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## Do Demographic Factors Influence Uveitis Patients' Understanding of Uveitis?

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**Title:** Do Demographic Factors Influence Uveitis Patients' Understanding of Uveitis?

**Subtitle:** Uveitis Patients' Understanding of their condition

**Keywords:** Demographics; Ethnicity; Index of Multiple Deprivation; Patient Understanding; Social Deprivation; Uveitis

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## **Subtitle**

Uveitis patients have poor understanding of their ophthalmic condition. Demographic factors and clinic attendance history have no independent influence on uveitis knowledge score. Strategies should be devised to improve patient knowledge in this important area.

## **Abstract**

**Purpose:** To establish how much uveitis patients know about their own condition and to investigate the contribution of demographic factors to that knowledge.

**Methods:** A self-designed questionnaire, comprising 20 questions about uveitis, was distributed to 200 consecutive patients attending a uveitis clinic. The questionnaire requested demographic details and required responses to uveitis-specific knowledge questions. Postcode was used to determine level of social deprivation using Index of Multiple Deprivation 2007. Univariate analyses with Mann-Whitney test and Kruskal-Wallis test were utilised. Multivariable logistic regression was performed to simultaneously measure the independent influence of demographic variables on the level of patients' understanding of their condition.

**Results:** Of the respondents, 62% were female, 71% aged >40 years and 67% of white ethnic origin, with 41% having been under the care of a uveitis specialist for >10 years and 72% attending  $\geq 3$  clinic appointments in the preceding 12 months. Median questionnaire score (out of 60) was 27 (interquartile range [IQR] 15). Females scored significantly higher than males (30 [15] versus 24 [15]  $p=0.001$ ), but there was no difference according to age, ethnicity or social deprivation quintile, nor the duration patients had been under ophthalmic review or number of clinic attendances in the preceding 12 months. Multivariable analyses determined no independent influence of any of the factors on uveitis questionnaire score.

**Conclusions:** Uveitis patients' understanding of their condition is poor. This has relevance for adherence to treatment, follow-up clinic attendance and eventual outcomes in these patients.

## **Introduction**

Uveitis is the collective name of a group of inflammatory conditions affecting the eye. It can affect any age group, but appears to be more common in those of working age, with an average annual incidence of 17 – 52 cases per 100,000 [1]. Uveitis can be visually devastating, secondary to complications such as cataract, glaucoma and macular edema. Indeed, uveitis accounts for up to 5 – 20% of cases of legal blindness in the United States and Europe, but also remains one of the few ocular conditions where visual loss may be treatable[2].

Although advances are being made in the clinical and scientific understanding of uveitis, there is a paucity of information concerning the level of uveitis patients' understanding of their condition, particularly regarding aetiology, risk factors, complications and eventual outcomes. Whilst there is ample information regarding patients' understanding of their own disease in a number of other medical conditions the data, overall, suggest that patients' understanding is poor [3,4].

Poor understanding of disease may contribute to increased levels of uncertainty and anxiety about the potential for visual loss, but may also have impact on clinical outcomes. For example, it has previously been highlighted that, in other ophthalmic conditions, those with greater knowledge of their condition have better treatment compliance [5].

In the United Kingdom the Health Foundation reviewed the evidence for patient-focused interventions in 2006 and concluded that health literacy, which encompasses a basic health knowledge, comprehension and evaluation of health

information, as well as application of self-care health behaviours, communications with health professionals and decision making, was a stronger predictor of health status than age, income, employment status, education level, race or ethnic group. Whilst United Kingdom data on the prevalence of health illiteracy is unavailable, United States data suggest that it affects up to 90 million adults, with likely serious consequences for health [6,7].

Because of the serious impact that uveitis can have for a patient's life and livelihood, it is important to determine where 'gaps' in patients' knowledge about uveitis may be. These areas of poor understanding can then be addressed with educational programmes. In addition, there is significant evidence demonstrating the effect of social factors on health, particularly in conditions such as cardiovascular disease [8], renal disease [9], diabetes mellitus [10], inflammatory bowel disease [11], systemic lupus erythematosus [12], and rheumatoid arthritis [13]. Ophthalmic diseases linked with social deprivation, include glaucoma[14], age-related macular degeneration [15], diabetic retinopathy [15], and thyroid eye disease [16]. However, no such investigation has yet been undertaken in uveitis. In this study we therefore aimed to explore the possible contribution of demographic factors, socioeconomic status, ethnicity, duration of disease and frequency of interaction with uveitis services to patients' understanding of uveitis.

