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A questionnaire based study to assess the challenges faced by clinicians and patients in the management of uveitis

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ABSTRACT

Background: Uveitis includes many conditions and requires detailed examination, multiple investigations, referrals, topical and systemic medications, and regular follow-up to achieve effective management.
Aims and Objectives: To understand the difficulties faced by patients and clinicians alike in the management of uveitis.
Materials and Methods: We conducted a focus group discussion among eight clinicians involved in the care of uveitis patients, and semi-structured interviews were conducted on ten uveitis patients of varying educational status to understand their difficulties.
Results: Braun and Clarke's six-phase approach was used for to coding and conducting a thematic analysis and six themes with sub-themes were identified. Among clinicians, the themes were challenges faced in the treatment of uveitis patients; Identification of gap areas/ support areas; and The need for health technology for the management of patients with uveitis The Patients themes identified were patients' knowledge of uveitis and relevant medication prescribed for its treatment; perceived barriers to uveitis treatment; opportunities to incorporate mobile health technology into treatment and care.
Conclusion: The prominent challenge that was revealed in the study was patient education along with multiple follow-ups and the cost of medication. It was identified time constraints in a busy clinic, and the need for multiple referrals, investigations, and regular follow-ups all played a critical part in the effective management of these patients. Both patients and clinicians understood that the problem could be solved by the use of technology and both were open to exploring the use of mobile health applications as part of the management of the disease.
Key messages: Patient education and counseling about disease symptoms, systemic association, and medication are vital to the treatment of uveitis. The use of mobile health applications as a means to achieve the above has been explored in this study.

1. Introduction

The uvea, when considered to be inflamed is referred to as uveitis.[1] There are several challenges involved in the management of uveitis effectively, due to its varied etiology, chronicity of the disease, and the need for long-term immunosuppressive therapy and monitoring. Hence, effective treatment of this condition can be challenging for clinicians and difficult to comprehend from the patient's perspective.

Digital health technology may be able to address these concerns as they have the potential to alter disease monitoring, and patient education, and enable better profiling of disease progression.[2]

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It is necessary to address the concerns of clinicians and patients to overcome the barriers that prevent the effective treatment of uveitis. There is a lack of research on patients' and ophthalmologists' attitudes to the treatment of uveitis.

Our study aims to examine the requirements of patients with uveitis, and their doctors about their diseases, and treatment, and to utilize these perspectives in the development of a health technology that can improve patient care.

2. Materials and Methods

A qualitative approach was employed in this study. We obtained information from two sources namely, semi-structured questionnaires administered to patients with uveitis and currently on treatment, and a focus group discussion (FGD) involving ophthalmologists who were overseeing the care of the patients included in this study. An abductive logic was used to analyze, where a semi-structured questionnaire and questions in FGD were derived from identified difficulties encountered in uveitis management while an inductive approach was used to analyse the responses.

FGD was chosen as a method to assimilate data among clinicians as it allowed a good number of discussants to participate in focus groups, which is essential for the analysis of group norms and values.[3] In addition to this, FGDs as an approach are recommended in several relevant guidelines like those of ISPOR.[4]

Semi-structured interviews were chosen as the method of data collection for patients as it allowed them to express points in their terms which increases the likelihood of response. Semi-structured interviews are capable of yielding credible, comparable qualitative data.[5]

The study was approved by the ethics committee of our institution. (MSRMC/EC/AP-07/08-2021.) and conducted as per the ethical standards of the Declaration of Helsinki.

Sampling: A non-probabilistic purposive sample of ten patients attending the outpatient department and eight healthcare professionals involved in the treatment of patients with uveitis was taken.

Focus group participants were recruited by an invitation from the investigator and involved a select number of ophthalmology faculty and residents, restricted to our institute. A total of eight clinicians took part in the discussion. Informed consent was obtained from each participant.

