

The Quality of Life in Patients with Pathologic Myopia

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Purpose: To evaluate the functional status in daily life and the quality of life (QOL) of pathologic myopia patients.

Methods: A cross-sectional study was conducted using data of consecutive pathologic myopia patients (n = 200) and control subjects (n = 144). The influence of the disease on the daily life and the QOL of patients were evaluated using a self-rated questionnaire. The questionnaire covered the full range of daily life activity, including daily tasks depending on visual acuity, social and emotional handicaps, and cognition of disease, and the QOL of pathologic myopia patients.

Results: The functional status in daily life and the QOL of patients were reduced compared with control subjects. The influence of pathologic myopia on a patient's daily life was primarily the result of three major factors, handicap, disability, and support. All three factors correlated with the QOL, the degree of handicap having the strongest correlation.

Conclusion: The functional status in daily life and the QOL of pathologic myopia patients were reduced; this decline in QOL was attributed to handicap and disability caused by the ocular disease. **Jpn J Ophthalmol 2001;45:84-92** © 2001 Japanese Ophthalmological Society

Key Words: Factor analysis, pathologic myopia, quality of life.

Introduction

Pathologic myopia is one of the major causes of visual disturbance in Japan.¹ According to a retrospective investigation of 61,025 patients at 67 university hospitals in Japan, the frequency of pathologic myopia was 2.16%.² Based on these results, the prevalence of pathologic myopia is estimated to be approximately 1% in the Japanese population, indicating that over 1.25 million patients suffer from this condition in Japan.

The clinical course of pathologic myopia is characterized by gradual progression that extends over sev-

eral decades.³ During its slow progression, many complications including posterior staphyloma, chorioretinal atrophy, choroidal neovascular membrane, and macular hemorrhage can occur. Visual acuity decreases rapidly if macular hemorrhages develop in association with posterior staphyloma.⁴ These complications are attributable to axial elongation. Although many investigations to clarify the mechanism of this disease have been conducted, no effective therapy to treat it or to prevent these complications is currently available.⁵

Pathologic myopia is a problem not only clinically but also socially. In recent years, there has been an increasing focus on the importance of incorporating patient-derived, subjective assessment of quality of life (QOL), satisfaction with health and functional status into healthcare decision-making.⁶ For such an intractable disease, further efforts should be made to improve the patient's QOL. Among ophthalmic dis-

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eases, the impact of disease on QOL has been assessed in patients with age-related macular degeneration,⁷ glaucoma,^{8,9} Grave's ophthalmopathy,¹⁰ and poor vision.¹¹ Despite the high prevalence, the slowly progressive nature, and the intractability of pathologic myopia, it seems no study has been conducted to evaluate the influence of visual disturbance on the QOL in pathologic myopia patients.

To fill this need, the present study was conducted to evaluate the impact of pathologic myopia on daily life and QOL, and to explore the potential factors that could improve the QOL for pathologic myopia patients.

Materials and Methods

Participants

To assess the QOL and related factors in pathologic myopia patients and control subjects, a cross-sectional study was conducted. Pathologic myopia is diagnosed when the measurement of refraction exceeds -8.0 diopters (D),¹²⁻¹⁴ our inclusion criteria followed this definition. During a 4-month period from January to April 1998, we enrolled 211 consecutive pathologic myopia patients (refraction exceeding -8.0 D in 1 eye or both eyes, age ≥ 18 years) who were referred to the outpatient clinic for pathologic myopia at the Tokyo Medical and Dental University Hospital. Of these, patients who suffered from pathologic myopia in only 1 eye ($n = 11$) were excluded in this report. However, since all these excluded subjects had emmetropia in 1 eye, their uncorrected visual acuity might strongly influence their QOL.

Methods of eyesight correction used by patients were glasses (far) 73%, contact lenses 21%, glasses (near) 45%, and a magnifier 14%. Control subjects were also recruited at the hospital, using the following inclusion criteria: best corrected visual acuity better than 0.8, refractive error between -3.0 and $+3.0$ D, and no ocular disease. During the same 4-month period, 144 consecutive control subjects who met these criteria were enrolled. Informed consent was obtained from each participant.