## **Methods**

We undertook a prospective, questionnaire-based study of 200 consecutive uveitis follow-up patients attending a tertiary referral clinic at Birmingham & Midland Eye Centre (BMEC), United Kingdom in the first quarter of 2012. The first page of this

questionnaire collected anonymised epidemiological data, including age, gender, self-reported ethnicity, level of education, employment status, residence postcode, length of time attending the uveitis clinic and number of follow-up appointments in the preceding 12 months. (Fig 1).

The second page comprised 20 uveitis-specific questions, exploring patients' understanding of disease definition, epidemiology, causes, symptoms, complications and treatment (Fig 2). The questionnaire was trialled by four uveitis patient groups and modified according to their comments. A three point Likert scale was used for the responses - Agree, Uncertain and Disagree.

For 12 questions (question 1, 3, 4, 6, 7, 9, 11, 12, 14, 16, 18, 19) the correct answer was 'Agree'. For the remaining 8 questions (question 2, 5, 8, 10, 13, 15, 17, 20) the correct answer was 'Disagree'. The answers were given recoded values from 1 to 3. If the correct answer was chosen it was scored with the maximum three points, whereas if the wrong answer was chosen it only scored one point.

To assess the level of social deprivation of each uveitis patient, we converted their residence postcode at questionnaire completion to an Index of Multiple Deprivation (IMD 2007) score. IMD 2007 is a well-validated quantifier that ranks areas across England based on the level of social deprivation of each Lower Super Output Area (LSOA) based on a number of 'domains', including income, employment, health deprivation and disability, educational skills and training, barriers to housing and services, crime, and living environment.

Postcodes were converted to IMD 2007 scores using online software (<http://geoconvert.mimas.ac.uk/>). Uveitis patients were ranked from lowest (least deprived) to highest (most deprived) IMD 2007 score and divided into West Midlands specific quintiles (quintile 1: least deprived; quintile 5: most deprived), with 33 patients in each quintile (Table 1).

We determined the number of questions the patients answered correctly and analysed whether there was any association with demographic data. Univariate analyses with Mann-Whitney test (for two groups) and Kruskal-Wallis test with Dunn's post-test (for more than two groups) were utilised using Prism version 5.0 (GraphPad Software, California 2008). Multivariable logistic regression was performed using SPSS version 18 (IBM, Chicago, IL) to simultaneously measure the independent influence of demographic variables on the level of patients' understanding of their condition.  $p \leq 0.05$  was considered statistically significant.

## **Results**

Of the 200 patients who completed the questionnaire 42.5% answered 6 to 10 uveitis-specific questions correctly. The second largest proportion (36%) only answered 0 to 5 questions correctly (Fig 3). None of the patients answered all questions correctly and only 22.5% scored more than 10 questions correct.

Of the 200 patients who completed the questionnaire there was acceptable demographic data completion in 165 cases (83%). Of the respondents with adequate data, 62% were female, 71% aged >40 years and 111 (67%) of white ethnic origin. Forty-one percent of these patients had been under the care of a uveitis specialist for

more than 10 years and 72% had attended three or more clinic appointments in the preceding 12 months.

Although 80.5% of patients knew the meaning of uveitis, 67% knew that uveitis can affect both the front and the back of the eye and 62.5% that uveitis may give a red and painful eye, only 51% knew that uveitis may be painless, 49.5% that uveitis may lead to cataract and 22% that steroid eye drops are ineffective for posterior uveitis (Table 2). It is also noteworthy that high proportions of patients were uncertain about the correct answers, stating 'Don't know' to many of the questions. Question 13, stating that computer use could worsen uveitis, was the question most often answered with uncertainty by 56.5%, whereas question 10, stating that uveitis treatment was lifelong, was answered incorrectly most often, by 33% of patients. These data highlight the poor knowledge of uveitis patients and the accompanying implications for patient care. It is important, for example, for ophthalmologists to note that only 40% of uveitis patients knew that steroid eye drops can increase the eye pressure as this may have a bearing on the importance patients place on ophthalmic examination at follow-up appointments and on their adherence to treatment. Likewise, for the 74% who answered incorrectly, or who did not know the correct answer to the statement of uveitis treatment being lifelong, the prospect of long-term out-patient clinic follow-up may come as an unpleasant surprise.

The median questionnaire score (out of 60) was 27 (interquartile range [IQR] 15). Univariate analysis determined that females scored significantly higher than males (females, 30 [15] versus males, 24 [15]  $p=0.001$ ), but there was no difference according to age, ethnicity, nor the duration patients had been under ophthalmic

review or number of clinic attendances in the preceding 12 months (Table 3). Kruskal-Wallis test (with Dunn's post-test) determined no significant differences in test scores by social deprivation quintile, although when the least deprived (quintile 1) and most deprived (quintile 5) were directly compared with Mann-Whitney test there was a significant difference (quintile 1, 27 [12] versus quintile 5, 24 [15]  $p=0.045$ ). Multivariate analyses determined no independent influence of any factor on uveitis questionnaire score.

