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Original Research

TRANSCULTURAL VALIDATION OF THE INDONESIAN VERSION OF THE ADHERENCE BARRIERS QUESTIONNAIRE INTRAVITREAL INJECTION (ABQ-IVT) IN NEOVASCULAR AGE-RELATED MACULAR DEGENERATION (nAMD)

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ABSTRACT

Introduction: Neovascular age-related macular degeneration (nAMD) is the leading cause of visual impairment and blindness worldwide. Intravitreal therapy (IVT) with anti-vascular endothelial growth factor (anti-VEGF) is the primary treatment option. However, there remains a substantial gap in visual acuity outcomes between clinical trial and real-world practice, with approximately 90% and 50%, respectively. Patient adherence with IVT influences treatment success; therefore, identifying the treatment burden is an important aspect. This study aimed to undertake the transcultural adaptation, validity, and reliability of the Indonesian version of the ABQ-IVT as an instrument to assess the treatment burden.

Methods: A cross-sectional study was conducted involving patients with nAMD who have received at least three routine anti-VEGF IVT treatments and were fluent in Indonesian language. The ABQ-IVT underwent a systematic validity and reliability process.

Results: The Indonesian version of the ABQ-IVT consisted of 17 items with content validity test showed an Individual-Content Validity Index (I-CVI) of 1.0, while construct validity testing produced correlation values (r) between 0.333 and 0.739 (r-calculated > r-table), indicating good result. The reliability test showed a Cronbach's alpha value of 0.725, indicating good consistency across the items.

Conclusion: The Indonesian of the ABQ-IVT was proven to be a valid and reliable instrument for assessing the treatment burden among nAMD patients.

Keywords: Age-related macular degeneration, ABQ-IVT, validity test, reliability test

Introduction

Age-related macular degeneration (AMD) is a retinal disorder and a leading cause of visual impairment and blindness. The highest prevalence of AMD is reported in Asian populations, ranging from 3% to 19.5%, including in Indonesia. [1,2] A descriptive study conducted at Cipto Mangunkusumo Hospital (RSCM) Kirana one year by Leonedine et al. reported 129 cases of neovascular AMD (nAMD) in 2022, and a previous study by Pambudy in 2017 that recorded 148 nAMD cases. [3,4]Intravitreal injections (IVT) of anti–vascular endothelial growth factor (anti-VEGF) agents have been the mainstay of nAMD and are administered using proactive regimens such as fixed-interval or treat-and-extend (TAE), or reactive regimens such as pro re nata (PRN). Clinical trials have shown that anti-VEGF IVT stabilizes visual function in 90% of nAMD patients. However, real-world studies report different outcomes, with visual stability achieved in only about 50% of patients. [5] One of the key factors influencing optimal outcomes is adherence to the anti-VEGF IVT schedule, as consistent injections and follow-up evaluations are essential for achieving the optimal therapeutic dose during the treatment phase. [6]

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Regular visits require patients to adhere to treatment recommendations and maintain persistence throughout the prescribed therapy duration. [6] A real world study by Shellvarajah et al. compared outcomes in 133 nAMD patients receiving real-world anti-VEGF IVT, divided into two groups based on adherence and persistence levels. Patients with good adherence and persistence experienced an improvement of 0.67 words, whereas those with poorer adherence experienced a decline of 2.30 words. [7] Thus, adherence and persistence play a crucial role in determining the success of anti-VEGF IVT. Nevertheless, routine IVT visits often pose a burden for patients, reported in 17.5% to 30% of cases. [7] Identifying the burden experienced by nAMD patients undergoing IVT is essential in clinical practice. A set of 17 items questionnaire for assessing treatment burden is the Adherence Barriers Questionnaire for Intravitreal Injection (ABQ-IVT), which evaluates the challenges faced by patients receiving repeated IVT. [8,9] Assessing treatment burden aims to capture patient perspectives and guide tailored interventions to reduce the risk of non-adherence and non-persistence. The ABQ-IVT is currently available in English, German, and Mandarin; however, it has not yet been adapted into Indonesian. Therefore, this study aims to conduct a cross-cultural adaptation as well as evaluate the validity and reliability of the Indonesian ABQ-IVT.

