Patient Perspectives on Intravitreal Injection Burden: A QUALITII Study in a Portuguese Center

Perspetiva do *Burden* pelos Doentes a Realizar Injeções Intravítreas: Estudo Baseado no QUALITII num Centro em Portugal

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ABSTRACT

INTRODUCTION: Intravitreal injections (IVIs) have transformed medical practice in ophthalmology for many retinal conditions with countless patients requiring continuing treatment. Patient adherence plays a pivotal role, influenced by their experiences and treatment challenges. Identifying sources of patient burden is vital for improving retinal disease management.

This study uses the Questionnaire to Assess Life Impact of Treatment by Intravitreal Injections (QUALITII) to assess the multifaceted burden of repeated IVIs within a single center.

METHODS: The validated QUALITII survey was translated and adapted to Portuguese. It was distributed to patients receiving IVIs at Centro Hospital de Leiria in Portugal. The Treatment Burden Score (TBS) was calculated to provide an overall assessment of patients' perspectives.

RESULTS: The 168 patients of our study were aged 75.9 ± 1.1 years on average and had been receiving IVIs for 3.0 ± 0.2 years (60.7% had undergone over 10 IVIs), most frequently every 4/5 weeks. TBS averaged 24.8 ± 0.9 (n=123, scale 1–54), higher in females, anxious patients, and those requiring assistance. Satisfaction rated at 4.5 ± 0.1 (scale 0–6), positively correlated with treatment duration and perceived vision preservation, but was lower for patients receiving injections every month. Peak anxiety levels averaged 3.1 ± 0.2 (scale 0–6), higher in women and anxious patients while correlated negatively with age and positively with treatment duration. To cope with the treatment, 7.7% used anxiolytics. IVIs' discomfort averaged 3.1 ± 0.2 (scale 0–6), and was also higher in females and anxious individuals, with 12.1% considering discontinuation. It did not affect overall satisfaction but led 13.2% to use oral pain-relief medication resulting in a higher TBS. Half of the patients reported limitations after injection for approximately 9.1 ± 1.0 hours, which also correlated with TBS. Time consumption was rated 3.2 ± 0.2 (scale 0–6) with 79.4% requiring assistance.

CONCLUSION: The burden experienced by patients under IVIs is complex with TBS offering valuable insights. Females, anxious patients, and those requiring assistance faced a higher burden. Longer treatment durations and perceived vision preservation were associated with increased satisfaction but anxiety, discomfort and post-IVI restrictions were prevalent. Addressing these issues can enhance the IVIs experience and adherence, ultimately improving patient quality of life.

KEYWORDS: Intravitreal Injections; Patient Care Management; Patient Compliance; Patient Satisfaction.

RESUMO

INTRODUÇÃO: As injeções intravítreas (IVIs) revolucionaram a oftalmologia com inúmeros doentes a realizar um tratamento contínuo para patologias retinianas. A adesão dos doentes, influenciada pelos desafios e experiências no tratamento, é fundamental. Compreender as fontes do *burden* é decisivo para aperfeiçoar estes tratamentos.

Este estudo utilizou o Questionário para Avaliar o Impacto na Vida do Doente sob Tratamento com IVIs (QUALITII) para avaliar os fatores responsáveis pelo *burden*.

MÉTODOS: O questionário validado QUALITII foi traduzido e adaptado para português. Posteriormente, foi distribuído aos doentes a realizar IVIs no Centro Hospital de Leiria em Portugal. O *score* do *burden* do tratamento (TBS) foi calculado.

RESULTADOS: Os 168 doentes do nosso trabalho tinham, em média, 75,9 ± 1,1 anos e recebiam IVIs há 3,0 ± 0,2 anos, mais frequentemente a cada 4/5 semanas. O TBS teve uma média de 24,8 ± 0,9 (n=123, escala 1-54), sendo mais elevado em mulheres, doentes ansiosos e os que necessitavam acompanhante. A satisfação foi avaliada em 4,5±0,1 (escala 0-6), correlacionando-se positivamente com a duração do tratamento e a perceção de preservação da visão, sendo menor nos que recebiam IVIs mensalmente. A ansiedade atingiu 3,1 ± 0,2 (escala 0-6), sendo maior em mulheres e doentes ansiosos, correlacionando-se negativamente com a idade e positivamente com a duração do tratamento. Usavam ansiolíticos para lidar com os tratamentos, 7,7% dos doentes. O desconforto das IVIs foi 3,1 ± 0,2 (escala 0-6), levou 12,1% a ponderar desistir e 13,2% a usar analgesia oral. Metade dos participantes relatou limitações após o tratamento, levando 9,1 ± 1,0 horas a retomar a atividade normal (correlação com o TBS). O tempo do tratamento foi avaliado em 3,2±0,2 (escala 0-6) com 79,4% a necessitar de acompanhante.

