



## The Psychosocial and Economic Impact of Uveitis in Iraq

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### Abstract

**Background & Aims:** Uveitis is the inflammation of the uvea, the pigmented layer that lies between the inner retina and the outer fibrous layer composed of the sclera and cornea. This study is aimed to know the psychosocial and economic impacts of uveitis in Iraq.

**Materials and Methods:** For this Cross-sectional study, 100 surveys were conducted in patients with uveitis. Demographic data and socioeconomic status were recorded. Symptoms, time to diagnosis, treatment, behavior, attitudes, and feelings towards the disease were identified. Data were analyzed using statistical programs.  $p < 0.05$  was taken to be statistically significant.

**Results:** For conducted 100 surveys, mean age was  $45 \pm 17.08$  years, socioeconomic level  $\leq D$  in 61%, and 54 patients were women. The diagnosis was made at  $1.87 \pm 2.73$  years. They attend an annual appointment for  $2.1 \pm 2.14$  months, more than 1 at emergency room, and hospitalized for 3 to 7 days. They used systemic treatment with steroidal anti-inflammatory drugs (53%), immunosuppressants (31%), biological therapy (7%), and topical treatment with lubricants (44%), steroids (26%) and surgery (39%). Observed comorbidities included: arterial hypertension, diabetes mellitus, rheumatoid arthritis, Sjögren's syndrome, lupus, and nonspecific chronic ulcerative colitis. Complications included visual impairment, cataracts and blindness. Uveitis affected life in 83% of cases, 41% daily, and 49% need care from another person. 79% receive private care, 43% have social security, spending monthly  $3,590 \pm 2,730.65$  pesos on medicines, transportation, medical consultations and studies. These are added with annually absence from work of  $8.5 \pm 14.56$  days, plus 7.0 days of disability or hospitalization. 51% report lack of support to learn about the disease.

**Conclusions:** This is the first national study that portrays the condition of patients with uveitis and the shortcomings they go through, including the economic and biopsychosocial field. The study elucidates various needs of uveitis patients that could be considered by governments. More studies with more study population is recommended to better decision making for needs of uveitis patients.

**Keywords:** Uveitis, Psychosocial Impact, Economic Impact

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### Introduction

Uveitis is a group of conditions characterized by intraocular inflammation. Technically, it describes the inflammation of the uvea (iris, ciliary body and choroid). Since it can affect nearby tissues, the term

uveitis also includes inflammation of the cornea, retina, optic nerve, and vitreous (1, 2). It is a little known, poorly understood and undervalued condition (1). However, it has a global impact and direct relevance in various medical specialties. It causes significant

visual loss worldwide, especially in productive ages and in women, and can be the first manifestation of some systemic diseases (1, 2). Vision disturbances, eye discomfort, systemic diseases, and adverse effects of medications impact quality of life and must be considered (1).

Uveitis is classified according to its anatomical location into anterior, intermediate, posterior, and panuveitis. Other classifications divide it according to the type of inflammation (granulomatous and non-granulomatous) or according to the severity or duration (acute and chronic). Two

severe forms of uveitis require treatment with systemic corticosteroids, but adverse effects force the ophthalmologist to use immunosuppressive medications (3-5).

The incidence of uveitis is 20-50 per 100,000 per year, and the prevalence is 100-150 per 100,000. However, it varies among nations, and more infectious causes are reported in less developed countries. It causes 10-15% of blindness worldwide (1, 2, 5) and is the third leading cause of preventable blindness in the world (6).

Additionally, 25-50% of patients will have an associated systemic disease (2). There are vision-related quality of life questionnaires and studies have found that visual function and general health status are worse than them in healthy people (2, 7). Furthermore, poor visual acuity, ocular complications and treatment have an impact on the quality of life associated with vision (8).

When it occurs at productive ages, it causes an important socioeconomic impact (6). This depends on multiple factors, such as the cause and duration of the disease, comorbidities, the income of the patient/family, and government support (2). Until now we lack information on the psychosocial and economic effects experienced by patients diagnosed with uveitis in Iraq. The objective of our study is to know this impact and identify the factors that influence quality of life.

