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Health Related Quality of Life after Surgical Removal of An Eye

Takaaki Kondo, M.D.^{1,2}, Walter T. Tillman, B.C.O.¹, Terry L. Schwartz, M.D.¹, John V. Linberg, M.D.¹, and J. Vernon Odom, Ph.D.¹

¹West Virginia University Eye Institute, Morgantown, WV 26506-9193

²Department of Ophthalmology, Teikyo University, Tokyo, Japan

Abstract

Purpose—This study compared the general health related quality of life (HRQOL) and the vision specific HRQOL in patients following the surgical removal of one eye who had good vision in the remaining eye to a group of binocular patients with good vision in both eyes.

Methods—The Medical Outcomes Study Short Form 12 (SF-12) and the National Eye Institute Visual Function Questionnaire (NEI VFQ) health related quality of life (HRQOL) surveys were administered to 29 patients who had surgical removal of an eye who attended an ocular prosthetics clinic and to 25 binocular persons who accompanied a patient. All subjects in each group had best corrected visual acuity of 20/40 or better. Overall statistical significance was tested using Cramer's V followed by individual t-tests for independent groups for each of the scales on the two questionnaires to determine if the means between the two groups differed statistically.

Results—The patient group had a mean age of 50.98 years (range 19 to 76). The control group had a mean age of 49.46 years (range 18 to 76). The mean time after loss of vision was 28.03 years (range 1-71 years) and the mean time from surgical removal of the eye was 23.6 years (range 0.5 to 59.5). There was an overall significant difference between the two groups on the 15 derived subscales of the two forms (Cramer's V, $p = 0.0025$). Three general HRQOL subscales (SF-12-mental component summary (MCS), SF-12 physical component summary (PCS), NEI VFQ-General Health) showed no differences between the two groups ($p = 0.48$, $p = 0.81$, $p = 0.78$ respectively). Three of the twelve vision specific NEI VFQ subscales demonstrated statistically significant differences between the patient and control groups: peripheral vision ($p = 0.0006$), role difficulties ($p = 0.015$) and the composite score ($p = 0.014$). Additionally, two monocular patients had given up driving compared to no binocular subjects ($p = 0.056$).

Conclusions—This population of monocular patients had general physical and mental HRQOL equivalent to the normal binocular group despite the surgical removal of one eye. However, the reduced vision specific HRQOL of monocular patients on the NEI VFQ indicates that there are substantial residual visual deficits even after prolonged monocular status.

Keywords

Quality of Life; monocular blindness; enucleation; evisceration; evisceration; exenteration; disability; visual field loss

Corresponding Author: J. Vernon Odom, Ph.D. Professor of Ophthalmology and Physiology and Pharmacology West Virginia University Eye Institute Robert C. Byrd Health Sciences Center of West Virginia University 1 Stadium Drive P.O. Box 9193 Morgantown, WV 26506-9193 U.S.A. Work Telephone +1 304 598 6959 FAX +1 304 598 6928 odomj@wvuhealthcare.com.

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On many tasks, binocular performance is better than monocular performance for binocular individuals¹. Although the monocular performance of patients who have lost vision in an eye is often equal to or better than the monocular vision of binocular individuals, it is seldom equal to the binocular performance of individuals who have two eyes with normal vision². Despite the visual deficits and the psychological consequences, monocular vision loss is seldom viewed as a disability requiring special rehabilitation³⁻⁵.

The study of monocular individuals has been of scientific interest for two reasons. First by comparing the performance of monocular individuals to those with normal and abnormal binocular vision one can gain an understanding of the role of binocular vision in normal vision e.g., 2, (Schwartz, et al. *Invest Ophthalmol Vis Sci* 29 (suppl.):434, 1988). Second, comparisons of persons who lost sight in one eye early in life versus later in life shed light on the role of neural reorganization in the shaping of visual performance e.g., 2, (Schwartz, et al. *Invest Ophthalmol Vis Sci* 28 (suppl.):304, 1987).

The surgical removal of an eye can result in depression, difficulties in driving, perceived problems with physical appearance and coping difficulties⁶⁻⁸. Some patients experience hallucinations associated with loss of vision, and for a small portion of patients, their hallucinations can be debilitating⁹⁻¹¹. In some patients the missing eye also gives rise to phantom pain and headaches^{12, 13}. Personal accounts of the difficulties of losing an eye and associated coping strategies are useful in understanding these phenomena^{4, 15-16}. In the absence of formal treatment strategies, the psychological and sensory issues involved require sensitivity on the part of the professionals involved in the treatment of the loss of an eye and the subsequent rehabilitation^{17, 18}.

Several studies have evaluated patients undergoing enucleation for ocular melanoma^{6-8, 19-21}, but these studies compared the patients undergoing enucleation to patients undergoing other therapies for ocular melanoma rather to binocular control groups. Two studies which evaluated the functional impact and recovery from acquired monocular vision and sampled a more diverse population of monocular patients^{22, 23} employed custom rather than validated questionnaires to evaluate the function and recovery of their patients. These studies, also, did not explicitly compare their monocular patients to binocular normals. To the best of our knowledge only two recent studies have compared the quality of life of binocular normals and patients who have had surgery to remove an eye^{24, 25}. Both found statistically significant differences between normals and those with monocular vision following surgery.