Patients attending the ophthalmology clinic in our institute, with a documented diagnosis of anterior, intermediate, posterior, or pan-uveitis and on treatment qualified as participants. The minimum age of participants was 18 years of age. Ten eligible participants were identified by the consultant ophthalmologists.

2.1. Data collection

2.1.1. Focus group discussion

The topic for the discussion was "difficulties encountered by the clinicians in treating uveitis patients". Questions to be discussed were displayed on a screen that had been prepared in advance by an experienced ophthalmologist. (Table 1) Participants were informed that confidentiality would be maintained. A moderator and a co-moderator presided over the session, one to facilitate the discussion of each question and the other to ensure smooth execution, as well as to take field notes. The session was about 90 minutes long, contained 11 questions, and was audio-recorded for transcription and analysis.

Table 1: Questions discussed in the focus group discussion among clinicians

1.	Do you face any problem while treating uveitis patients? If yes, what are they?
2.	Do you find it difficult to explain that is inflammation and cause can be anywhere else in body?
3.	Do you find It difficult to explain it to patient why we need multiple expensive investigations to diagnose them? If yes, how do you tackle?
4.	DO you find that your patients have not understood your explanation and you have lost them for follow up?
5.	DO you often see patients with complications which you think could have been prevented if treated timely?
6.	Do your patients understand why they need multiple consults ? If no how do you convince them?
7.	Do you use any technology to explain the patient about their disease?
8.	Do you think if you had simple customised animated videos, you could explain better by showing them?
9.	Do you use smart phones to educate your patients?
10.	Do you think a customised application will help increase the compliance with your patients?
11.	Do you think an interactive application will help you manage the patients well?

2.1.2. Semi-structured interviews

A semi-structured questionnaire comprising 15 questions was presented to the participants. Informed consent was taken before the commencement of the interview. The questions focussed on the level of understanding of uveitis, its treatment, physician-patient communication, barriers to administering medication, and the perceived need for mobile health technology. (Table 2) Each interview was audio-recorded and transcribed.

2.2. Data analysis

Data from the interviews and focus group discussions was analyzed using Braun and Clarke's six-phase approach to coding and conducting a thematic analysis.[6] Two independent researchers generated initial codes from the

Table 2: The semi-structured questionnaire employed to understand patient's perspectives

1.	Do you know what disease you suffer from? Can you explain in few words?
2.	Has the doctor explained the disease to you well? If no what else would you want to know?
3.	Did you use any other· resources to learn about your disease? If so which ones?
4.	Do you understand why these medications have been prescribed to you?
5.	Do you understand why you have prescribed tablets for your eye condition?
6.	Has the doctor explained to you why you need multiple consults and repeated follow up? If yes do you agree with it and understand it?
7.	Do you have any difficulty in understanding the drops that have to be applied and their timing?
8.	Have you faced confusion about the drops and timing of the drops?
9.	What do you do when you forget to instil drops?
10.	Do you think if someone reminded you every time about the drops it would be easier for you to follow the advice?
11.	Do you think the prescription given to you in writing is adequate and helps you apply the drops correctly?
12.	Do you know about the side effects of the drugs prescribed to you?
13.	Do you use a smart phone? IF yes do use many apps in it?
14.	Do you think an app to remind you of the drops, their timing will help you to apply drops correctly without any mistake?
15.	Would you use the application if installed in your phone?

data available to improve reliability. The codes that fit together were identified as a theme. Our themes were predominantly inductive i.e. data-driven analysis where the data was categorized without attempting to incorporate it into an already-existing coding framework or the researcher's analytical preconceptions.

3. Results

A total of 18 participants were involved in the study, including both patients and ophthalmologists. Thematic analysis of the FGD conducted among the ophthalmologists yielded three central themes.

3.1. Ophthalmologists perspectives: (Figure 1)

3.1.1. Theme 1: Challenges faced in the treatment of uveitis patients

The challenges faced by clinicians were broadly classified as 1) Explaining the disease to the patient 2) Explaining the need for multiple investigations and referrals 3) Time constraints 4) Documentation 5) Chronicity of the disease.