Questionnaire and Data Collection

A self-rated questionnaire that had been developed to evaluate the QOL of pathologic myopia patients in a previous study¹⁵ was used (Appendix 1). All participants were requested to complete the questionnaire when they were referred to the outpatient clinic. In cases when it was difficult, because of the patient's poor visual acuity, doctors took charge of recording the answers.

The questionnaire consisted of 52 questions (Q1 to Q52). Of these, Q1 to Q32 were to evaluate patient's daily life activity and the influence of their disease on the QOL. All questions except for Q22, Q23, Q24, Q25 used 4-point response (from 1 to 4) scales, representing intensity or frequency. Four (Q22, Q23, Q24, Q25) questions used 2-point response scales (from 1 to 2). Patients were requested to give high scores when the conditions were good. As shown in Appendix 1, Q1 to Q32 are classified into 5 subscales: vision related daily tasks (Q1-Q8, full score 32); social handicap (Q9-Q15, full score 28); emotional handicap (Q16-Q20, full score 20); leisure and support (Q21-Q29, full score 28); and cognition of disease (Q30-Q32, full score 12). Some examples of the answer sheets are shown in Appendix 2. The other questions, Q33 to Q52, were to evaluate the patient's self-rated QOL, defined as an individual's overall satisfaction with life, and one's general sense of personal well-being.¹⁶ Of those, 18 questions (Q33 to Q50) concerning psychological status over the last month comprise the General Well-Being Schedule (GWBS), questions to measure subjective well-being and distress.^{17,18} These questions were originally intended to form 6 subscales concerning the properties anxiety (Q34, Q37, Q40, Q48), depression (Q36, Q44, Q50), positive well-being (Q33, Q38, Q43), self-control (Q35, Q39, Q45), vitality (Q41, Q46, Q49), and general health (Q42, Q47). The total score represents one's comprehensive subjective well-being. The GWBS includes both positive and negative questions (eg, Q50 and Q41, respectively; see Appendix 2). The first 14 questions (Q33-Q46) use 6-point response scales representing intensity or frequency, the other four questions (Q47-Q50) use 0-10 rating scales defined by adjectives at each end. The total score of GWBS is calculated as $(Q34+Q36+Q37+Q40+Q42+Q44+Q46+Q49+Q50)(Q33+Q35+Q38+Q39+Q41+Q43+Q45+Q47+Q48) + 55$, so that the score falls in a range of 0 to 110, a lower score representing more severe distress. Dupuy proposed cut-off points to represent three levels of disorder; a score of 0-60 reflected "severe distress," 61-72 "moderate distress," and 73-110 represented "positive well-being."¹⁸ The original English version of the questionnaire has been applied to both healthy individuals and clinical patients.¹⁹⁻²³ The GWBS was translated into Japanese, and its psychometric properties have been confirmed in terms of validity, reliability, and acceptability in 1,224 healthy volunteers.²⁴ Q51 is a question specifically about satisfaction with eye condition. Q52 concerns satisfaction with life. Then the QOL

was measured by three indices, ie, GWBS, eye satisfaction, and life satisfaction.²⁵

Statistical Analysis

Factor analysis was performed to extract potential factors that may affect QOL from the questionnaire Q1 to Q32. Factor analysis is a statistical technique to identify independent factors within a multivariate set of data.²⁵ By this technique, a small number of new groups or patterns, called “factors,” emerge from a large number of variables (Q1–Q32 in this study). In other words, “factors” are summary indices of many variables. The magnitude of each factor is quantitatively expressed as a factor score, calculated so that the mean = 0 and the standard deviation = 1. The strength of association between each factor and the variables are expressed as factor loadings, by which it may be possible to interpret what the extracted factor means. To decide the number of factors that should be extracted from Q1 to Q32, we used a scree plot, a simple plot of successive eigenvalues.²⁵ The factor scores were saved for each individual after varimax rotation, and then used for the following analyses. Mean values of the factor scores were compared between the case and control groups by the Student *t*-test.

Spearman’s rank correlation analysis was performed to examine associations of the factors with clinical and demographic characteristics. Analysis of covariance was performed to assess the effect of these factors on the differences between the QOL in the case and in the control groups. All analyses were conducted using the SAS statistical package (Version 6.12, SAS Institute, Cary, NC, USA.).