Methods

This study was a cross-sectional design and conducted in the Vitreoretinal Division of RSCM Kirana with approval from the institutional ethics committee (KET-779/UN2.F1/ETIK /PPM.00.02/2025).

The research consisted of the first phase of cross-cultural adaptation and the second phase of validity and reliability testing of the Indonesian ABQ-IVT. The study subjects were patients with nAMD who were undergoing anti-VEGF intravitreal therapy (IVT) in the Vitreoretinal Division of RSCM Kirana and met the inclusion criteria, namely having received at least three routine anti-VEGF IVT and being able to communicate verbally and/or in writing in Indonesian language to adequately understand the study information and provide informed consent. Patients were excluded if they declined participation or refused to sign the informed consent form. The original questionnaire was published by Muller, et al in the International Journal of Retina and Vitreous as an open-access article. As stated on the first page, the article is licensed under the Creative Commons Attribution 4.0 International License, permitting use, sharing, adaptation, distribution, and reproduction in any medium or format, provided appropriate credit is given to the original authors and source.

Result

The cross-cultural adaptation of the ABQ-IVT from English to Indonesian followed several stages: (1) Forward translation, conducted independently by a professional linguist from the Lembaga Bahasa Universitas Indonesia and a medical translator who is familiar with ophthalmology terminologies, with no communication between the translators to prevent mutual influence during the translation process;

(2) First panel reconciliation, the team reviewed discrepancies and standardized multiple variations of the original terms such as “eye injections,” “my injection,” and “intravitreal” into a simpler and more consistent Indonesian term, “suntikan ke dalam mata” (“Injection into the eye”). Several Indonesian sentences underwent simplification without altering their meaning, specifically items 10, 12, and 16;

3) Backward translation, performed by two different translators who were not provided with nor familiar with the original ABQ-IVT; (4) Second panel reconciliation, in which the team reviewed the back-translated version. Adjustments were made to item 7, in which “discouraged” was translated as “putus asa” (“desperate”; item 13, where the word “keluarga” (“family”) was removed; and item 15, where the term “penyakit” (“disease”) was refined to “masalah kesehatan” (“health problems”) to better align with the original questionnaire; (5) Preliminary pilot testing, consisting of cognitive debriefing with 10 patients, identified one item (item 7) as “unclear” by one participant. The panel discussion addressed this by adding a standardized explanation at the beginning of the questionnaire, instructing patients to answer each item based on their macular condition and the intravitreal injections they were receiving. After finalizing the Indonesian ABQ-IVT, the study proceeded with validity and reliability testing involving 40 subjects. The demographic and clinical characteristics of the patients, along with the mean ABQ-IVT scores for each patient group, are presented in Table 1.

Further descriptive analysis assessed the treatment burden experienced by patients. Responses scored 3 or 4 were classified as “feeling burdened,” consistent with the classification used in the original questionnaire. The percentage for each item is presented in Table 2. The three most significant burdens identified were long travel or waiting times for patients and/or their families (82.5%), difficulties in finding a companion (32.5%), and patients’ concerns about being a burden to their families and needing to ask for assistance (32.5%).

Content validity testing resulted in an I-CVI of 1.00 for all 17 items of the Indonesian ABQ-IVT. Construct validity testing, assessed using Spearman’s correlation coefficient, showed r values ranging from 0.333 to 0.739 (Table 3). Since all calculated r values exceeded the critical r values, all 17 items of the Indonesian ABQ-IVT were considered valid.

Reliability testing showed a Cronbach’s α of 0.725, indicating acceptable reliability. Further assessment was conducted using Cronbach’s α if Item Deleted to evaluate potential increases in the total Cronbach’s α if individual items were removed. Deletion of any single item in the ABQ-IVT did not result in a significant increase, with Cronbach’s α if Item Deleted ranging from 0.700 to 0.719. Therefore, all questionnaire items were retained (Table 4).