CONCLUSÃO: O *burden* experienciado pelos doentes a realizar tratamento com IVIs é complexo, com o TBS a oferecer informações valiosas. Mulheres, doentes ansiosos e os que necessitam de acompanhante apresentaram um *burden* mais elevado. A maior duração do tratamento e perceção de preservação da visão estão associadas a uma maior satisfação, mas a ansiedade, desconforto e restrições pós-tratamento foram prevalentes. A reflexão sobre estas questões pode permitir melhorar a experiência, a adesão ao tratamento, e, em última análise, a qualidade de vida do doente.

PALAVRAS-CHAVE: Adesão ao Tratamento; Gestão de Cuidados ao Doente; Injeções Intravítreas; Satisfação do Doente.

INTRODUCTION

The landscape of medical practice in ophthalmology has undergone a transformative revolution with the emergence of intravitreal therapy for the treatment of retinal diseases.[1] Intravitreal injections (IVIs), involving the administration of anti-vascular endothelial growth factor (VEGF) agents, have emerged as a first-line treatment for conditions such as neovascular macular disease and foveal-involving macular edema.[2] This treatment has gained worldwide prevalence, with millions of IVIs administered annually.[3,4] While flexible regimens like pro re nata (PRN) and treat-and-extend (T&E) have been developed, patient adherence remains critical for successful outcomes.[5]

Patient experiences, satisfaction, and perceived burden play vital roles in adherence, as the need for frequent IVIs can prove burdensome for patients, caregivers, and healthcare systems alike.[6–9] Common barriers to adherence encompass treatment-related anxiety, adverse events, long travel distances to ophthalmic clinics, and systemic comorbidities.[10] Additionally, factors such as financial constraints, baseline visual acuity, and scepticism regarding treatment benefits can influence patient compliance.[10] Understanding and addressing these barriers is of paramount importance, given studies revealing high rates of nonadherence and non-persistence, especially within the initial 12 months of treatment.[11] Drawing inspiration from chronic disease management, proactive strategies, including assessing patients' willingness to continue treatment and providing patient education at different stages, can significantly enhance adherence.[10]

To comprehensively assess patient burden concerning intravitreal injections, the "Questionnaire to Assess Life Impact

of Treatment by Intravitreal Injections" (QUALITII) was developed.[12,13] This validated questionnaire evaluates five dimensions of patient burden: disruption of normal routines, anxiety, visit frequency, chronicity of the disease, and perceived treatment value. To further enhance the assessment, a Treatment Burden Score (TBS) was created based on responses to nine key questions.[12]

Despite the significance of these issues, remains a notable absence of data regarding how intravitreal therapy burden impacts patients in Portugal. Understanding this influence is not only critical for optimizing treatment strategies but is also essential for resource allocation within healthcare systems that face unique challenges.

In light of these considerations, this study aims to characterize the burden of repeated intravitreal injections using the QUALITII survey within a single center in Portugal.

MATERIAL AND METHODS

PATIENT SELECTION

Patients undergoing IVIs at Centro Hospitalar de Leiria in Leiria, Portugal, were invited to participate in this study. Inclusion criteria encompassed patients with exudative retinal diseases who were currently receiving IVIs. The specific demographic details of the patient sample are detailed in the Results section. Patient confidentiality was strictly maintained throughout the study and this research adhered to the ethical principles outlined in the Declaration of Helsinki. Approval for the study was obtained from the Local Ethics Committee.

