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Impacts of Impaired Vision and Eye Diseases on Vision-Related Quality of Life in Indonesia

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Impacts of Impaired Vision and Eye Diseases on Vision-Related Quality of Life in Indonesia

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Abstract

Background: To determine the impacts of visual impairment and eye diseases on vision-related quality of life (QoL) in populations with severe visual impairment (SVI) and blindness in Indonesia. **Methods:** A cross-sectional study was conducted on 134 respondents from, 5 different provinces, simultaneously with a validation study using data from the 2013 National Basic Health Survey. Participants aged ≥ 18 years with visual acuity of $< 6/60$ underwent an ocular examination and guided interview. The impact of vision impairment related to their QoL was assessed using the NEI-VFQ 25 questionnaire. The scores were then compared between participants with blindness ($< 3/60$) and participants with SVI ($> 3/60$ to $< 5/60$), and the causes of visual impairment. **Results:** Severe visual impairment and blindness were mostly found in productive aged females with lower education and income levels, and cataracts were the leading cause. Vision-related quality of life was lower in the blind group compared to the SVI group ($p = 0.001$). The impacts of visual impairment related mostly to distance activities ($p = 0.007$), social functions, and near activities ($p = 0.002$). NEI-VFQ 25 scores were lower in glaucoma respondents than cataract respondents. **Conclusions:** Results suggest that subjects with blindness had a lower total QoL score than those with SVI, in addition to the subscale scores. Furthermore, glaucoma disease had the lowest QoL score.

Keywords: *impact vision, quality of life, NEI-VFQ 25, severe visual impairment, blindness, ocular morbidity*

Introduction

According to the WHO, it is estimated that the number of people with visual impairment worldwide is 285 million, and the majority of those (87%) live in developing countries.¹ According to the National Eye Health Survey carried out between 1993 and 1996, blindness in Indonesia had reached 1.5% of the total population, with the leading causes of blindness being cataracts, glaucoma, and uncorrected refractive errors.² Visual impairment and blindness may result in decreased quality of life (QoL), which is associated with a reduction in one's ability to work, to spend leisure time, or perform daily activities. Additionally, they experience a higher risk of falls, fractures of the femur, and medication errors.³⁻⁹

The formal examination of visual acuity and visual fields may not be the most objective way of testing patients, as it does not accurately show the overall impacts of vision-related disorders experienced by the patient. Subjective assessments (self-reported evaluations) on quality of life, using a questionnaire, are necessary to provide a more comprehensive eye health assessment.¹⁰⁻¹⁵ Further studies demonstrating the QoL

of people with impaired vision, based on their type of diseases, are essential particularly for appropriate input on policies regarding prevention of blindness.¹⁶⁻²⁰ Numerous studies in various countries have demonstrated that the NEI-VFQ 25 questionnaire is a valid instrument in assessing vision-related quality of life.^{10-12,16,18} By using this questionnaire in the present research, it is expected that the results of this study can be compared to other research that has used the same tools. Additionally, the questionnaire has specific instructions on how to answer the questions, thus all the answers can be standardised.^{12,21}

The Indonesian National Basic Health Research (INBHR) has conducted epidemiological studies on multiple health issues in several areas of Indonesia, including eye morbidity and blindness.²² Their 2013 study suggested that cases of blindness have decreased to 0.9% of the total population in Indonesia, however their methodology differed to the standard survey recommended by the WHO. As such, data relating to blindness and eye morbidity from the 2013 INBHR needs to be validated. This present study was one of several validation studies conducted by the Indonesian Ophthalmologist Association. It aims to determine the

impacts of visual impairment and ocular morbidity on vision-related QoL within the Indonesian population who experience SVI and blindness and compare the findings with those reported by the INBHR.