Table 1. Sociodemographic Characteristics and ABQ-IVT Scores

Subjects' data	N	Percentage	Mean ABQ-IVT Score (Median, Range)
Age, years (mean ± standard deviation)		69,5 ± 1,26 years old	
Gender			
Male	19	4,750%	35 (28 – 43)
Female	21	5,250%	35 (24 – 47)
Marriage status			
Unmarried	6	1,500%	38 (28 – 47)
Married	25	6,250%	35 (24 – 43)
Divorced/widowed	9	2,250%	32,5 (28 – 37)
Occupations			
Unemployed	12	3,000%	34,5 (27 – 39)
Housewife	10	2,500%	35,5 (25 – 42)
Retired	11	2,750%	35 (28 – 47)
Business	2	500%	36 (24 – 43)
Others	5	1,250%	35 (28 – 47)
Highest Education Level			
Junior High	4	10.00%	36 (27 – 47)
Senior High	22	5,500%	36 (25 – 41)
Diploma	1	250%	35
Bachelor	9	2,250%	36 (24 – 43)
Master	4	1,000%	29,5 (28 – 34)
Income			
< 1,5 million	34	8,500%	36 (25 – 47)
1,5 – 3,5 million	3	750%	34 (34 – 41)
> 3,5 million	3	750%	28 (24 – 28)
Length of illness (months)		33 (6 – 144)	
Length of therapy (months)		24 (4 – 144)	
Mean Waiting Time on Injection Day (minutes)		180 (60 -360)	
Types of anti-VEGF IVT			
Bevacizumab	29	7,250%	36 (29 – 42)
Ranibizumab	11	2,750%	28 (24 – 47)
Regiments of anti-VEGF IVT			
Proactive (fixed interval / TAE)	4	1,000%	32 (24 – 36)
Reactive (PRN)	36	9,000%	35 (25 – 47)
Total of anti-VEGF IVT (times)		8,5 (3 – 34)	
Frequencies anti-VEGF annually (times)		4,5 (2 – 8)	
Accompanying Person			
Available	34	8,500%	35 (24 – 47)
None	6	1,500%	35 (28 – 41)
Comorbidities			
Diabetes	8	2,000%	35,5 (28 – 41)
Hypertension	15	3,750%	35 (24 – 47)
Dyslipidaemia	4	1,000%	37 (33 – 39)
Benign Prostate Hyperplasia	2	500%	36 (36 – 36)
Asthma	1	250%	36
Other comorbidities	3	750%	34 (34 – 36)
None	12	3,000%	34 (25 – 38)

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Table 2. Percentage of Each Item Considered a Burden by Patients

Item Number	Number of Respondents Feeling Burdened (N)	Percentage of Respondents Feeling Burdened (%)
1	2	500%
2	0	0%
3	0	0%
4	9	2,250%
5	6	1,500%
6	6	1,500%
7	11	2,750%
8	3	750%
9	10	2,500%
10	33	8,250%
11	10	2,500%
12	13	3,250%
13	13	3,250%
14	4	1,000%
15	9	2,250%
16	5	1,250%
17	8	2,000%

Table 3. Construct Validity Results of the Indonesian ABQ-IVT

Item Number	r-table's value	r values	p-value	Validity status
1		419	7	Valid
2		346	29	Valid
3		433	5	Valid
4		486	1	Valid
5		333	36	Valid
6		464	3	Valid
7		457	3	Valid
8		538	0	Valid
9	312	458	3	Valid
10		371	18	Valid
11		478	2	Valid
12		404	10	Valid
13		739	0	Valid
14		373	18	Valid
15		508	1	Valid
16		359	23	Valid
17		474	2	Valid

Table 4. Reliability Result of the Indonesian ABQ-IVT

Item Number	Reliability Test of *Cronbach- α*	Item score (*Cronbach- α "If item deleted"*)
1		714
2		717
3		714
4		702
5		713
6		710
7		713
8		711
9		712
10		714
11		715
12	0,725a	713
13		700
14		718
15		708
16		719
17		712

a *Cronbach-α* ≥0,7 is reliable

Discussion

The cross-cultural adaptation of the ABQ-IVT questionnaire involved systematic translation in aligning with cultural context, linguistic style, and meaning, which could influence interpretation and prevent misinterpretation. The process began with forward translation to ensure that the translation was both medically relevant and comprehensible to the general population. [10-13]The translated version was then reconciled during the first panel discussion to select the Indonesian version that was the easiest to understand and similar to the original meaning. [14] Variations in word choice were simplified without altering meaning. [15]