ADAPTATION OF QUALITII SURVEY

The "Questionnaire to Assess Life Impact of Treatment by Intravitreal Injections" (QUALITII), originally developed by McClard *et al*,[12] was translated into the Portuguese language and adapted to the unique realities of the Portuguese healthcare system and culture (Annex 1). The questionnaire consisted of multiple-choice items, 7-point Likert scales and free-responses. Patients were given the questionnaires on the day of their treatment and were provided with clear instructions to self-administer them either at the hospital or at home. Any queries or concerns raised by patients were addressed promptly.

CALCULATION OF TREATMENT BURDEN SCORE (TBS)

The TBS, an essential metric for assessing the overall burden experienced by patients, was computed as described previously by McClard *et al*.[12] This score is based on a subset of nine items, thoughtfully selected for their significance in measuring the treatment burden. The theoretical range of the TBS is 1 to 54, where a score of 54 represents the maximum treatment burden.

STATISTICAL ANALYSIS

For data analysis, we utilized the Statistical Package for the Social Sciences for Windows, version 23 (IBM SPSS Statistics®). All data variables were transformed into numerical values for statistical analysis, where applicable. Continuous variables were described using mean (M) and standard deviation (SD). The normality of quantitative variables was evaluated using the Kolmogorov-Smirnov and Shapiro-Wilk tests. In cases where these assumptions were met, independent samples were analysed using a t-test. If these assumptions were not satisfied, the Mann-Whitney test was applied. Logistic regression was utilized to predict categorical dependent variables, and for correlation analyses, both Pearson and Spearman correlations were employed. A *p*-value less than 0.05 was considered statistically significant.

Table 1. Characteristics of Study Participants.

		NUMBER	PERCENT (%)
Age	Mean	75.9 ± 1.1 years	
Gender	Male	94	55.9
	Female	74	44.1
Disease	AMD	86	51.2
	DMO/RD	40	23.8
	RVO	34	20.2
	Other	8	4.8
Eye under treatment	Both	61	36.3
	Right	55	32.7
	Left	52	31.0
Number of IVIs	0-5	29	17.3
	6-10	37	22.0
	11-20	25	14.9
	21-50	44	26.2
	50+	33	19.6
Treatment duration	Mean	3.0 ± 0.2 years	
Time of diagnosis	Last year	37	22.0
	1-4 years	66	39.3
	5-10 years	45	26.8
	10+	17	10.1
	Uncertain	3	1.8
Injection in the RE (n=116)	Every 4-5 weeks	85	73.3
	Every 6-8 weeks	26	22.4
	Every 10-12 weeks	3	2.6
	Every 13-16 weeks	1	0.9
	Uncertain	1	0.9
Injection in the LE (n=113)	Every 4-5 weeks	78	69.0
	Every 6-8 weeks	28	24.8
	Every 10-12 weeks	5	4.4
	Every 13-16 weeks	1	0.9
	Uncertain	1	0.9
Consultation	Less than 3 months interval	56	33.3
	Every 3-6 months	40	23.8
	Every 6-9 months	32	19.0
	Once a year	15	8.9
	Uncertain	25	14.9

AMD - age-related macular degeneration; DMO/DR - diabetic macular oedema and/or diabetic retinopathy; RVO - retinal venous occlusion; RE – right eye; LE – left eye; IVIs - intravitreal injections.

Annex 1. Questionnaire.

1. **Idade** _____ **anos**

2. **Género**
   - ○ Feminino
   - ○ Masculino

3. **Quantas injeções no olho já fez?**
   - ○ Menos de 6
   - ○ Entre 6 e 10
   - ○ Entre 11 e 20
   - ○ Entre 20 e 50
   - ○ Mais de 50

4. **Para que doença ocular realiza injeções no olho?**
   - ○ DMI - Degenerescência Macular da Idade
   - ○ Retinopatia diabética/Edema macular diabético
   - ○ Oclusão venosa da retina
   - ○ Não sei
   - ○ Outra opção... _____

5. **Há quanto tempo foi diagnosticado com essa doença?**
   - ○ No último ano
   - ○ Entre 1 - 4 anos
   - ○ Entre 5 a 10 anos
   - ○ Mais de 10 anos
   - ○ Não sei

6. **Há quanto tempo faz injeções no olho?** _____ **meses/anos**
   (riscar o que não interessa)