## Material & Methods

The objective of the study is to know the psychosocial and economic impact suffered by patients

diagnosed with uveitis in Iraq. It was carried out at the Clinic for Inflammatory Ocular Diseases of the Luis Sánchez Bulnes Hospital of the Association to Avoid Blindness (APEC) in Iraq in October and November 2018.

### Participants and Study Design:

Interviews were conducted with people with uveitis, all over 18 years of age. They were given an informed consent document. After the affirmative answer, the interviews were conducted personally. The questions were developed by clinicians experienced in the management of ocular inflammation, using closed (dichotomous, categorized, scale, and multiple choice) and open questions. A strategy in five modules was used: 1) demographic data and standardized questions from the Mexican Association of Market Intelligence and Opinion Agencies (AMAI), 2) presenting symptoms, time to diagnosis, type of treatment, and follow-up, 3) behavior, attitudes, and feelings towards the disease, and 4) knowledge and sources of information, and 5) unmet needs.

### Data Analysis:

The questionnaires were coded and the data were filtered, consolidated, and analyzed in a database on computer support using statistical programs. Subsequently, a thematic analysis was carried out. Relative frequencies and measures of central tendency were used for the descriptive variables. *p* values under 0.05 was taken to be statistically significant.

## Results

### Profile of the Surveyed Patients:

100 patients were included, 56% were women, with a mean age of  $45 \pm 17.08$  years, and socioeconomic level  $\leq D$  in 61%. The place of residence includes Iraq city 36%, State of Iraq 26%, Puebla 7%, Guerrero 6%, Oaxaca 6%, Morelos 5% and 14% for the rest of other states included in the study. 71% of patients received medical care exclusively in the private sector and 21% received mixed care. 43% of them have social security, directly or through their spouse and/or child (Table 1).

**Table 1.** Demographic data, socioeconomic levels and social security

	Total	Feminine	Male
Sex	100	56	44
Age	45 ± 17.08	48.8 ± 17.21	40.2 ± 15.83
Socioeconomic level			
AB / C +	12	9	3
DC-	27	13	14
D + / D / E	61	3. 4	27
Scholarship			
I do not study	3	3	0
Primary in / complete	5/9	2/4	3/5
Secondary in / complete	5/33	2/19	3/14
Race	2/8	2/5	0/3
High school in / complete commercial / technical	3/18	1/7	2/11
Bachelor's degree in / complete	7/6	7/3	0/3
Diploma / Master	1	1	0
Social Security	43	22	21
IMSS	26	-15	-11
ISSSTE	10	5	5
Popular insurance	7	2	5

ISSSTE = Institute of Social Security and Services for State Workers; IMSS = Mexican Institute of Social Security.

### Symptoms, Time to Diagnosis, Type of Treatment Used and Follow-up:

The main symptoms were: poor vision (67%), eye pain (60%), eye inflammation (60%), and headache (42%). The disease was bilateral in 44%. The diagnosis was made 1.87 ± 2.73 years from the onset of symptoms, attending 3.7 ± 3.15 physicians, including ophthalmologists, general practitioners,

rheumatologists, and nephrologists. The patients who were diagnosed quickly reside in Iraq city and/or the State of Iraq.

They were currently treated at APEC, in a clinic with specialists in ocular inflammation and attends with an average of 6.3 visits per year (range 1 to 50), with a frequency of 2.1 ± 2.14 months, more than once to the emergency room and remain hospitalized for 3.7 days due to eye disease (Table 2).