Methods

Population. This present study was conducted simultaneously with the Blindness Validation Study performed by the Indonesian Ophthalmologists Association, in order to evaluate the validity of the INBHR study. This was a cross-sectional population based study that was performed by the investigator and other residents, who had received training on how to correctly fill in the questionnaire. Ethical approval from the Ethics Committee of the Ministry of Health (LB.02.01/5.2/KE.402/2013) was obtained, as suggested by the Helsinki Declaration. The 2013 INBHR study showed that there was 1154 subjects categorised as blind and 2259 with SVI in 8 provinces across Indonesia. The validation team selected 3 districts from 5 provinces that had a higher proportion of visual impairment and blind patients to be included in the study. All subjects who had been diagnosed with SVI or blindness in the INBHR study were visited door to door or invited to the Primary Health Care Unit. They underwent eye evaluations, including a visual acuity test (Snellen chart), measurement of intraocular pressure (applanation tonometry), assessment of the eye using a slit-lamp, and evaluation of the fundus retina. There were a total of 145 subjects diagnosed with SVI or blindness by the validation team that met our inclusion criteria. Purposive sampling was carried out for the inclusion and exclusion criteria amongst the 145 subjects, and they were categorised with either SVI or blind by the validation team. All respondents aged 18 years and older with SVI ($\geq 3/60$ to $< 6/60$ in their better eye) were placed into Group 1, and those with blindness ($< 3/60$ in their better eye) were placed into Group 2 and were included in the study. All respondents signed an informed consent form prior to participation in the study.

Instruments for QoL Questionnaire. After the respondents completed an ophthalmologic examination, which was performed to determine the cause of visual impairment, they were interviewed using questionnaires by trained interviewers. The modified and translated National Eye Institute Visual Function Questionnaire 25 (NEI-VFQ 25) was used to assess the vision related QoL among all respondents, and this questionnaire had been validated beforehand. The Medical Education Program at the Faculty of Medicine conducted the validation of the questionnaire. A staff member of the Department of Medical Education carried out the assessment of significant similarities between the original and translated questionnaires. The format of the

questionnaire was also modified slightly to make it easier for the interviewer to fill in responses. Demographic information including age, gender, education, household income, marital status, cause of blindness, and systemic health diseases were noted. The modified NEI-VFQ 25 contained a total of 25 questions, which was divided into 3 groups. Part 1 was a general health and visual health questionnaire. Part 2 related to the difficulty experienced in doing daily activities, social functions, and mental health, and part 3 was mostly related to responses regarding vision problems. Each question had a range of 0 to 100, with 100 being the highest score and 0 being the lowest score. Each question in part 2 and 3 consisted of subscale questions, and the average number of scores was taken. The composite of all the scores was the total number of visual functionality. The total and subscale QoL scores were compared between groups, and the causes of eye disease and blindness onset were also evaluated. Interviewers in different locations were briefed on how to conduct the interviews in order to have similar perceptions of the questionnaire. As different locations have their own language dialects, interviewers were allowed to communicate in the local dialects so that the respondents of the study were able to understand the questions clearly.

Statistic analysis. The statistical analysis was performed using SPSS version 16.0, with 2 tail $p < 0.05$ considered significant. The minimum sample size for each group was 50 respondents, which was calculated using the formula of mean values for unpaired two-sample t-test. Numerical data was presented as mean and standard deviations for data with normal distribution, and as median, minimum, and maximum values for data without normal distribution. The descriptive analysis of variables used was t-tests for quantitative and χ^2 tests for categorical variables to compare different groups.

Results

Demographic Characteristics. A total of 145 respondents were included in the study, however 11 respondents were excluded due to hearing loss and attention deficit disorder. The remaining 134 respondents were analysed. There were 88 subjects diagnosed with blindness (65.7%) and 46 subjects with SVI (34.3%), as outlined in Table 1. There were more female (64.2%) than male (35.8%) subjects in the study. The mean age was 67.4 (± 12.3) years and 46 respondents (34.3%) were at their productive age. Most respondents had low educational levels (65.7%) and low incomes (71.6%), and 26.7% of them had experienced blindness for more than 5 years. The mean duration of visual impairment was 6.4 (± 10.3) years (0.08 to 50 years).