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7. **Com que frequência faz injeções no olho direito?**
   - ○ Não faço injeções no olho direito
   - ○ A cada 4-5 semanas
   - ○ A cada 6-8 semanas
   - ○ A cada 10-12 semanas
   - ○ A cada 13-16 semanas
   - ○ Não sei
   - ○ Outra opção... _____

8. **Com que frequência faz injeções no olho esquerdo?**
   - ○ Não faço injeções no olho esquerdo
   - ○ A cada 4-5 semanas
   - ○ A cada 6-8 semanas
   - ○ A cada 10-12 semanas
   - ○ A cada 13-16 semanas
   - ○ Não sei
   - ○ Outra opção... _____

9. **Com que frequência tem consulta de oftalmologia?**
   - ○ A cada 2-3 meses
   - ○ A cada 3-6 meses
   - ○ A cada 6-9 meses
   - ○ Uma vez por ano
   - ○ Não sei
   - ○ Outra opção... _____

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10. **Qual o grau de satisfação com o tratamento do seu olho?**

	0	1	2	3	4	5	6	
Muito insatisfeito	○	○	○	○	○	○	○	Muito satisfeito

11. **Na sua opinião, quão eficazes são as injeções na melhoria da sua visão?**

	0	1	2	3	4	5	6	
Muito ineficazes	○	○	○	○	○	○	○	Muito eficazes

12. **Na sua opinião, quão eficazes são as injeções na preservação da sua visão?**

	0	1	2	3	4	5	6	
Muito ineficazes	○	○	○	○	○	○	○	Muito eficazes

13. **Com que frequência experiencia algum destes sintomas após a injeção?**

	Sempre	Frequentemente (mais de metade das vezes)	Por vezes (metade das vezes)	Raramente	Nunca
Não tenho sintomas após a injeção	○	○	○	○	○
Dor ou desconforto no olho	○	○	○	○	○
Moscas volantes depois do primeiro dia	○	○	○	○	○
Aumento da sensibilidade à luz	○	○	○	○	○
Diminuição da visão depois da primeira hora	○	○	○	○	○
Hemorragia/sangue no olho	○	○	○	○	○

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14. **Qual o grau de incomodo dos sintomas após a injeção?**

	0	1	2	3	4	5	6	
Não incomodam	○	○	○	○	○	○	○	Muito incómodo

15. **Os sintomas após a injeção já o levaram a pensar desistir do tratamento com injeções?**
   - ○ Sim
   - ○ Não

16. **Qual o grau de dor ou desconforto da injeção?**

	0	1	2	3	4	5	6	
Insignificante	○	○	○	○	○	○	○	Muito significativo

17. **Quanto tempo dura a dor ou desconforto após a injeção?**
   - ○ Não sinto dor/desconforto
   - ○ Menos de 10 minutos
   - ○ Entre 10 minutos e 1 hora
   - ○ Entre 1 a 2 horas
   - ○ Entre 2 a 4 horas
   - ○ Entre 4 a 8 horas
   - ○ Entre 8 a 24 horas
   - ○ Entre 1 a 2 dias
   - ○ Mais de 2 dias

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18. **Que aspeto acha que causa mais desconforto ou dor?**

- ◯ Não sinto dor/desconforto
- ◯ Anestesia do olho
- ◯ Colocação do instrumento para manter o olho aberto (blefarostato)
- ◯ Aplicação do antiséptico castanho antes da injeção (betadine)
- ◯ Injeção no olho
- ◯ Lavagem do olho após a injeção
- ◯ Desconforto após passar o efeito da anestesia do olho
- ◯ Outra opção... _____

19. **Utiliza gotas para alívio da dor/desconforto do olho em casa?**

- ◯ Sim
- ◯ Não

20. **Utiliza medicação oral (comprimidos) para alívio da dor/desconforto do olho em casa?**

- ◯ Sim
- ◯ Não

21. **Depois da injeção, sente que não consegue fazer a sua atividade normal por causa da dor/desconforto?**

- ◯ Sim
- ◯ Não

22. **Quantas horas após a injeção demora a retomar a sua atividade normal?** _____ **horas**