1. Explaining the disease as Inflammation/ Infection: Most participants faced this challenge and they were of the consensus that the word inflammation was difficult to explain. One of the participants commented "Most of the time, we end up saying that the patient has an eye infection instead of inflammation."(C1)

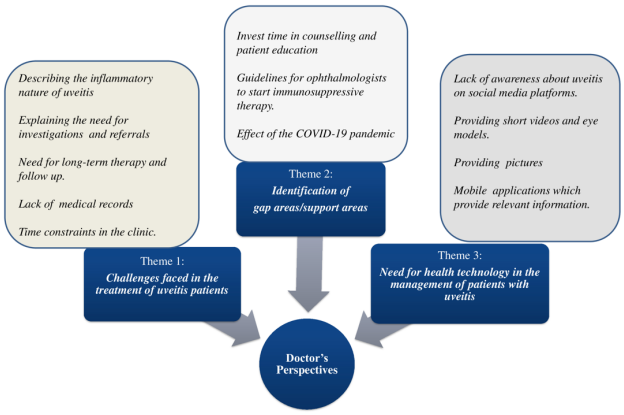

Figure 1: Ophthalmologists perspectives- themes and subthemes

Patients' educational status also determined the ease with which the clinicians could explain the disease to them. One participant suggested encouraging people to learn about their condition on their own would be a good option. Most clinicians agreed that based on the literacy level of patients, the level of detailed explanation about uveitis varied.

"People with low literacy find it difficult to understand. With educated people, I ask them to read the information available online, and understanding gets better, especially of the complications. (C1)

One of the participants commented on the role of the patient's personality "I feel that the patient's personality matters and that is not under our control – as some patients are in denial and resort to doctor shopping."(C2)

2. Explaining the need for multiple investigations and referrals: In uveitis, multiple investigations are required to confirm the etiology. Patients may deem umpteen investigations as unnecessary and expensive and hence it is important to explain the need for the same. Some ophthalmologists referred to internists to evaluate the patients systemically and assumed that patients would understand the systemic associations better if explained by internists.

"I fail to explain to my patients. I send them to the physician instead. They usually advise the need for systemic treatment." The same clinician also commented "Symptoms like back pain and joint pain are not easy to explain by ophthalmologist. It takes up your consultation time."(C1)

Some doctors found that the explanation given in the clinic may not have been sufficient and the patients were subsequently lost to follow-up. "There is a loss to follow up because of limited knowledge of the disease." (C2)

Another participant commented "In Multi-specialty hospitals, there is the ease of cross-consultation and the disease is explained better. If immunosuppressive drugs

are given, then they have side effects and patients tend to discontinue them and go for other alternate treatments. It's imperative to make them understand that these don't help."(C3)

From the above statements, it is understood that ophthalmologists find it challenging to explain the need for multiple blood investigations for an eye condition and some clinicians prefer to refer the patient to a physician for the systemic workup of patients and also assume that patients may gain a deeper understanding of their condition and the systemic etiology of the disease. This also highlights the imperative need for cross-consultation and the importance of timely referrals for the best possible patient care and outcomes.

3. Time constraints: Loss to follow-up was identified as one of the most commonly encountered challenges. One may not always have the time to explain the reason for the patient's symptoms and the need for multiple investigations leading to patients not returning for continued care. Time constraint was highlighted as a participant stated "It takes a lot of time to explain. Lack of explanation is the reason for loss to follow up."(C4)

"It is difficult to explain recurrences and cost of investigations. Counselling them and referrals to other departments might help" (C5)

4. Documentation: The lack of continuity of follow-up and difficulties faced due to poor documentation were discussed. In India where there is no centralized medical records system, doctors rely heavily on the notes and prescriptions provided at the center where the patient was previously treated. When these prescription sheets are unavailable, providing the best treatment plan can be a challenge as doctors have to rely heavily on patient history. In uveitis where treatment may be prolonged, patients may have difficulty in providing the relevant history. One clinician expressed their concerns "I think documentation is very difficult to procure. Many hospitals do not give their documents to the patients and patients have only their laboratory reports. Every time the patient sees a new consultant, investigations get repeated and management also changes." (C2).