Results

Descriptive Analysis

Demographic and clinical characteristics of pathologic myopia patients (n = 200) and control subjects

(n = 144) are summarized in Table 1. There was no significant difference in the age or sex between the case and control groups. Not surprisingly, best-corrected visual acuity was much worse in the case group; the mean refraction of the case group was –13.0 D in the right eye and –12.8 D in the left eye, whereas that in the control group was below –2.0 D.

Questionnaire Responses

The mean values of the five subscales of Q1 to Q32, and the three indices of QOL are shown in Table 2. Pathologic myopia patients demonstrated lower scores in vision-related daily tasks and social handicap, and they showed significantly higher scores in cognition of disease than control subjects. Of the indices of the QOL, no difference was found in GWBS scores between the case and control subjects, while the mean scores for eye satisfaction and life satisfaction in the case group were lower than those of the control subjects.

Factor Analysis

Based on the scree plot (data not shown), we decided that three factors should be extracted from the 32 questions (Table 3). As explained in the Statistical Analysis section, the factor loading indicates the magnitude of association between the factor and each of the questions (Q1 to Q32). Questions that loaded at 0.20 or greater were considered to be making a relatively large contribution to the factor and, therefore, for simplicity, the factor loadings are shown only for such questions. Questions that loaded high on the first factor were related to role limitations in social life and emotional distress due to eye problems. Thus, we called this factor “handicap.” Questions that loaded high on the second factor could be attributed to the ability to do daily tasks dependent on visual acuity. This factor was thus called “disability.” Questions that loaded high on the

Table 1. Characteristics of Case and Control Subjects

Variables	Cases (n = 200)	Controls (n = 144)
Age in years (range)	50.0 ± 16.0 (18–87)	50.6 ± 17.8 (18–88)
Sex (male %)	39.0%	37.5%
Best corrected visual acuity		
Better eye	0.64 ± 0.44	0.98 ± 0.03
Worse eye	0.21 ± 0.19	0.95 ± 0.04
Spherical equivalent refraction (diopter)		
Right eye	–13.0 ± 5.3	–1.3 ± 2.3
Left eye	–12.8 ± 5.5	–1.2 ± 2.3

Values are mean ± SD unless otherwise indicated.

Table 2. Comparisons of Five Subscales of Daily Life Activities (Q1–Q32) and three Indicators of Quality of Life (Q33–Q52) Between Cases and Controls

Variables	Cases	Controls	P-Value*
	Mean ± SD	Mean ± SD	
Subscales of daily life activity			
Vision-related daily tasks	21.1 ± 2.8	30.3 ± 1.9	<.001
Social handicap	14.7 ± 2.6	23.7 ± 2.8	<.001
Emotional handicap	11.2 ± 2.3	14.7 ± 2.0	.022
Leisure and support	21.2 ± 2.9	20.6 ± 2.5	.209
Cognition of disease	8.0 ± 2.1	7.3 ± 1.6	.002
Indicators of QOL			
General well-being schedule	68.8 ± 17.5	69.6 ± 16.5	.738
Eye satisfaction	2.6 ± 2.6	4.7 ± 2.7	<.001
Life satisfaction	5.8 ± 2.6	6.6 ± 2.5	.013

*By Student *t*-test.

third factor primarily concerned relationships with the environment. This factor was called “support.” The scores of these three factors (the factor scores) were calculated for each individual based on his/her answers and the factor loadings. In Table 4, the mean values of the factor scores were separately shown for case and control groups. Statistically significant differences were observed for all three factors. The mean levels of handicap score and disability score of pathologic myopia patients were lower than those of control subjects. These results imply that pathologic myopia patients are obstructed in their social lives and their ability to do vision-related daily tasks. However, pathologic myopia patients presented a higher support score than that of the control subjects.

Using Spearman’s rank correlation analysis (Table 5), it was found that age was correlated significantly with disability and support in patients with pathologic myopia. Sex had no significant correlation to the three subscales. In the case group, visual acuity of the better eye had a stronger correlation to disability than did visual acuity of the worse eye or average visual acuity of both eyes. On the other hand, correlations between visual acuity and handicap and support were not statistically significant. There was no correlation between visual acuity and any factor in control subjects. A statistically significant correlation was found between the three QOL indicators, (GWBS, eye satisfaction, life satisfaction) and the factors of handicap and support. Unexpectedly, a relatively weak correlation was observed between disability and the three QOL indicators.

