glaucoma, leading to preserve the remaining eyesight diminishes.

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**Keywords:** Barrier to adherence, Experience, Patient with glaucoma, Qualitative research

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### Introduction

Glaucoma is the second leading cause of blindness in Thailand and worldwide. It is a chronic, progressive, and asymptomatic disease. The condition is initially asymptomatic, whether an untreated process

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E-mail: ksirilak9@yahoo.com Received: 19th March 2019 Accepted: 27th July 2019 Published: 10th November 2019 can result in gradual visual field loss and, eventually, blindness. Despite the condition being an "incurable disease," glaucoma is still treatable, and the primary objective of glaucoma therapy is to prevent progressive visual field loss, disability, and blindness.<sup>1-2</sup> Patient adherence has long been recognized as an essential factor in controlling glaucoma. If patients are not adherent to the therapeutic regimen, the patient exhibits higher IOPs and more advanced visual field loss. Then, the chance of preserving

their remaining eyesight diminishes.<sup>3-4</sup> Several published studies in Southeast Asia suggest that medical adherence among glaucoma patients is inadequate, between 50% and 63.4%.<sup>5-6</sup> The nonadherence can be summarized as intentional and unintentional nonadherence. The prevalence of unintentional nonadherence may vary depending on the patient's age, forget, understanding of glaucomatous progression, motivation, and confidence in their doctor.<sup>7-8</sup> As healthcare providers, we need to recognize the noncompliance barriers in the viewpoint of glaucoma patients in their contexts.

# **Objective**

To explore patients' experience in terms of barriers to adherence with glaucoma therapy regarding the barrier to adherence with glaucoma therapy and the importance of adherence to the health outcomes.

#### Method

This study used a qualitative approach. Purposive sampling was used to recruit ten glaucoma patients who met the following inclusion criteria: (a) patients who were diagnosed by ophthalmologists as glaucoma received at least 1 glaucoma drop for more than 3 months (b) able to communicate and understand Thai (c) consented to participate in this research. Exclusion criteria: (a) informants have acute glaucoma and (b) having other complications (e.g., cataract, uveitis, and eye trauma, etc.).

The primary research served as the instrument of data collection, along with the interview guidelines. The primary researcher used a memo note, reflexivity during data collection and data analysis. In this study, the data collection method included: in-depth interviews, participation observation, and used field records. Interview times and places were arranged at the informants' convenience and ranged from 15-30 minutes. All informants allowed

audio-taping of the interviews. Interviews were started with a general question (What is your goal when you receive glaucoma treatment?). The probing technique was used to gather more information. The second interview was conducted with eight informants. The third interview was requested from two informants for clarification and assurance that the data were completed.

Moreover, the primary researcher used field notes and participant observation. Data collection continued until the informants and data offered no new information were being repeated. Finally, all of the informants gave feedback about the accuracy of the interpretation of the findings. The study was approved by the Research Ethics Committee of Thammasat University (No. 3), Thammasat University, Thailand and was considered by the principle on International Conference on Harmonization-Good Clinical Practice, ID 031/2558.

This study adopted validity and reliability techniques based on Sandelowski's and Mayan's recommendation.9-10 According to address validity, various data sources were used, a saturation of the data was carried out, and accuracy validation of the findings, between the primary researcher and informants, was conducted. To attain reliability, the principal investigator described her background to the informants, approached informant two to three timed for interviews, and used various data sources. Throughout the research process and analysis, the primary researcher asked for input from peers and the other members of the research team.

Data analysis was based on Dey's content analyses.<sup>11</sup>

#### Result

The findings can be categorized into two parts as (1) general data, and (2) the patient experience with therapeutic glaucoma adherence.

#### Part 1 general data

Informants consisted of ten patients with glaucoma, both male and female equally (50%); aged between 61 and 70 years old was the highest (40%). Half of them were married; seventy percent was graduated from an elementary school. Seventy percent of them were diagnosed with primary angle-closure glaucoma; time since diagnosed was between 1 and 10 years (80%). Two types of eye drop treated fifty percent of the informants; seventy percent of them (7 informants) used a hired motorcycle and a public transportation for ophthalmologist visiting (see table 1).

Part 2 the patient experience with the rapeutic glaucoma adherence

The patient experience with glaucoma therapeutic adherence barriers are categorized as (1) therapeutic adherence barriers; and (2) the adherence importance to health outcomes as based on the following findings:

#### 1. Therapeutic adherence barriers

Most of the key informants revealed that therapeutic adherence barriers could be concluded into two themes, as follows:

- Lacking essential knowledge

The key informants mentioned relating the therapeutic adherence barriers as (1) lacking essential knowledge; it meant that patients with glaucoma had inadequate information and understanding relating disease, treatment plan, and progressive disease outcomes, resulting in ignorance regarding proper healthcare. The following sentences supported this notion:

"Other patients I spoke with, they didn't use eye drops...they stored their eye drops and didn't use them...they didn't know their eyes will be blinded" (informant #2)

"Frankly...I didn't know...they [doctor/ nurse] told me that I needed to take care of myself; I didn't do it...frankly speaking" (informant #6) "I Did not know both disease and treatment...need to know from the beginning...If a doctor instructed from the beginning, I would have better cooperated" (informant #9)

According to essential knowledge or information, most key informants mentioned that they required knowledge relating disease, treatment plans, or continued modification of treatment plans, including progressive disease outcomes in cases of improper healthcare.