5. Chronicity of the disease: Even after providing adequate treatment, doctors noted that some patients are dissatisfied. The need for long-term use of eye drops and/ or systemic medication for what is perceived to be a simple eye problem is baffling to most patients. Patients obtain consults from multiple healthcare practitioners to be convinced of the suggested treatment.

Doctors identified a delay in presenting to the ophthalmologist as an important issue they faced. Long-term deprivation of treatment may lead to more severe disease with increased complications which may hamper the successful management of some cases. Timely diagnosis with early institution of therapy was discussed as one of the challenges faced by a treating ophthalmologist.

"Timely diagnosis is difficult in uveitis. If there is delayed presentation it is difficult to explain to the patient." (C6)

All clinicians came to a consensus that patient education was the key to overcoming the challenges of multiple referrals, investigations, loss to follow-up, and compliance with the treatment regimen.

3.1.2. Theme 2: Identification of gap areas/ support areas

Participants were encouraged to discuss solutions and to overcome the challenges faced in the management of uveitis patients. The main recommendations from this theme were to provide a detailed explanation of the cause of symptoms to the patients. This awareness may ensure that the patient would self-monitor closely, follow doctors' instructions regarding the dosing of medication, and also make an attempt to follow up regularly. Doctors also noted the need for clear-cut guidelines for ophthalmologists to start immunosuppressive therapy.

The COVID-19 pandemic was weaving its effects on doctors and patients alike at the time this study was being conducted and therefore was factored in. It was brought to notice that due to apprehension about visiting a hospital, patients stayed at home and continued to use topical medication such as steroids for prolonged periods or discontinued the same on their own.

Since uveitis is usually treated with both topical and systemic corticosteroids, it is important to monitor disease activity. Patients need to be informed regarding the side effects that may develop due to treatment.

"Drugs like steroids are the magical drug that helps patients but they continue using it and come back with complications and these are difficult to treat."(C7)

The need for an effective medium for doctor-patient communication was highlighted when doctors felt that patient education was lacking - The systemic association of uveitis, proper techniques to administer medication, monitoring of side effects, and the need for regular follow-up.

"Over usage of medication can be a possibility as patients buy the same bottle repeatedly. Therefore, patient education is important. But in a busy practice, one might fail to do so."(C8)

"Educate the patient and Internal medicine specialists and pediatricians that uveitis can be associated with systemic conditions as well. "(C3)

In this theme, taking time to explain the disease, its chronicity, side effects of the treatment, and complications were identified as the main support areas.

3.1.3. Theme 3: Need for health technology for the management of patients with uveitis

The FGD encouraged clinicians to delve into the possibility of using technology to find solutions for the problems encountered during the treatment of uveitis patients. It was identified that uveitis is not discussed on social media unlike other diseases and hence ophthalmologists are the primary educators for the patient with uveitis.

Various modalities to improve patient education were discussed :

1. Employing simple terminology while counseling and using pictures/ images as an adjunct.
2. Provision of Short videos/Eye models.
3. An interactive mobile application with tailored information provided to the patient about their ophthalmic condition.
4. An integrated approach to management with inter-departmental involvement.

3.2. Patient perspectives (Figure 2)

A total of 10 patients were recruited for the study out of which four were males and six were females. The mean age of the participants was 40.3 years. Most participants were literate (80%), two holding a degree, one completed class 12, and five high school graduates. Out of the 10 participants, 8 of them owned and used smartphones.