To evaluate the impact of these three factors on the difference in QOL between the case and control subjects, an analysis of covariance was performed (Table 6). The mean levels of these three indicators

of QOL were adjusted by each factor separately. The significant difference in eye satisfaction was virtually unchanged when adjusted for handicap, disability, or support. On the other hand, the significant difference in life satisfaction between the case and the control groups disappeared when adjusted for handicap. An adjustment for handicap significantly increased the GWBS score of the case group.

Discussion

We measured the QOL in terms of three indicators, GWBS (Q33–Q50), eye satisfaction (Q51), and life satisfaction (Q52). The GWBS score obtained from control subjects (69.6 ± 16.5 SD) was not very different from that of healthy Japanese volunteers in an earlier study (70.7 ± 14.4 SD).²³ Therefore, the present control group was thought to be appropriate. The case group showed significantly lower scores in eye satisfaction and life satisfaction than the control subjects. In contrast, the GWBS score was not reduced in the case group. The reason we obtained seemingly contradictory results between the different indicators of QOL measurements might be explained by the difference in the time scale of these QOL indicators. The GWBS is intended to evaluate the patient’s psychological status over the last month.^{17,18} On the other hand, life satisfaction can measure the total of an individual’s attitude toward present, future, and even past events.²⁶

Factor analysis was performed, and three factors that have influenced QOL were obtained from Q1 to Q32. We designated these three factors as handicap, disability, and support, respectively. We examined how pathologic myopia influenced a patient’s QOL through these factors. Based on the results of factor analysis, the structure of QOL in pathologic myopia

Table 3. Assessment of the Factor-Loading Matrix for Pathologic Myopia Patients and Control Subjects in a Factor Analysis of Daily Life Activity (Q1–Q32)

Questions	Factors		
	1 Handicap	2 Disability	3 Support
1. Shopping		0.85	
2. Buying a train ticket	0.22	0.82	
3. Reading platform signs	0.23	0.81	
4. Bus		0.83	
5. Television		0.44	
6. Letter		0.88	
7. Newspaper		0.79	
8. Recognizing someone		0.66	
9. Change school or occupation	0.68		
10. Cannot perform studies or jobs	0.72	0.23	
11. Selection of job	0.62		
12. Facial expressions	0.65	0.40	
13. Good communication with peers	0.56	0.31	
14. Salary level	0.59		
15. Cost of glasses, contact lenses	0.26		
16. Visual acuity testing	0.55		
17. Embarrassed to look closely	0.53		
18. Insomnia	0.71		
19. Difficulty to do something	0.69	0.33	
20. Nervousness about eye condition	0.72	0.24	
21. Go out with friends		0.47	0.39
22. Hobbies			
23. Cheer you up		0.27	0.38
24. Something to live for			0.48
25. Live with family			
26. Family understanding			0.62
27. Public accommodations			0.30
28. Eye hospital			0.60
29. Information from doctor			0.46
30. Understanding your eye	0.35		
31. Anxiety about visual acuity	0.49		
32. Acceptance of your eye condition	0.46		
Eigenvalues*	5.80	4.98	2.08
Proportion of variability†	33.64	24.80	4.33

Values are factor loadings. Values of <0.200 were excluded from table for simplicity.

*Eigenvalues refer to total variance represented by each factor.

†Percentage of total variance in questionnaire, attributable to each factor.

patients is modeled in Figure 1. To construct this model, ICIDH-2: International Classification of Functioning and Disability, which was proposed by the World Health Organization,²⁷ was used. According to ICIDH-2, the influence of disease on patients can be explained in terms of four dimensions: (1) impairment, (2) activity limitation, (3) participation restriction, and (4) environmental factor. Impairment is defined as a problem in bodily function or structure, causing a significant deviation or loss. Activity limitation is defined as difficulties an individual may have in the performance of activities. Participation restriction is defined as a problem that an individual may have in the manner or extent of involvement in

life situations. Environmental factor is defined as the physical, social, and attitudinal settings in which people live and conduct their lives. The QOL is defined as an individual's overall satisfaction with life, and one's general sense of personal general well-being, which is affected by these four factors.²⁸ In the case of pathologic myopia, the three factors we extracted by factor analysis will be classified as follows: disability as activity limitation, handicap as participation limitation, and support as an environmental factor. And then impairment will be represented by visual acuity (Figure 1).