Table 1. Demographic Characteristics of Subjects, Duration, and Cause of Eye Diseases based on Level of Visual impairment (n = 134)

Variables	Total Respondents		Blindness		SVI		<i>p</i>
	(N = 134)		(N = 88)		(N = 46)		
	n	%	n	%	n	%	
Sex							
Male	48	35.8	28	31.8	20	3.5	0.181 ^a
Female	86	64.2	60	68.2	26	6.5	
Mean age (years)	67.4 ± 12.3		69.5 (38-95)		67.5 (28-92)		0.173 ^b
Age Group							
18-64 years	46	34.3	34	38.6	12	26.1	0.232 ^a
> 64 years	88	65.7	54	61.4	34	73.9	
Level of Education							
Low	88	65.7	60	68.2	28	60.9	0.392 ^a
Medium	43	32.1	26	29.5	17	36.9	
High	3	2.2	2	2.3	1	2.2	
Income Level							
Low	96	71.6	60	68.2	36	78.3	0.462 ^a
Medium	20	14.9	15	17	5	10.9	
High	10	7.5	8	9.1	2	4.3	
Very High	8	6	5	5.7	3	6.5	
Duration of visual impairment (years)	6.4 ± 10		2 (0.08 to 30)		3 (0.08 to 54)		0.104 ^b
Duration of blindness							
< 1 year	37	28.2	21	24.1	6	36.4	0.104 ^b
1-5 years	59	45.1	41	47.1	8	40.9	
> 5 years	35	26.7	25	28.8	0	22.7	
Types of eye disease							
Cataracts	99	73.9	63	71.6	36	78.3	
Glaucoma	7	5.2	6	6.8	1	2.2	
Refractive errors	9	6.7	4	4.5	5	10.9	
Corneal abnormalities	5	3.7	5	5.7	0	0	
AMD	2	1.5	2	2.3	0	0	
Optic neuropathy	7	5.2	4	4.5	3	6.5	
Diabetic retinopathy	1	0.7	0	0	1	2.2	
Retinal detachments	2	1.5	2	2.3	0	0	
Other eye disorders	2	1.5	2	2.3	0	0	

^aChi-square test ; ^bMann-Whitney test

Cataract was the major leading cause of visual impairment (73.9%), which was followed by refractive errors (6.7%), and glaucoma (5.2%). Statistical tests of multiple variables on demographic characteristics and duration of vision impairment showed that the distribution of the samples were homogeneous ($p > 0.05$). The Impact of Visual Impairment on their Quality of Life. The mean total score of QoL (composite score) of all respondents was 41.97 (± 19.66), as presented in Table 2. Male respondents had a better mean total score of QoL than women, however the score between both groups was not significantly significant ($p = 0.280$). Quality of Life in the productive age respondents was higher than those in the non-productive age group ($p =$

0.007). The duration of visual impairment was not associated with QoL score.

The Impact on Subjects with Blindness and Severe Visual Impairment in QoL. The mean total score of QoL in the blind group was lower than those with SVI ($p = 0.001$), however the average QoL subscale scores for both groups were varied. Subjects with blindness were more likely to have lower subscale QoL scores than those with SVI, especially in social functions ($p = 0.001$), difficulty in maintaining their job role ($p = 0.008$), near activities ($p = 0.000$), and distance activities ($p = 0.000$). There were no significant differences in general health subscale scores ($p = 0.740$), eye pain ($p = 0.098$), mental

health ($p = 0.210$), and dependency ($p = 0.080$) between both groups, as outlined in Table 3.

The Impact of QoL Scores Amongst Subjects with Various Eye Diseases. As presented in Table 4, respondents with glaucoma had the lowest total QoL score than subjects with any other disease. Since the sample size for each aetiology varied widely, the statistical comparisons were performed among only three groups of diseases, glaucoma, cataracts, and refractive errors. Respondents with glaucoma had the lowest QoL scores, especially in dependency parameters. Moreover, regarding almost all the subscale scores, except for the score on difficulty in maintaining job role, our study showed that respondents with glaucoma had a lower score than those with cataracts.

The number of female respondents with SVI and blindness was higher than the male subjects, 2 out of 3 respondents, results that are again consistent with a WHO report and various other studies.²³ However, the total scores between the male and female subjects were

relatively similar and the difference was not statistically significant. We found that 25% of respondents with blindness were in their productive age. The total QoL score in subjects in the productive age group was higher than those in the non-productive age group. The higher score was likely due to comorbidities and the aging process that can affect quality of life in subjects of the non-productive age group. Most respondents had a lower level of education that was closely associated with illiteracy and low income. Endeavours that promote education regarding eye health and prevention of disease are necessary and should be adjusted with the education level of the respondents.