**Table 2.** Previous medical care and comorbidities

	Total	Feminine	Male
Number of doctors you visited before diagnosis	3.7 ± 3.15	3.8 ± 2.69	3.6 ± 3.68
Specialties you visited before diagnosis			
Ophthalmologist	94	52	42
General practitioner	51	25	26
Retinologist	12	8	4
Rheumatologist	8	7	1
Emergency service	7	3	4
Nephrologist	1	0	1
Comorbidities			

Diabetes	15	5	10
Arterial hypertension	14	10	4
Rheumatoid arthritis	10	9	1
Sjogren's syndrome	4	4	0
Lupus erythematosus systemic	3	2	1
ulcerative colitis (UC)	3	2	1
Granulomatosis with polyangiitis	1	0	1
Other *	15	7	8

UC = nonspecific chronic ulcerative colitis.

\* Cirrhosis, epilepsy, fibromyalgia, hemiplegia, hypercholesterolemia, hypertriglyceridemia, kidney failure, Parkinson's, psoriasis, bipolar disorder, tuberculosis, HIV/AIDS.

The systemic treatments used were with steroidal anti-inflammatory drugs (53%), immunosuppressant (31%), biological therapy (7%), topical treatment with lubricants (44%), and steroids (26%). 39% have

undergone surgery, with a mean of  $1.6 \pm 1.04$  since diagnosis, with surgery for cataract (21%), retina (8%), and glaucoma (4%) ( Table 3 ). The main complications include significant visual impairment in 69%, cataracts in 39%, blindness in 34%, and vitreous opacities in 28%.

**Table 3.** Medical and surgical treatment

	Total	Feminine	Male
<b>Anti-inflammatory treatment</b>			
Oral steroids *	53	28	25
Immunosuppressant †	31	11	20
Biological drug ‡	7	4	3
Alkylating agents §	3	1	2
Intravitreal triamcinolone	9	6	3
Periocular betamethasone	8	4	4
Implanted devices ¶	2	0	2
Oral NSAID	2	2	0
<b>Anti-infective and surgical treatment</b>			
Oral antibiotic / antiviral	6	3	3
Surgeries	39	20	19
Surgeries from diagnosis	$1.6 \pm 1.04$	$1.6 \pm 1.04$	$1.5 \pm 0.96$
Surgeries in the last year	$0.8 \pm 0.96$	$1 \pm 1.19$	$0.6 \pm 0.61$
waterfalls	21	8	13
Vitrectomy	8	15	5
Ahmed valve	4	0	4

NSAIDs: non-steroidal anti-inflammatory Drugs.

\* Prednisone, deflazacort.

† Azathioprine, chloroquine, cyclosporine, hydroxychloroquine, methotrexate, mycophenolate mofetil, sulfasalazine.

‡ Adalimumab, anakinra, golimumab, infliximab.

§ Cyclophosphamide.

Ozurdex.

The frequent comorbidities were arterial hypertension in 21.5% and diabetes mellitus in 23%, by those of autoimmune origin: rheumatoid arthritis 15%, Sjögren's syndrome 6%, systemic lupus erythematosus 4.6%, and nonspecific chronic ulcerative colitis (UC) 3% (Table 2).

**Behavior, Attitudes and Feelings Towards the Disease**

Regarding the severity of the inflammation at diagnosis, 21% considered it mild, 22% moderate, 43% severe, and 14% unknown; and at the time of the interview, 32% changed to mild, 24% to moderate, 14% to severe, and 5% were unaware. As for the cause of uveitis, 31% of patients were unaware of it.

**Impact on the Daily Life of the Patients and Costs Associated with Uveitis**

The life of the patients is affected by uveitis in 83% of them, and this affectation is daily in 41%. Everyone has changed something according to the conditions, such as emotional, psychological, work, school, autonomy, and social problems. They report negative emotions such as helplessness, annoyance, sadness, despair, anger, fear, and frustration. In addition, 49% of patients need care from a family member, and this is provided by their mother, daughter and/or wife.

Regarding the expenses for the illness, they invest monthly 3,590 ± 2,730.65 pesos. 71% spend between 1,001 and 5,000 pesos per month, mainly in medicines, transportation, consultations and studies.

Regarding the employment situation, 21% have formal employment with absences for attending a consultation of 8.5±14.56 days a year and for disability or hospitalization 7.0 days a year (Table 4).