Next, backward translation was conducted, translating the Indonesian version back into the original language to ensure that no item deviated in meaning. [10,11]For statements showing discrepancies between the language translator and the medical translator, the panel selected the Indonesian wording that best matched the original meaning and was easily understood. All items were considered semantically and conceptually equivalent, with no significant changes in meaning. The pre-final questionnaire underwent cognitive debriefing with 10 respondents. Items deemed unclear by less than 20% of respondents did not require further revision. This process resulted in the finalized Indonesian ABQ-IVT questionnaire (Figure 1).

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KUESIONER ABQ-IVT Nama / Usia / NRM : No HP : Visus OD : OS :
Waktu pengisian : - Cara pengisian : Mandiri / Dibacakan

Setiap item pernyataan dalam kuesioner ini dijawab sesuai dengan penyakit makula yang dialami pasien dan suntikan pada mata yang dijalani.

1. **Saya merasa mendapatkan informasi yang baik mengenai pengobatan penyakit mata saya.**
   1 sangat setuju 2 setuju 3 tidak setuju 4 sangat tidak setuju
2. **Saya percaya pada dokter mata saya.**
   1 sangat setuju 2 setuju 3 tidak setuju 4 sangat tidak setuju
3. **Dokter mata mengikutsertakan saya dalam pengambilan keputusan terkait pengobatan mata saya.**
   1 sangat setuju 2 setuju 3 tidak setuju 4 sangat tidak setuju
4. **Saya sering merasa tidak nyaman di ruang praktik dokter.**
   1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
5. **Terkadang saya merasa ragu apakah suntikan ke dalam mata saya memang diperlukan.**
   1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
6. **Saya tidak puas dengan perawatan / pengobatan saya saat ini.**
   1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
7. **Umumnya, saya sering merasa sedih dan terkadang merasa putus asa dan depresi.**
   1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
8. **Biaya untuk suntikan ke dalam mata saya memerlukan biaya yang besar bagi saya.**
   1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
9. **Saya takut terhadap terapi suntikan ke dalam mata dan efek sampingnya.**
   1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
10. **Kontrol dan bertemu dokter mata menimbulkan perjalanan/waktu tunggu yang lama bagi saya dan/atau keluarga.**
    1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
11. **Kontrol dan bertemu dokter mata menyebabkan beban keuangan yang besar (misal: biaya perjalanan/ absen pekerjaan) bagi saya dan/atau keluarga.**
    1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
12. **Kunjungan ke dokter memerlukan pendamping, hal ini merupakan tantangan.**
    1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
13. **Saya khawatir membebani keluarga dan harus meminta bantuan.**
    1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
14. **Saya membutuhkan bantuan setiap hari (terutama dalam hal perawatan kesehatan), namun saya tidak mendapatkannya.**
    1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
15. **Selain kondisi mata saya, saya juga memiliki masalah kesehatan lain yang menyulitkan untuk datang berobat.**
    1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
16. **Saya memiliki keperluan pribadi / pekerjaan yang sulit disesuaikan dengan pengobatan mata saya.**
    1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju
17. **Karena usia saya yang lanjut, saya ragu apakah terapi suntikan ke dalam mata ini masih bermanfaat.**
    1 sangat tidak setuju 2 tidak setuju 3 setuju 4 sangat setuju