The majority of respondents in the present study had experienced blindness for the past 1 to 5 years. Nispen *et al.*²⁰ suggested that reduced quality of life is affected by comorbidities, however other authors have not confirmed the suggestion.⁸ The longer a person experiences blindness their quality of life tends to improve, this is likely caused by the adaptation mechanism (coping index).²⁴⁻²⁷

Table 2. Total QoL Scores based on Gender, Age Group, and Duration of Blindness

Variables	Average (mean \pm SD)	Median (min-max)	<i>p</i>
The mean total score (N)	41.9 \pm 19.6	39.82 (2.5-89.4)	
Gender			
Male	43.4 \pm 16.7	42.1 (15-84.6)	0.280 ^a
Female	41.2 \pm 21.2	39.2 (2.5-89.4)	
Age group (year)			
18-64 years	48.5 \pm 20.5	45.7 (10.4-89.4)	0.007 ^a
> 64 years	38.5 \pm 18.4	33.7 (2.5-86.8)	
Duration of blindness			
< 1 year	43.3 \pm 18.4	39.0 (17.5-83.7)	0.710 ^b
1-5 years	40.6 \pm 20.3	39.8 (2.5-86.8)	
> 5 years	42.9 \pm 18.9	40.5 (10.4-89.4)	

a = Mann-Whitney test; b = Kruskal-Wallis test

Table 3. Total and Subscale Scores of QoL based on Level of Visual Impairment

Variable Scores	Severe visual impairment (n = 46)		Blindness (n = 88)		<i>p</i>
	Mean \pm SD	Median	Mean \pm SD	Median	
Total score	49.8 \pm 19.20	49.7 (16.5-89.4)	37.8 \pm 18.80	33.5 (2.5-85.7)	0.001
General health	36.1 \pm 22.30	25.0 (0-100)	36.0 \pm 21.90	25.0 (0-100)	0.740
Eye Health	33.8 \pm 13.40	40.0 (20-60)	24.4 \pm 15.80	20.0 (0-60)	0.003
Eye pain	68.5 \pm 21.60	62.5 (25-100)	74.7 \pm 23.70	75.0 (0-100)	0.098
Near activity	46.7 \pm 30.40	50.0 (0-100)	26.2 \pm 24.50	25.0 (0-100)	0.000
Distance activity	46.6 \pm 26.60	50.0 (0-100)	25.9 \pm 25.50	20.8 (0-100)	0.000
Social function	52.7 \pm 28.80	50.0 (0-100)	33.2 \pm 28.00	25.0 (0-100)	0.001
Mental Health	53.6 \pm 21.50	50 (12.5 to 100)	48.7 \pm 21.40	50 (0-100)	0.210*
Difficulty in maintaining role	44.4 \pm 24.06	37.5 (0-100)	35.7 \pm 25.20	25.0 (0-100)	0.009
Dependency	49.2 \pm 26.70	50.0 (0-100)	36.5 \pm 26.70	33.3 (0-100)	0.080
Colour vision	62.2 \pm 32.20	50.0 (0-100)	42.7 \pm 34.90	37.5 (0-100)	0.002
Peripheral vision	50.5 \pm 31.70	50.0 (0-100)	28.5 \pm 28.70	25.0 (0-100)	0.000

* = Independent T-test;

Table 4. Comparison of the Total and Subscale Scores of QoL in Several Diseases (n = 134)