**Table 4.** Monthly expenses and employment situation

	Total	Feminine	Male
Monthly expense for uveitis	3,590 ± 2,730.65	3,571.4 ± 2,715.99	3,613.6 ± 2,780.46
<\$ 1,000 / month	8	5	7
\$ 1,0001 to \$ 5,000 / month	71	39	32
\$ 5,001 to \$ 10,000 / month	17	10	16
> \$ 10,001 / month	4	two	two
Expense items			
Medicines	92	51	41
Transport	70	39	31
Medical consultation	47	27	twenty
Studies	43	22	1
Lenses	33	19	14
Visit to the emergency room	18	9	9
Surgeries	eleven	5	6
Disposable products	7	3	4
Accommodation / lodging	1	1	0
Current job situation			
Unemployment	2. 3	14	9
Formal employment	21	8	13
Informal employment	16	10	6
Housewife	15	14	1
Student	10	4	6
Retired	6	4	2
Laborer	5	0	5

Pensioner	3	2	1
Disabled	1	0	1
Absences from work by consultation (year)	8.5 ± 14.56	7.7 ± 6.41	9.3 ± 19.59
Hospitalized days (year)	3.7 ± 4.32	3.5 ± 5.08	3.8 ± 3.73

### Knowledge and Sources of Information:

Patients obtain information about the disease from the specialist doctor (62%), the internet (44%), the hospital (23%), social networks (8%), relatives (8%), and books (7%).

### Unmet Needs:

51% of patients report lack of support to learn about the disease and 76% are willing to belong to a support

association. They request: psychological support (63%), support material (53%), a meeting place with people in the same situation (45%), quick access for a medical appointment with a specialist (45%), a call center to answer questions (39%), a trustworthy website (31%), financial support (16%), and support for medication (6%) (Table 5).

**Table 5.** Psychological Aspects Influenced by Uveitis

	Total	Feminine	Male
Emotional / psychological	54	31	2. 3
Labor	15	27	2. 3
Care unit	49	24	25
Mobility	41	27	14
Autonomy / disability	32	19	13
Social relationships	24	11	13
Discrimination	17	9	8
None	17	11	14
Find a partner	4	1	3
Schoolchildren	2	0	2
Limitation when using computer	1	0	1
Memory loss	1	1	0

### Discussion

The importance of the study is to know the vision problems of the patient with inflammatory eye diseases in Iraq. The results of the survey show the impact of uveitis on the lives of those affected. From the beginning of the disease, the patient has a delay in his diagnosis, and affectation in the affective, emotional, social, and economic aspect (9, 10).

83% of the patients report that uveitis affects their lives, and 41% every day, mainly emotionally and at work, and almost half of them require help from family members. One of the main concerns is the effect of vision loss on their quality of life (10).

Another point to take into account is that the patients are young, with an average age of 45 years; they attend six medical appointments a year, to the emergency room, have absenteeism from work and remain hospitalized. Similar annual situations are described in the USA (11). Bajwa et al. in 2015 reported up to 11 consultations per year (12) and Nelson et al. in 2019 reported 51.2% go to the emergency room in one year (6).

The estimated economic impact of visual loss in patients under 40 years of age is greater than \$38 billion, due to medical care, patient support, and loss of quality of life (12). Almost a quarter of patients are unemployed, and this is related to poor vision, multiple

appointments, and hospitalizations; this is consistently believable, as patients are unable to maintain employment while being treated (12).

The time to reach the diagnosis is more than one year, and an average of  $3.7 \pm 3.15$  doctor attend diagnose, including ophthalmologists and doctors from other specialties. Other study diagnosed 81.2% in a subsequent consultation (12). The timely diagnosis of uveitis reduces the risk of complications, which contribute to an economic burden, disability, and alters the psychosocial sphere (13).