3.2.1. Theme 1: Patients' knowledge of Uveitis and relevant medication prescribed for its treatment

Subtheme 1: Knowledge about uveitis- the disease

Most patients were unaware of their diagnosis and had limited knowledge about possible associated complications. However, patients reported different symptoms to describe their condition, which for some affected day-to-day activities. Some stated that they were suffering from an infection. Only one participant was able to respond aptly stating that uveitis was an inflammation involving the eye.

"I'm not sure, my eyes keep repeatedly getting red and when I see light I have difficulty. Also I have pain frequently associated with headache."(P5)

"Some dust fell into my eye two months ago following which I had severe headaches and pain. They give me drops and tablets. But the pain is too severe and my eyes are red. This is an infection due to dust." (P4)

Subtheme 2: Knowledge about the medication used in uveitis

Three out of ten patients were able to correctly state the medication they were using but had no understanding of steroid use or its complications. None of the patients in our study reported experiencing significant side effects from medication. It is essential to emphasize the need for close monitoring of patients started on steroids and the complications that may arise with its long-term use.

"They have given me Wysolone tablets and some eye drops but I am not sure why."(P2)

3.2.2. Theme 2: Perceived barriers to uveitis treatment

Subtheme 1: Challenges faced in patient interaction with the doctor

Most patients had no difficulty during their interaction with the care provider in the clinic. Few participants identified a significant deficit in the knowledge of the disease provided to them by their doctor.

"Doctor has not said much to me except that it a reaction. I want to know why it is so frequently coming with associated pain."(P5)

"We asked the physician too. But they haven't told us anything about the eyes."(P7)

Most patients believed that they wanted the clinicians or internists to explain them about their disease.

Subtheme 2: Challenges faced in administering prescribed treatment

The majority of the patients did not have any trouble using medication about the drops and the timing of administering it except one patient who could not maintain the time interval between drops on occasion.

"I don't forget but sometimes I'm not able to put it on time."(P1)

Subtheme 3: Challenges faced for timely follow-up

Accessibility can influence adherence to treatments. One patient reported "I was unable to go for regular consults as my residence was far from the hospital" (P1).

The need for multiple consults and repeated follow-ups is understood by the patient. Several patients agreed with the doctor when the requirement of frequent visits to the clinic was expressed and understood the need for it.

"I have to come so that my treatment can be altered at the next visit."(P10)

"They have told me that there's a chance of it occurring repeatedly so I come to get it checked often"(P7).

Accessibility and adherence to the follow-up schedule were important in the management of patients. Though the patients agreed on the need for regular follow-up they acknowledged that adhering to the schedule was difficult due to distance from the hospital, frequent loss of work, and frequent follow-ups.

3.2.3. Theme 3: Opportunities to incorporate mobile health technology into treatment and care

Subtheme 1:Adoption of technology (Smartphone use)

Most patients (almost 80%) owned a smartphone with many applications installed. Two individuals did not own a smartphone due to barriers of financial inability and illiteracy.

Subtheme 2: Perceived ease of adoption of technology

All the participants who used a smartphone unanimously agreed that an application that ensured timely reminders

through notifications, provided education on the subject, and also monitored progress if introduced, would be received well and beneficial.

Subtheme 3: Perceived ease of using a mobile health application

The majority of participants expressed agreement to the use of a mobile application for uveitis if made accessible to them and if it was tailored to their eye condition they would be comfortable using it.