23. **Qual o seu grau de ansiedade antes da injeção?**

	0	1	2	3	4	5	6	
Nada ansioso	◯	◯	◯	◯	◯	◯	◯	Muito ansioso

24. **Qual o seu grau de ansiedade durante a injeção?**

	0	1	2	3	4	5	6	
Nada ansioso	◯	◯	◯	◯	◯	◯	◯	Muito ansioso

25. **Qual o seu grau de ansiedade após a injeção?**

	0	1	2	3	4	5	6	
Nada ansioso	◯	◯	◯	◯	◯	◯	◯	Muito ansioso

26. **Sente ansiedade ou tristeza não relacionada com o seu tratamento dos olhos?**

- ◯ Sim
- ◯ Não

27. **O que melhora a sua ansiedade durante o tratamento?**

_____
_____
_____
_____

28. **O que piora a sua ansiedade durante o tratamento?**

_____
_____
_____
_____

29. **Faz medicação oral (comprimidos) para a ansiedade por causa do seu tratamento?**

- ◯ Sim
- ◯ Não

30. **Considera que o seu tratamento ocular requer muito tempo?**

	0	1	2	3	4	5	6	
Nada demorado	◯	◯	◯	◯	◯	◯	◯	Muito demorado

31. **Quantas horas passa no hospital cada vez que vem fazer uma injeção?**

- ◯ Menos de 1 hora
- ◯ Entre 1 a 3 horas
- ◯ Entre 3 a 4 horas
- ◯ Mais de 4 horas

32. **Quantas horas no total precisa para vir ao hospital fazer cada tratamento e voltar para casa?**

- ◯ Menos de 1 hora
- ◯ Entre 1 a 4 horas
- ◯ Entre 4 a 8 horas
- ◯ Mais de 8 horas

33. **Precisa de alguém para vir consigo aos tratamentos?**

- ◯ Sim
- ◯ Não

34. **Quão conveniente é, para o seu acompanhante, traze-lo aos tratamentos?**

	0	1	2	3	4	5	6	
Nada conveniente	◯	◯	◯	◯	◯	◯	◯	Muito conveniente

35. **Quantas horas gasta o seu acompanhante, em cada tratamento, para o transportar e ajudar a recuperar?** _____ **horas**

36. **Se alguém tivesse um problema semelhante ao seu, recomendar-lhe-ia este tipo de tratamento?**

- ◯ Sim
- ◯ Não

37. **Se alguém tivesse um problema semelhante ao seu, recomendar-lhe-ia este hospital para tratamento?**

- ◯ Sim
- ◯ Não

38. **Há mais algum aspeto de satisfação ou descontentamento com o seu tratamento ocular que queira mencionar?**

_____
_____
_____
_____
_____
_____
_____
_____
_____
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_____
_____
_____

FIM

Obrigado pela sua participação!

Por favor devolver no Serviço de Oftalmologia

ou na Cirurgia de Ambulatório

RESULTS

Demographics

A total of 168 patients participated in this study, with an average age of 75.9 ± 1.1 years, and comprising 55.9% males (Table 1). The distribution of patients by the disease under treatment include 51.2% received treatment for age-related macular degeneration (AMD), 23.8% for diabetic macular oedema and/or diabetic retinopathy (DMO/DR), 20.2% for retinal venous occlusion (RVO), and 4.8% for other retinal or choroidal diseases, including angioid streaks, pachychoroid spectrum disorders, and macular telangiectasias. Notably, only 54.2% of respondents were aware of their specific eye condition.

Regarding intravitreal treatment details, 36.3% reported receiving treatment for both eyes, 32.7% for the right eye exclusively, and 31.0% for the left eye alone. The majority of patients (60.7%) had undergone more than 10 IVIs, with 19.6% having received over 50 injections.

On average, patients had been receiving IVIs for 3.0 ± 0.2 years, most frequently administered every 4 to 5 weeks. Approximately 22.0% received their diagnosis within the past year, while 36.9% had been living with the diagnosis for over 5 years. More than half of the patients (57.1%) had consultations at least every 6 months, with 14.9% being uncertain about their consultation frequency.

TREATMENT BURDEN SCORE (TBS) AND SATISFACTION

The TBS exhibited an average score of 24.8 ± 0.9 (n=123), on a scale ranging from 1 to 54. A detailed distribution of TBS is presented in Fig. 1.