Variable Scores	Cataract (N = 99)	Glaucoma (N = 9)	Abnormalities refraction (N = 9)	Retinal abnormalities (N = 5)	Optic neuropathy (N = 7)	Corneal abnormalities (N = 5)
Total score	40.5 ± 19.2	33.1 ± 9.0	62.4 ± 19.8	52.3 ± 24.8	45.0 ± 16.2	49.0 ± 19.6
General health	25 (0-75)	50 (25-100)	50 (25-100)	60 ± 28.5	50 (0-50)	25.0 ± 25.0
Eye Health	20 (0-60)	20 ± 16.3	40 (20-60)	32 ± 30	20 (20-40)	40 (0-40)
Eye pain	72 (25-100)	74.8 ± 17.8	71.3 ± 25	72.5 ± 20	76.8 ± 16.8	74.9 ± 23.5
Near activity	25 (0-100)	20.7 ± 18.2	57.8 ± 29.4	41.6 ± 27.6	28.5 ± 19.8	54.9 ± 28
Distance activity	25 (0-100)	8.3 (8-58.3)	55.2 ± 32.4	48.3 ± 36.9	41.6 (0-50)	44.9 ± 30.4
Social function	37 (0-100)	32 ± 21.5	70.3 ± 24.0	55 ± 45	42.8 ± 27.8	44.9 ± 36
Mental Health	50 (0-100)	40.2 ± 9.4	64.1 ± 27.5	60 ± 27.1	58.9 ± 11.3	56.25 ± 22.1
Difficulty in maintaining role	25 (0-100)	48.2 ± 36	43.75 ± 31.3	47.5 ± 22.3	42.8 ± 18.9	37.5 ± 37.5
Dependence	33.3 (0-100)	23.8 ± 20.6	65.6 ± 30.7	56.6 ± 34.1	45.2 ± 25.4	38.3 ± 33.6
Colour vision	50 (0-100)	25 (0-100)	92.3 (50-100)	65 (0-100)	71.4 ± 22.5	70 (25-100)
Peripheral vision	25 (0-100)	10.7 ± 13.4	68.7 ± 29.1	45 ± 51	28.6 ± 22.5	50 ± 25

The QoL scores in the blind group were lower than those in the SVI group and the difference was statistically significant. The differences were in terms of the severity of the total scores and for almost all of the subscale scores, except for the mental health aspect. It appears that since there were significant differences in visual acuity, which is essential in daily activities, subjects with blindness experienced impairment in both near and distance activities. Mental health including anxiety, fear, and frustration was relatively similar between both groups. Productivity was much more disturbed in subjects with blindness compared to those with SVI. It is assumed that psychosocial and spiritual factors may also contribute to these findings, evidence which is also supported by other studies.^{27,28}

Respondents with glaucoma had the lowest QoL scores than respondents with other eye diseases in all measured parameters, including general vision, mental health, near activity, and role difficulty. As a result, the glaucoma subjects are more dependent on other persons. This happens because the deficit that occurs in glaucoma is a combination of central and peripheral vision disorders, as shown in this study. Glaucoma is an irreversible chronic disease that is not easily detected in early cases and typically causes permanent blindness.^{29,30} The impact on the individual, and the lifetime risk of causing disability and dependency,

increased the burden on their family and community. Early detection of avoidable blindness, including glaucoma, is essential in high-risk groups, especially in those over 40 years of age, with reduced corneal thickness, of African descent, and with a family history of glaucoma.³¹ Quality of life scores from respondents with uncorrected refractive errors was the highest when compared to subjects with other diseases, such as cataracts and glaucoma. Blindness due to refractive errors and cataracts are usually avoidable. Refractive error can be treated with glasses or other low vision aids, and this may be the reason for the reported better quality of life. Moreover, cataracts, without other abnormalities, can be managed via a surgical approach and the quality of life will increase significantly. The respondent will usually be productive again in a relatively period of short time, if the procedure is performed appropriately.

A limitation of our study is in regards to the appropriateness of the validated NEI-VFG 25 questionnaire. The questionnaires were used by more than one interviewer and took place in five provinces, to reflect the QoL in Indonesian communities who are visually impaired. Although training for interviewers regarding the procedure of completing the questionnaire was provided, there was still a potential bias due to the use of local dialects due to a limited command of

Bahasa Indonesia. Furthermore, the sample size for the groups of subjects who were blind and those with SVI were not proportionally balanced.

Conclusions

Results suggest that subjects with blindness had a lower total QoL score than those with SVI. Furthermore, glaucoma disease had the lowest QoL score when compared to other diseases.

Conflict of Interest Statement

None of the authors have any proprietary interests or conflicts of interest related to this submission.

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