# - Forgetfulness

Other therapeutic adherence barriers were forgetfulness; forgetful patients with glaucoma did not use medications as prescribed because of busy daily activities or work, including inconvenience to carry on medication due to proper medication storage (e.g., eyedrops requiring cold storage). The following sentences supported this notion:

"Forgot...my hands were sometimes dirty after work...after prolonged work; I then didn't want to make the medication dirty, or my wife sometimes dropped medication for me" (informant #4)

"Didn't always use eye drop...forgot sometimes...went out and didn't use eye drops...afraid of expired medication since a doctor told me that medication needed to be in a refrigerator all the time" (informant #10)

# 2. Adherence importance to health outcomes

However, most key informants presented that treatment cooperation is significant to health outcomes in patients with glaucoma because treatment adherence is related to the ability to proper healthcare, leading improve treatment outcomes and able to independent living. Appropriate healthcare resulted from having essential glaucoma information to apply for patients' participation and delayed disease progression through a discussion with related healthcare personals. The following statements supported this notion:

"I wish the doctor and I spoke about treatment...discussed the instructions ... asked me if I any issues or informed me of some self-care tips sometimes ...it would be good. A patient will understand, then properly follow instructions" (informant #5)

"I Want to take care of myself...actually; if I went to see a doctor from the beginning, it might be good" (informant #6)

Positive treatment outcomes result from proper performance according to instruction and treatment applying in daily life, leading to decreased incorporative treatment barriers, resulting in attaining medication as prescribed, for example, if a patient uses eye drop punctually, eye drops can control and reduce ocular pressure. Also, it can be immediately cured in case of complications, resulting in a higher treatment success rate or delayed disease progression. Consequently, the blindness rate is reduced. As stated by three key informants:

"Surely, supposed that he (a doctor) told me to use eye drops and use every 12 hrs., yet I cannot. It cannot reduce ocular pressure; it seems that visit to the doctor did not get me better" (informant #1)

"Importantly...glaucoma was very important to me since my first diagnosis, by myself...I confronted it. If I let it progress, it will give me acute pain and lead to operation and blindness...If I can control it, maybe I won't have blindness" (informant #3)

"Very important...firstly, a doctor would know regarding treatment outcomes improvement. Secondly, it provided benefit for patients...treatment outcomes would be rapidly improved" (informant #8)

Being capable of independent living results from adequate preservation of quality vision. Besides, patients with glaucoma can better interact with social networks and activities, leading to a happy life. The following statements supported this notion:

"Very important...important for my body...I want to improve...able to see... want to strong...able to go anywhere with the ability to see" (informant #7)

"If my eyes could not see anything... did not want to go anywhere...did not do anything... If eyes were blurred when went out, it was not funny. Others invited me to go out, but I didn't like to...unable to vision" (informant #2)

"If I could not see, a vision was not clear, led to transportation mistaking...everything was not clear, an accident would happen" (informant #4)

#### Discussion

The goal of this study was to study obstacles that patients with glaucoma experience when attempting to adherence to glaucoma regimens. The barriers to adherence for the patient with glaucoma are significant. Major reasons cited for nonadherence include lacking essential knowledge and forgetfulness. Lacking essential knowledge, Taylor, Galbraith, Mills<sup>3</sup> stated that patients generally want to be knowledgeable about glaucoma, healthcare providers are encouraged to inform patients about new medications that become available and help them understand each of their options, including laser and surgery. As Kosoko, Quigley, Vitale, Enger, Kerrigan, Tielsch<sup>12</sup> suggested that Poor understanding of the disease is also associated with poor adherence. Then, communication between providers and patients is a vital factor in adherence for glaucoma patients. Specifically, patients would like their providers to tell them about new/ alternate medications, and procedures have become available, and offer new ways to make their regiment easier.3,13

Almost half of these adherence obstacles reflected patient factors of forgetfulness. Taylor, Galbraith, Mills<sup>3</sup> also reported that patient forgetfulness was the number one reason for nonadherence. Forgetfulness is

included being away from home and the medication, inconvenient timing.<sup>13</sup>

In conclusion, this study, cause of nonadherence can be summarized as unintentional nonadherence in order to it occurred when the patient intends to take the treatment but is prevented from doing so by limitations in capacity and resource (forgetting, lack of essential knowledge). Most of the informant intend to treatment cooperate because they comprehend that glaucoma is a health condition which can be cured, and worse disease progression leading to blindness. Therefore, all informants mentioned that treatment cooperative is essential in case of attaining and comprehending necessary knowledge as needed, resulting in proper healthcare. Consequently, adequate healthcare leads to delay glaucoma progression, decrease optic nerve degeneration, maintain eyesight ability, resulting in independence daily living, and then they can typically interact with their social networks, leading to a better quality of life.

As Horn, Parham, Driscoll, Robinson<sup>6</sup> stated that unintentional nonadherence is common among chronic diseases. The most informants in this study (9 participants) that were interviewed expressed that they try to be adherent because they understand that they will go blind if their glaucoma progresses. However, glaucoma is a preventable cause of blindness if effective and successful treatment can be provided at the appropriate time.<sup>14</sup>

## Conclusion

The results of this study demonstrate that significant barriers for patients with glaucoma are lacking essential knowledge, and forgetfulness. These barriers recognized and handled to assist health care providers in developing appropriate interventions and guidelines to optimize patient education regarding enhancing, and nursing care related to adherence, which leads to the

change of preserving the remaining eyesight deterioration of patients.

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