The TBS was observed to be higher in female patients, with a mean TBS of 27.7 ± 1.3, in contrast to male patients with a mean TBS of 22.5 ± 1.1 (p=0.003). Age, specific disease, the number of IVIs received, and the duration of treatment did not exert a significant influence on the TBS.

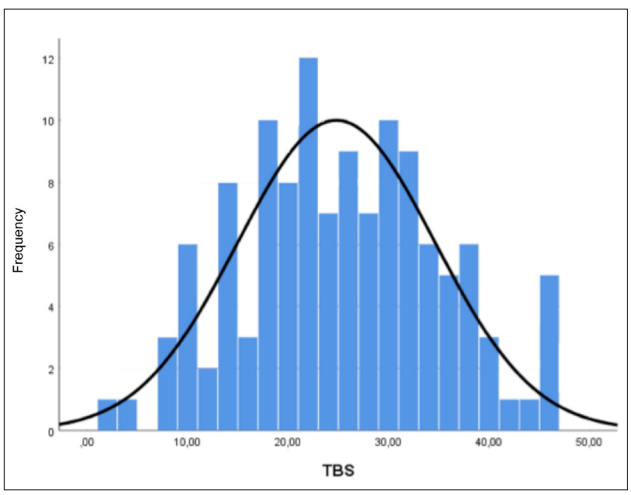

Figure 1. Distribution of the TBS.

TBS - Treatment Burden Score.

Overall patient satisfaction with the treatment, rated on a scale of 0 to 6, averaged at 4.5 ± 0.1 (n=168; Fig. 2). This satisfaction score exhibited a positive correlation with treatment duration (correlation coefficient +0.24; p=0.011) and perceived preservation of vision (correlation coefficient +0.69; p<0.001). Patients receiving at least one monthly injection reported lower satisfaction rates (4.3 ± 0.2) compared to those with less frequent injections (5.0 ± 0.2, p=0.016).

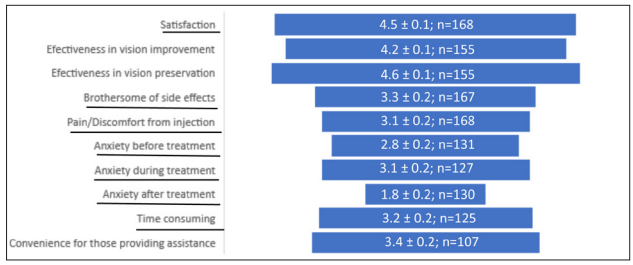

Figure 2. Patients experience of IVIs treatment – 7-point Likert scale responses. Parameters underlined incorporate the TBS calculation..

IVIs - intravitreal injections; TBS - Treatment Burden Score.

DISCOMFORT AND SIDE EFFECTS

Patients reported an average inconvenience level of 3.3 ± 0.2 (n=167; scale of 0 to 6) in relation to side effects. Notably, the most frequently cited side effect was pain or discomfort in the eye, followed by increased sensitivity to light, reduced vision beyond the first hour post-IVI, and an increase in floaters after the first day. Conversely, subconjunctival haemorrhage was the least commonly reported side effect. Approximately 12.1% of patients considered discontinuing treatment due to side effect inconveniences.

Pain or discomfort resulting from the eye injection was rated at 3.1 ± 0.2 (n=168; scale of 0 to 6). These discomfort levels were noted to be higher in female patients (3.6 ± 0.2) compared to male patients (2.8 ± 0.2, p=0.008) and in anxious individuals (4.1 ± 0.3) compared to not anxious counterparts (2.8 ± 0.2, p=0.001). It is noteworthy that discomfort levels did not exhibit a significant correlation with overall satisfaction (p=0.383).

Approximately 28.1% of patients reported that their discomfort persisted for less than 1 hour, with 48.8% stating that it disappeared within 4 hours. In contrast, 6.7% of patients suffered discomfort for more than 24 hours, while 7.4% reported no discomfort following IVIs. Notably, the injection into the eye was identified as the primary source of discomfort (44.4%). For 16.5% of patients, the lid speculum emerged as the main source of discomfort, while 15.8% cited discomfort arising after the anaesthetic effect had worn off.

Around 20.7% of patients employed topical treatments, such as eye lubricants, for pain management at home, while 13.2% resorted to oral pain medication. Patients using oral pain medication exhibited a significantly higher TBS (30.5 ± 2.2) compared to those who did not (24.0 ± 0.9, p=0.016).