When comparing the average factor scores of these three extracted factors between the case and

Table 4. Comparisons of Factor Scores Obtained From Factor Analysis in Cases and Controls

Factor	Cases	Controls	P-Value*
	Mean ± SD	Mean ± SD	
Handicap	-0.52 ± 0.84	0.73 ± 0.71	<.001
Disability	-0.18 ± 1.21	0.25 ± 0.44	<.001
Support	0.15 ± 1.11	-0.20 ± 0.78	<.001

Values are mean ± SD of factor scores.
 *By Student *t*-test.

control subjects, the factor scores for handicap and disability were reduced in the cases (Table 4). Nevertheless, we concluded that the pathologic myopia patients were strongly affected by his disease, especially in the individual and social functional status in their daily lives.

There was a strong correlation between visual acuity and disability (Table 5) in the cases, while no such correlation was seen in the controls. Spearman's rank correlation coefficients between the three factors and life satisfaction in the case group were statistically significant (Table 5). Therefore, these factors were regarded as regulatory factors in the QOL of pathologic myopia patients. When the mean level of life satisfaction was adjusted for handicap, the difference between the case and control groups disappeared (Table 6). Thus, among the three factors, handicap had the strongest relationship with QOL. These results suggest that the QOL model may ap-

propriately represent the structure of QOL in pathologic myopia patients.

The result that handicap was more strongly correlated with QOL than disability might be due to the chronic nature of pathologic myopia; once patients come to terms with having long-term visual disturbance, adjustments occur in their QOL, even when they have severe visual disturbance.²⁹ This adjustment might weaken the impact of the loss of visual acuity on a patient's QOL. Halsted reported that symptomatic and physical effects of disease are less meaningful than the nonbiological consequences, such as loss of work, marital discord, or social limitations.³⁰ This tendency has also been shown for other ocular diseases. Wändell et al⁸ studied the QOL of Swedish glaucoma patients using a self-rated QOL questionnaire, the Swedish Health-Related Quality of Life Survey. Their findings indicated that health-related QOL in glaucoma patients was good and that topical β -blockers did not cause negative influences.⁸ On the other hand, patients with AMD experienced significant deterioration in key aspects of their daily lives.⁷ Their ratings for QOL and emotional distress were significantly worse than those for similarly aged community adults and were comparable with those reported by people with chronic illness (eg, arthritis, chronic obstructive pulmonary disease, acquired immunodeficiency syndrome, and bone marrow transplants). They also reported that a patient group with unilateral macular degeneration was more distressed

Table 5. Spearman's Rank Correlation Coefficients Between Influencing Factors and Clinical Characteristics, General Well-Being Schedule, Eye Satisfaction, and Overall Satisfaction in Cases and Controls

Variables	Factors					
	Handicap		Disability		Support	
	Cases	Controls	Cases	Controls	Cases	Controls
Age	0.04	-0.16	-0.36*	-0.33*	0.16*	-0.04
Sex	-0.10	-0.09	-0.09	0.06	0.12	-0.03
Visual acuity of better eye	-0.10	-0.09	-0.59*	-0.12	0.05	-0.08
	(-0.06)	(-0.05)	(-0.65*)	(-0.15)	(-0.04)	(-0.04)
Visual acuity of worse eye	-0.11	-0.10	-0.44*	-0.13	0.11	-0.07
	(-0.04)	(-0.01)	(-0.47*)	(-0.01)	(-0.05)	(-0.09)
Average of visual acuity both eyes	-0.12	-0.11	-0.48*	-0.11	0.10	-0.06
	(-0.01)	(-0.03)	(-0.58*)	-0.09	(-0.03)	(-0.07)
General well-being schedule	0.39*	0.37*	0.05	-0.06	0.39*	0.31*
	(0.37*)	(0.40*)	(0.14*)	(-0.01)	(0.44*)	(0.36*)
Eye satisfaction	0.27*	0.35*	0.07	-0.14	0.16*	0.20*
	(0.25*)	(0.38*)	(0.15*)	(-0.13)	(0.19*)	(0.25*)
Life satisfaction	0.29*	0.05	0.16*	0.08	0.27*	0.13
	(0.25*)	(-0.01)	(0.21*)	-0.03	(0.22*)	(0.20*)

Values in parentheses are partial correlation coefficients adjusted for sex and age.
 **P* < .05.