Figure 1. Final Indonesian Version of the ABQ-IVT

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The finalized ABQ-IVT questionnaire was completed by 40 patients. The mean age of nAMD patients was 69.5 ± 1.26 years, slightly younger than reported by Muller et al., who observed a mean age of 78.2 ± 8.3 years. [16] Female patients accounted for 52.5% of the study population, like Muller et al., who reported 60.9% female participants. [8] Most patients were married (62.5%) and not employed (30%), with current incomes below 1.5 million IDR (85%). The distribution of employment was like Vasilijevic et al., with 47.4% of patients being retired. Additionally, 55% of patients had completed junior high school, reflecting social, economic, and cultural influences on healthcare-seeking behavior. Factors affecting non-adherence and non-persistence in treatment included social and economic status, with an odds ratio of 1.52 for lower adherence among patients with lower socioeconomic status. [17,18]

Clinical data showed that the median duration since nAMD diagnosis was 33 months, with IVT treatment lasting a median of 24 months. Patients received a median of 8.5 injections, with an annual frequency of 4.5 injections. Variability in IVT visits likely reflected the burden of adhering to scheduled appointments and the presence of comorbidities. According to Okada et al., multiple factors influence adherence and persistence, including patient condition, therapy type, socioeconomic factors, and healthcare system characteristics. [17] One identified system factor was the long median waiting time of 180 minutes per IVT session, which was reported as the greatest treatment burden by 82.5% of patients, consistent with findings by Muller et al. [8]

Bevacizumab was used in 72.5% of patients in this study. The type of anti-VEGF medication varies by country depending on availability.[17,19,20] Most patients (90%) received reactive PRN regimens, adjusted based on anatomical, functional, and clinical assessments conducted monthly. Consistent with Okada et al., PRN regimens are commonly used internationally because they are easier for clinicians to apply and patients to understand for monthly follow-up scheduling. Polat et al. reported that 39.8% of patients failed to complete IVT under PRN regimens within one year. [21] Long-term IVT and declining visual function increase reliance on a companion during treatment. In this study, 85% of patients had a companion, although 32.5% considered it a treatment burden. Muller et al. reported that 43.1% of IVT patients had trouble finding a companion due to factors such as work or other commitments.[8]

Patient treatment burden was assessed using the Indonesian ABQ-IVT, which underwent content and construct validity testing. Panel review confirmed that all 17 items were relevant, with an I-CVI of 1.00 and Spearman correlation coefficients ranging from 0.333 (item 5) to 0.739 (item 13), exceeding the critical r value of 0.312, indicating validity. Reliability testing was conducted on the validated items, measuring internal consistency using Cronbach's α, which ranges from 0 to 1. Values ≥0.70 indicate acceptable internal consistency, while pilot studies may consider ≥0.60.[22] This study found a Cronbach's α of 0.725, confirming that the Indonesian ABQ-IVT is reliable for assessing IVT treatment burden. Values exceeding 0.95 were not observed, as excessively high α indicates redundancy among items.

Further analysis using Cronbach's α if Item Deleted showed no significant increase upon removal of any item, and all items were retained to preserve construct representation. These results are comparable to Muller et al., who reported a Cronbach's α of 0.780, and Chi et al., whose item-level α ranged from 0.706 to 0.759. [8,23] This study represents the first validity and reliability assessment of the Indonesian ABQ-IVT for evaluating IVT treatment burden in nAMD patients. The questionnaire is useful for identifying multifactorial treatment burdens and has clinical importance in promoting adherence and persistence, which improves therapeutic outcomes by reducing suboptimal dosing. [24,25]

The Indonesian ABQ-IVT is user-friendly, with clear print and large font size to accommodate elderly patients with visual impairment. The mean completion time was approximately 8 minutes, and respondents were able to provide complete answers. The demographic and clinical profile of patients in this tertiary healthcare setting in Indonesia closely resembles other studies, supporting the clinical applicability of the Indonesian ABQ-IVT for assessing treatment burden from the start of IVT therapy in nAMD patients

Conclusion

The Indonesian version of the ABQ-IVT which has cross-cultural adaptation, is a valid and reliable instrument for assessing the intravitreal injection (IVT) treatment burden in nAMD patients. It can be applied in routine clinical practice to evaluate patient burden during IVT therapy. Examiners are expected to be thoroughly familiar with the administration of the Indonesian ABQ-IVT and provide clear instructions to patients, ensuring accurate completion of the questionnaire.

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