After receiving an IVI, roughly half of the patients (50.4%) reported a temporary inability to perform their typical activities. This subgroup of patients was associat-

ed with a TBS of 28.8 ± 1.2, which was significantly higher than those who did not report activity limitations (20.8 ± 1.1, $p<0.001$). These patients required approximately 9.1 ± 1.0 hours to resume their normal activities, a duration that correlated with TBS (correlation coefficient +0.46, $p<0.001$).

ANXIETY

Anxiety levels were observed to peak during the treatment phase, with a rating of 3.1 ± 0.2 (n=131) on a scale of 0 to 6. Prior to treatment, anxiety levels remained considerably elevated, with a mean of 2.8 ± 0.2 (n=127). Subsequently, post-treatment anxiety levels were the lowest, averaging 1.8 ± 0.2 (n=130).

During the treatment phase, anxiety levels were notably higher in female patients (3.7 ± 0.2) compared to males (2.7 ± 0.3, $p=0.009$), displayed a negative correlation with age (correlation coefficient -0.18, $p=0.044$), and a positive correlation with treatment duration (correlation coefficient +0.24, $p=0.010$).

Approximately 28.7% of patients acknowledged experiencing inherent anxiety unrelated to their ocular treatment. Notably, these patients exhibited a higher TBS (30.7 ± 1.5) in comparison to those without inherent anxiety (22.5 ± 1.0, $p<0.001$). As expected, anxiety levels during treatment were also notably elevated in patients with inherent anxiety ($p=0.001$).

Approximately 7.7% of patients reported using anti-anxiety medication to cope with the treatment. In free-text responses, patients cited various strategies for managing anxiety, including rest, breathing exercises, shorter waiting times, empathy from healthcare personnel, and positive thinking. Conversely, factors exacerbating anxiety included extended waiting times, fear of complications or vision loss, and pain associated with the injection.

TIME CONSUMPTION

Patients rated the time consumption associated with the treatment as 3.2 ± 0.2 (n=125) on a scale of 0 to 6. A significant proportion (78.1%) reported spending between 1 to 3 hours at the hospital, while only 16.4% spent more than 3 hours. Remarkably, a total journey time (to and back from the hospital) exceeding 4 hours was reported by 24.2% of patients.

Moreover, 79.4% of patients required assistance for transportation, spending on average 4.1 ± 0.3 hours for appointments. The convenience rating for those providing transportation assistance was 3.4 ± 0.2 (n=107) on a scale of 0 to 6. The need for assistance in transportation was significantly associated with a higher TBS (26.2 ± 1.0) compared to those who did not require assistance (19.2 ± 1.4, $p=0.001$).

In summary, 96.1% of patients expressed their willingness to recommend this treatment to others, while 97.7% would recommend the hospital for such treatment. In free-text responses concerning satisfaction or discontentment, many patients expressed gratitude for the efforts of healthcare professionals in delivering not only a high standard of service but also an empathetic care. Nonetheless, some patients highlighted that waiting times at the hospital could be excessively long and suggested that having the same physician for consultations and procedures could enhance their experience.

DISCUSSION

The burden experienced by patients undergoing IVIs for the treatment of retinal conditions is a complex and multifaceted issue.[6–9] The comprehensive analysis presented in this study provides valuable insights into the challenges faced by these patients. The introduction of a standardized scoring system, the TBS, is not only essential for evaluating the outcomes within a single center but also for enabling meaningful comparisons with other research studies or for assessing the effectiveness of implemented strategies aimed at improving patient experiences.[12]

Our findings revealed that the TBS score in our study was notably higher than that reported in previous studies conducted by McClard *et al* and Wang *et al*.[12,13] These earlier studies reported TBS scores ranging between 14.8 and 21.6 in different healthcare settings. In contrast, our study identified specific factors associated with a higher TBS, such as female gender, anxiety and the necessity for assistance. These associations were not observed in the aforementioned prior studies, suggesting that the burden experienced by patients in our center may be distinct from that of other populations. These variations could be attributed to cultural factors and the different practice setting in Portugal, where IVIs are typically conducted in an operating room rather than an office-based environment.