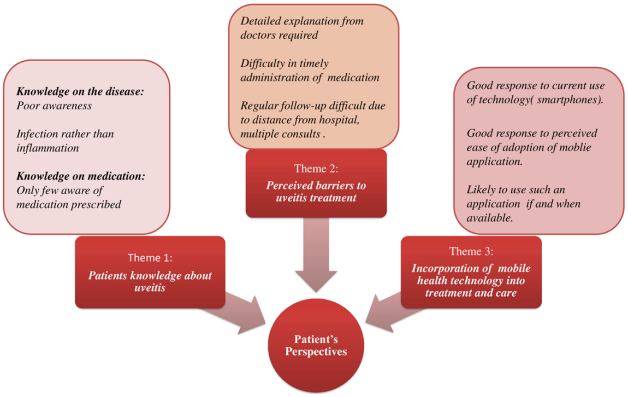

Figure 2: Patient's perspectives-themes and subthemes

4. Discussion

In recent times, there has been a greater understanding of the value of the patient's voice in ophthalmology.[7] This shift in thinking has its impact on clinical practice and in terms of how we perceive the effects of disease and the effectiveness of treatments.[8] The influence of uveitis on the quality of life in adults has only been studied utilizing patient-reported outcome measures (PROMs) which are non specific to uveitis. The SF-36 Health Survey[9] and the 25-item National Eye Institute Visual Function Questionnaire (NEI-VFQ-25)[10] are frequently used questionnaires for patients to assess general health-related quality of life and vision-related quality of life, respectively. Studies have been conducted to improve this aspect with disease-specific measurement instruments of the impact of uveitis in patients with the disease, although they have been conducted in the background of chronic uveitis,[11] non-infectious posterior segment uveitis,[12] and juvenile idiopathic arthritis-associated uveitis[13] and Behcet's disease.[14,15]

Our study aimed at examining the challenges faced and requirements by patients with uveitis and their clinicians. To our knowledge, this is the first study conducted that assessed adult patients with different levels of education and diagnosed with anterior, intermediate, posterior, and pan uveitis; and doctors with varying years of experience. Our study also addressed the prospect of integrating technology into the day-to-day management of uveitis patients and the key elements that must be factored in while doing so.

The ophthalmologist's primary concerns were discussed including the difficulty in explaining the disease, multiple investigations and referrals to the patient, loss to follow-up, delay in presenting to the clinic, the need for an effective medium for doctor-patient communication, and the prevention of complications. Tallouzi et al also noted that doctor-patient communication was key for the effective management of uveitis.[16] In our study the challenge identified was patient education about the disease. The clinicians identified the patient's educational status, personality, and time constraints as limiting factors in imparting education about the disease. Though some clinicians assumed that a cross-consultation would help increase patient awareness, patients expressed that even the internist had failed to explain the disease to them.

Patients had limited knowledge of disease and medication and did not come for regular follow up. Other studies showed that patients were not aware of relapses and side effects of systemic medications, but were willing to follow the advice of the clinician.[17]

There exists a perceived requirement for mobile health technology for uveitis patients by both doctors and patients. Most patients owned and used a smartphone and were interested in the prospect of such an application that would aid in the better management of their condition. The clinicians too felt that the use of customized mobile applications would overcome the challenges of patient education. The COVID-19 pandemic has taught us that the future of health care is in technology and it is vital to integrate the two. The obvious health benefits of mobile health applications utilizing a self-monitoring tool can only be determined through a clinical trial of an application. Nonetheless, perceived benefits from self-documentation can increase a consumer's engagement with a health application, and this approach would theoretically improve self-management if the measurements are valid and reliable. Nilges et al have shown in their study that health application resulted in positive self-management of dental hygiene.[18] Hence, patient outcomes may be enhanced by using a self-care tool to assist patients in managing their uveitis.

For the clinician, an application that provides customized information to uveitis patients and allows to track the progress of the patients will help in the effective management of these patients.

5. Conclusion

Patient education was identified as a major challenge in uveitis management by both FGD of clinicians and interviews of patients. It was recognized that the use of technology could aid in a better understanding of the disease and help in the effective management of these patients. Both clinicians and patients believed they were comfortable using technology and perceived it to be useful in the management

of uveitis. This allows for the exploration and development of computer applications addressing individual diseases and thus improves patient involvement in disease management.

6. Source of Funding

None.

7. Conflict of Interest

None.

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