## **Discussion**

To our knowledge this is the first study to formally assess the knowledge base of uveitis patients and to attempt to stratify their knowledge by important demographic factors. This study found the understanding of uveitis by patients with uveitis to be poor with only 22.5% (45/200) answering more than half of the questions correctly and no single patient answering all questions correctly. However, we did not note any independent association between the level of understanding of uveitis and variables such as age, ethnicity, level of social deprivation, duration under ophthalmic review or number of clinic attendances in the preceding 12 months. Females did achieve significantly higher score than males, although the reason and relevance of this is unknown.

It is interesting to note that while the majority of patients knew the meaning of uveitis only a third were aware that the treatment of their uveitis may need to be continued throughout their lives. This is important as, despite the possibilities for treatment of uveitis, the available data suggests that uveitis patients have an impaired quality of life, both due to visual impairment itself as well as the effects of associated systemic

diseases and those of steroid and immunomodulatory treatments [1]. It is important for patients to know about the chronicity of their condition and possibility that it may continue or recur to be able to plan for the future.

An association of depression and anxiety with chronic diseases has been studied for heart disease, stroke, diabetes, asthma, cancer, arthritis and osteoporosis, with a systematic review of the available evidence confirming a strong association. Furthermore, it was determined that these mental health issues may impact on clinical outcomes [17]. Similar studies specifically focussed on patients with acute anterior uveitis examined the psychological state of both inactive [18], and active uveitis patients [19,20]. Both groups had a tendency toward depression and overall reduced quality of life, which was more prominent in patients with work dissatisfaction.

In the current concordance model of healthcare delivery the patient is considered an equal partner who, with the doctor makes informed decisions and agrees the optimal treatment plan for their illness, which is then adhered to for the best outcome . There are many variables at play but patient knowledge of their condition, its potential consequences for health and the various treatment modalities, is an important factor that contributes to better adherence with treatment plans, clinic attendances and achievement of disease control.[21,22]

Having an ophthalmic condition for a prolonged period, or being under regular ophthalmic review, is no guarantee of increased patient knowledge about their condition. No assumptions should therefore be made on the basis of follow-up

duration. In a study of glaucoma patients, Danesh-Meyer et al (2008) found that those with glaucoma for six months or more had only slightly higher glaucoma knowledge scores than those glaucoma patients referred for the first time to an ophthalmologist. However, both of these groups did have significantly higher knowledge scores than a control population of non-ophthalmic patients [5]. This is certainly a limitation of our study in that we did not have a control population either of ophthalmic patients without uveitis or of the general public.

The importance of patient understanding of their illness has been highlighted by the International Uveitis Patient Interest Association (INTUPIA), which formed in 2012. A primary objective of this collaboration was to ensure better communication between doctors and patients and to improve patient education through the provision of information about the condition, its treatment, current research and clinical trials, as well as the publication of a specialised journal 'Uveitis'. The journal has so far covered topics such as macular edema, ocular toxoplasmosis, steroids in uveitis, low vision and uveitis and glaucoma in uveitis.

In this context, the interaction between a patient and their ophthalmologist is often the first step in their process of gaining information about their condition and subsequently gaining 'ownership' of it. Many patients are motivated to search the internet for information about their disease [23], although it has been determined that online information, even that supposedly tailored to patients, is often of poor readability and therefore likely to be of little use in expanding patient understanding of a range of ophthalmic conditions, including uveitis [24,25]. In this regard there may be a role for uveitis specialist nurses in providing easy access to answers to patient

questions, as well as education and advocacy provided by patient groups specifically related to uveitis.

In conclusion, patients with uveitis appear to have a poor understanding of the basis of their condition. Whether this is of relevance to their treatment compliance, disease outcome or psychosocial well-being is uncertain. These factors need further investigation. It would be interesting to assess whether an intensive programme of education may increase levels of patient understanding, or whether patients actively engaging in disease interest groups have better understanding of uveitis.

#### **Declaration of Interest**

The authors have no financial or conflicts of interest to disclose. The authors alone are responsible for the content and writing of the paper.

## **Legends for Figures**

**Fig 1.** Anonymised epidemiological data collection sheet, requesting such information as age and gender, but also ethnic origin, qualifications, residence postcode and previous and recent uveitis clinic attendance.

**Fig 2.** Twenty uveitis-specific questions, exploring patients' understanding of disease definition, epidemiology, causes, symptoms, complications and treatment. The questionnaire was trialled by four uveitis patient groups and modified according to their comments. A three point Likert scale was used for the responses – 'Agree', 'Uncertain' and 'Disagree'.

**Fig 3.** Number of correct answers given by different percentages of uveitis patients.

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