The level of patient satisfaction in our study was found to be lower compared to previous research.[12,13] Notably, our findings suggest an inverse relationship between injection frequency and satisfaction, underscoring the concept that more frequent injections are associated with a greater burden. Furthermore, the duration of treatment appears to play a significant role in enhancing patient satisfaction. Over time, patients may develop a deeper understanding of the treatment's importance and the potential for preserving their vision, leading to an increase in overall satisfaction.

Patients in our study reported higher levels of inconvenience related to side effects and pain/discomfort compared to previous reports.[12,13] Notably, this heightened inconvenience did not have a discernible impact on overall satisfaction. Similar to the TBS, we observed that these factors were more prominent in female patients and those with anxiety. The use of oral pain medication at home was associated with a higher treatment burden. It is important to consider that topical treatments, such as eye lubricants, may serve as an initial alternative for dealing with discomfort, but their administration should be managed by a qualified physician. Surprisingly, our study did not find evidence of desensitization to discomfort over the course of repeated IVIs.[14] Hence, discussing potential side effects with patients and setting realistic expectations may help them develop coping mechanisms and alleviate some of this burden.

Anxiety levels among patients were notably elevated in our study, even though they were lower in older patients.

Contrary to previous findings,[12,13] we identified a positive correlation between anxiety and treatment duration. This suggests that as patients become more experienced with the treatment and its associated discomfort, their expectations for further improvement may diminish. Older patients might develop greater resilience and a decreased sensitivity. Options for managing anxiety include anti-anxiety medication, but practical interventions such as reducing waiting times, assigning the same physician for consultations and procedures, and creating a stress-free environment can be equally effective. Notably, healthcare personnel's display of empathy is pivotal, not only in reducing anxiety but also in shaping patients' perceptions of the treatment.[11]

The time consumed by the treatment is a substantial contributor to the overall burden faced by patients.[6–8] This extends not only to the patients themselves but also to those providing transportation assistance and may cause a sense of guilt on the firsts. In our study, a significant proportion of patients (almost 80%) required assistance, resulting in an expected higher TBS. The economic and social implications of this should not be underestimated, particularly considering that many patients travel from distance to access treatment.[6–8,10] Implementing strategies, such as bilateral injections, could potentially reduce the number of patient visits and, subsequently, the treatment burden.[10] However, it should be noted that some studies suggest that bilateral side effects may increase patient inconvenience.[10,13]

Despite the elevated parameters analysed in our study, the vast majority of patients expressed their willingness to recommend the treatment at our hospital. This indicates that, despite the challenges and burdens faced, they value the quality of care and treatment outcomes.

The limitations of this study include incomplete responses from some participants and the patients willing to participate may differ from those who choose not to. Also, the self-administration of the survey may introduce bias, but it enhances the authenticity of patient responses. Future research in this field can further explore the specific interventions and support mechanisms that can improve the overall patient experience and treatment outcomes. Additionally, the adaptation and utilization of the questionnaire in more medical centers can provide valuable insights into the universality of patient burden.

CONCLUSION

Our findings indicate that the burden associated with IVIs is influenced by various factors. Gender, intrinsic anxiety, the requirement for assistance, treatment duration, and perceived preservation of vision all contribute to the overall burden or impact on patients' satisfaction. Anxiety and discomfort during IVIs are prevalent challenges, as are post-IVI restrictions. To improve the overall patient experience, adherence to IVI regimens and ultimately patients' quality of life, several key strategies can be employed, including enhancing patient education and communication, implementing effective pain and anxiety management, and optimizing treatment scheduling.

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CONTRIBUTORSHIP STATEMENT / DECLARAÇÃO DE CONTRIBUIÇÃO

JR and SS: Study design, collection and interpretation of data, drafting and revising the manuscript.

NO and RT: Interpretation of data, drafting and revising the manuscript.

AC and JPS: Study design, supervision and revising the manuscript.

All authors read and approved the final version to be published.

JR e SS: Desenho do estudo, colheita e interpretação dos dados, redação e revisão do manuscrito.

NO e RT: Interpretação dos dados, redação e revisão do manuscrito.

AC e JPS: Desenho do estudo, supervisão do projeto e revisão do manuscrito.

Todos os autores leram e aprovaram a versão final a ser publicada.

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