Table 6. Comparisons of Eye Satisfaction, Overall Satisfaction, and General Well-Being Schedule Scores Between Cases and Controls Adjusting for Factors by Analysis of Covariance

Adjusted factor	Eye Satisfaction (Q51)			Life Satisfaction (Q52)			General Well-Being Schedule Score		
	Cases		P-Value	Cases		P-Value	Cases		P-Value
	Mean ± SE	Controls Mean ± SE		Mean ± SE	Controls Mean ± SE		Mean ± SE	Controls Mean ± SE	
Unadjusted	2.57 ± 0.18	4.34 ± 0.22	<.001	5.82 ± 0.18	6.60 ± 0.22	.005	68.99 ± 1.20	69.60 ± 1.42	.738
Handicap	3.08 ± 0.19	3.65 ± 0.24	.010	6.17 ± 0.20	6.23 ± 0.25	.872	70.28 ± 1.15	62.50 ± 2.63	.011
Disability	2.49 ± 0.18	4.62 ± 0.21	<.001	5.80 ± 0.18	6.60 ± 0.22	.059	69.01 ± 1.18	67.14 ± 1.44	.978
Support	2.65 ± 0.18	4.78 ± 0.22	<.001	5.84 ± 0.17	6.52 ± 0.21	.002	68.01 ± 1.20	71.40 ± 2.49	.154

Values are least square mean ± standard errors of quality of life indices adjusted for each factor by analysis of covariance.

than a group with bilateral macular degeneration. The authors suggested that anxiety about losing visual acuity in the contralateral eye as a result of the disease may create greater distress than would be expected by changes in visual acuity alone. The QOL of pathologic myopia patients resembles that of glaucoma patients. The reason for this resemblance may be the progressive nature of the disease.

In summary, this study demonstrated that the QOL of pathologic myopia patients is not markedly reduced compared with that of control subjects. The functional status of daily life is strongly associated with the QOL for pathologic myopia patients. For such an intractable disease, the goal of treatment is to improve the patient's functional status in daily life and QOL, until effective therapy to improve visual function is developed. The associations between clinical measures (visual acuity) and functional status of daily life and self-rated QOL are not always strong in pathologic myopia patients and, therefore, the functional status of daily life and self-rated QOL should be taken into account in patient manage-

ment.³¹ When the goal of treatment is to improve functional capacity and well-being (rather than to prolong life) and correlations between clinical measures and the patient's experiences are low, then QOL assessment is imperative in the evaluation of treatment. Our questionnaire would be helpful for this purpose because it is easy to answer (it took 13 minutes, on average, to complete) and can properly assess the effect of this disease on the patient's functional status in daily life and QOL.

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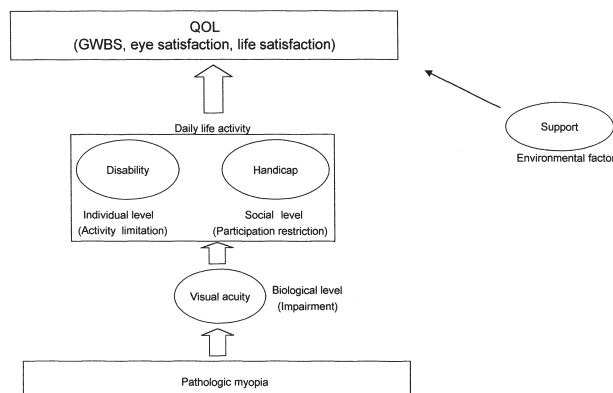


Figure 1. Structure of quality of life (QOL) in pathologic myopia patients. This disease directly affects visual acuity and may influence the daily life activity of patients. QOL is modified through these changes and through environmental factors (support).

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Appendix 1. Questionnaire for Evaluating Quality of Life of Pathologic Myopia Patients

Vision-related daily tasks

Please answer these questions assuming that you are or are not wearing your glasses, whichever is better in a given situation. (Q1-Q8)

- Q1. How much difficulty do you have when you go shopping alone?
- Q2. How much difficulty do you have when buying a train ticket at a ticket vending machine?
- Q3. How much difficulty do you have in reading the platform signs at the train station?
- Q4. How much difficulty do you have in reading the bus destination board?
- Q5. How much difficulty do you have watching television?
- Q6. How much difficulty do you have in reading or writing a letter?
- Q7. How much difficulty do you have in reading the smallest type in the newspaper?
- Q8. How much difficulty do you have in recognizing someone as he/she comes closer to you?