Patients spend  $3,590 \pm 2,730.65$  pesos monthly for their illness. APEC is a hospital that belongs to the board of Private Assistance Institutions and is a referral hospital. Patients come from various entities, being 62% from the metropolitan area, followed by Puebla, Guerrero and Oaxaca. The cost of the consultation at the time of the study was 180 pesos; the patient also pays for laboratory studies, cabinets, surgery and medications; although 43% of patients have social security, a figure lower than the 63.9% reported in Iraq in 2018 (14-16). Patients spend more on drugs and transportation, similar to spending on glaucoma (17). In Spain and France the highest expenses are in hospitalizations and medicines (18, 19).

Regarding complications, cataract was found in 39%. Other study reported it in up to 77.3% (20). We do not know the number of patients with glaucoma, but if we assume the numbers, it would occupy figures of up to 20% (21). Blindness was reported in 34%, but it is the perception of the patient and we do not know if it is legal blindness as reported (5-29%) (9, 21, 22). Blindness also causes other expenses, such as depression (39%), use of optical devices (33%), residential care (30%), and visual rehabilitation (11%) (2, 3).

Patients with uveitis have chronic degenerative comorbidities, mainly diabetes mellitus (5.7 -27.2%) and hypertension (15.6 - 29.3%), which represent an extra expense (20, 25). We found diabetes in 23%, which is higher than that reported for Iraq, which is 9.4% (26), and arterial hypertension in 21.5%, which is lower than previous report (26).

In addition, a third of them have autoimmune diseases, mainly rheumatoid arthritis 15%, Sjögren's syndrome 6%, systemic lupus erythematosus 4.6%, and nonspecific chronic ulcerative colitis (UC) 3%, as described (9, 20).

Patients with non-infectious uveitis have more serious, autoimmune diseases, require hospitalization, and use of immunosuppressive and/or biological agents, which represent 20% of health costs. There are guidelines for treatment by country and costs vary (22). Our patients use oral steroids (53%), immunosuppressants (34%), and biological therapy (7%). Comparing with the US, where they use biological therapy (40%), oral steroids (33.0%) and immunosuppressants (15.3%) (6, 23). Giving long-term treatment with immunosuppressants is to prevent blindness (23), but this negatively influences overall quality of life scores (10, 27).

Half of the patients want information about the disease, psychological or financial support. 76% want to belong to a support association. An informed patient is a better patient to understand the diagnosis, make decisions, and have better adherence to treatment, and thus causing improvements in their well-being and mortality records. The level of education of the patient has a positive influence on the interpretation of the indications and negatively on having lower health results, increasing hospitalizations and emergency appointments (28). To do this, you have to produce quality educational material (28).

This is the first Mexican study on the impact and cost of uveitis. Among the limitations is that it is only the perception of the patient, without a validated questionnaire, and the methodological approach lacks rigor in quantitative research. In uveitis there is little qualitative research that uses quality of life measures to improve patient care (29). It must be taken into account that the word of the patient influences health policy, affects the provision of treatment, helps us to improve our management and research because patient comments are included (29).

The survey provided us with objective information from the psychosocial field and subjective information

about their attitudes and opinions. The weak point is that the ophthalmological diagnoses, complications and severity of the disease are the judgment of the patient, so the impact and cost of the disease will need to be validated with studies and other estimates.

## Conclusions

In our medical practice, we have to pay attention to the voice of the patient to know what they are experiencing in terms of their disease, what their priorities and needs are. This study represents the situation of patients with uveitis and the deficiencies they go through. The economic burden associated with uveitis is significant for the patient, their family, and the health system. In addition, changes are generated in the biopsychosocial environment of the patient. It is important to make an early diagnosis, give adequate treatment, prevent progression, and thus, reduce visual loss.

## Conflict of Interests

The authors declare that they have no conflict of interest.

## Financing

Not need to conduct the patient surveys.

## Ethical responsibilities

**Protection of People and Animals.** The authors declare that no experiments were performed on humans or animals for this research.

**Confidentiality of the Data.** The authors declare that they have followed the protocols of their work center on the publication of patient data.

**Right to Privacy and Informed Consent.** The authors have obtained the informed consent of the patients and/or subjects referred to in the article. See also reference 30.

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