Social handicaps

- Q9. How often have you felt obliged to change your school or occupation because of your eye condition?
- Q10. How often have you felt that you cannot perform your studies or jobs efficiently because of your eye condition?
- Q11. How often have you felt that your job selection was affected by your eye condition?
- Q12. How often have you felt bothered that it is difficult to read a person's facial expression because of your reduced visual acuity?
- Q13. Have you felt that you cannot have good communication with your peers at your school or office because of your eye condition?
- Q14. Do you feel that your salary level is influenced by your eye condition?
- Q15. What is your opinion about the cost of glasses or contact lenses?

Emotional handicaps

- Q16. How embarrassed do you feel when your visual acuity is being tested?
- Q17. To what degree do you feel embarrassed when you have to look at things very close up in the presence of others?
- Q18. How often do you have insomnia due to worrying about your eye condition?
- Q19. How often have you felt that it was difficult for you to do something you wanted to do?
- Q20. How often have you felt nervous about your eye condition?

Leisure and support

- Q21. How often do you go out with your friends?
- Q22. Do you have any hobbies?
- Q23. Is there someone who can cheer you up when you are feeling depressed?

Appendix 1. Continued

- Q24. Do you have something to live for?
- Q25. Do you live with any family members?
- Q26. How well does your family understand your eye condition?
- Q27. What is your opinion about the level of public accommodations for people with reduced vision?
- Q28. How satisfied are you with your eye hospital?
- Q29. How much information does your eye doctor give you about your eye condition?

Cognition about disease

- Q30. How well do you understand your eye condition?
- Q31. How anxious do you feel about your visual acuity in the future?
- Q32. To what extent do you accept your eye condition?

QOL

GWBS (general well-being schedule)

This section of the questionnaire contains questions about how you feel and how things have been going with you during the past month.

- Q33. How have you been feeling in general?
- Q34. Have you been bothered by nervousness or your 'nerves'?
- Q35. Have you been in firm control of your behavior, thoughts, emotions or feelings?
- Q36. Have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile?
- Q37. Have you been under or felt you were under any strain, stress, or pressure?
- Q38. How happy, satisfied, or pleased have you been with your personal life?
- Q39. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or losing your memory?
- Q40. Have you been anxious, worried, or upset?
- Q41. Have you been waking fresh and rested?
- Q42. Have you been bothered by any illness, bodily disorder, pains, or fears about your health?
- Q43. Has your daily life been full of things that were interesting to you?
- Q44. Have you felt downhearted and blue?
- Q45. Have you been feeling emotionally stable and sure of yourself?
- Q46. Have you felt tired, worn out, used-up, or exhausted?
- Q47. How concerned or worried about health have you been?
- Q48. How relaxed or tense have you been?
- Q49. How much energy, pep, vitality have you felt?
- Q50. How depressed or cheerful have you been?

Eye satisfaction

- Q51. How much are you satisfied with your eye condition?

Life satisfaction

- Q52. How much are you satisfied with your overall life, in spite of your eye condition?
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Appendix 2. Examples from Answer Sheets of Questionnaire for Evaluating Quality of Life of Pathologic Myopia Patients (Translated from Japanese)

Please answer these questions.

- Q1. How much difficulty do you have, even with glasses, shopping alone?

- 1. A lot of difficulty
- 2. Some difficulty
- 3. A little
- 4. No difficulty

- Q22. Do you have any hobbies?

- 1. No
- 2. Yes

- Q41. Have you been waking fresh and rested?

- 1. Every day
- 2. Most every day
- 3. Fairly often
- 4. Less than half the time
- 5. Rarely
- 6. None of the time

- Q50. How depressed or cheerful have you been?

- | | | | | | | | | | | |
|-----------|---|---|---|---|----------|---|---|---|---|----|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Very | | | | | Very | | | | | |
| depressed | | | | | cheerful | | | | | |

- Q51. How much are you satisfied with your eye condition?

- | | | | | | | | | | | |
|------------------|---|---|---|---|----------------|---|---|---|---|----|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Not | | | | | Very | | | | | |
| satisfied at all | | | | | much satisfied | | | | | |
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