This study was conducted to quantify long-term differences in the health-related quality of life of patients after surgical removal of an eye as compared to normal patients. We used an established quantitative general health questionnaire, the Medical Outcomes Study Short Form 12 question (SF-12)^{26,27} and a vision specific instrument, the National Eye Institute Visual Function Questionnaire (NEI VFQ)^{28,29}, to compare the quality of life of patients having acquired monocular vision and surgical removal of an eye with that of a similarly aged control group with binocular vision.

Methods

The study was conducted with the approval of the Robert C. Byrd Health Sciences Center Institutional Review Board and consistent with the Declaration of Helsinki. Patients who had surgical removal of an eye (enucleation, evisceration, or exenteration) for any reason were eligible to participate if their best corrected vision in the remaining eye was normal (better than 20/40). Normal control subjects were eligible if their best corrected vision in each eye was better than 20/40. While attending the West Virginia University Eye Institute

for routine follow-up care for their ocular prosthesis, 29 adult monocular patients (16 male and 13 female) completed the SF-12 and the NEI VFQ health related quality of life (HRQOL) surveys as well as providing information about the loss of vision and the surgical removal of their eye. Surveys were also administered to a normally sighted binocular control group of 25 persons, 16 female and 9 male. In order to reduce social and cultural bias the control group was comprised of persons accompanied a patients to their appointment with the ocularist (WTT). The members of the control group were not necessarily accompanying the monocular patients who completed the HRQOL surveys. After completing the surveys, subjects had their acuities measured using a standard projection Snellen chart at a distance of 4 meters. All monocular and binocular subjects had normal vision (best corrected 20/40 or better) in each eye.

The SF-12 Health Survey is a short form, multipurpose, generic measure of health status developed by the Health Assessment Lab at the New England Medical Center. It contains 12 items using one or two items to measure each of eight concepts commonly represented in health surveys: Physical Functioning (2), Role-Physical (2), Bodily Pain (1), General Health (1), Energy/Fatigue (1), Social Functioning (1), Role-Emotional (2), and Mental Health (2). The scores for these eight scales are employed to calculate summary scales for both physical and mental health. The physical health (Physical Component Summary-PCS) measure is comprised of scores from the physical functioning, role limitations secondary to physical health problems, bodily pain and general health scales. The mental health (Mental Component Summary-MCS) measure is scored from the vitality (energy/fatigue), social functioning, role limitations due to emotional problems, and mental health (psychological distress and psychological well-being) scales²⁶. It generally performs comparably to longer forms such as the SF-36²⁷.

The NEI VFQ was designed to cover areas of functioning and well being identified as important for persons with eye diseases. The NEI VFQ generates 12 subscales from 39 items with 1 to 6 items per subscale: General Health (2), General Vision (2), Ocular Pain (2), Near Activities (6), Distance Activities (6), Social Functioning (3), Mental Health (5), Role Difficulties (4), Dependency (4), Driving (3), Color Vision (1) and Peripheral Vision (1). A vision specific composite score is calculated by averaging the vision targeted subscale scores, i.e., excluding the general health item^{28, 29}.

Statistical analyses were performed comparing the scores between the patient and normal control groups on 15 scales (12 subscales and the composite score from the NEI VFQ and the SF-12 physical and mental summary measures).

All statistical calculations were performed using Statistica 5.1 (Statsoft, Inc., 1998). Demographic differences between the groups were analyzed using t-tests for independent groups or using the χ^2 . Overall statistical significance was tested on the questionnaire scales using Cramer's V. Individual t-tests for independent groups were employed to test the differences between groups on each of the scales on the two questionnaires.

Results

Demography

The mean time period following the loss of an eye was 23.6 years with a standard deviation of 18.01 years. The mean age of the monocular group was 50.98 years with a standard deviation of 14.17 years. The binocular control group's mean age was 49.46 years with a standard deviation of 13.80 years. There was no significant difference between the ages, education level, marital status, or visual acuities of the monocular subjects and the binocular groups.

Table 1 presents the demographic data for the individual monocular patients. It includes information on the patient reported age of vision loss, age of surgery, time since vision loss and time since surgery. Table 2 summarizes and compares the comparable demographic data of the monocular and binocular groups. The only significant difference between the two groups was in the distributions of sexes in the two groups ($\chi^2 = 5.4$, $p = 0.0201$). The control group had more women and fewer men, relatively than the monocular group.

Questionnaire Results

Multivariate analysis demonstrated a statistically significant difference (Cramer's V; $p = 0.0025$). Figure 1 presents the means and standard errors of all 15 scales. The SF-12 mental and physical health component summary scores, the general health measure of the NEI VFQ and most of the vision specific health subscales derived from the NEI VFQ revealed no significant difference in the quality of life between the monocular and normal binocular groups (Figure 1). Two of the twelve vision specific subscale scores generated by the vision specific NEI VFQ demonstrated statistically significant differences between the patient and control group: peripheral vision ($p = 0.0006$) and role difficulties ($p = 0.015$). Additionally the NEI VFQ composite score was significantly different between the two groups ($p = 0.014$).

Two patients had stopped driving, one for reasons other than vision and one because of perceived changes in vision. Missing data alters interpretation of the scales of the NEI VFQ³⁰. Depending on the scoring of the data of those two patients as missing or not, the difference between the two groups is either not significant ($p = 0.09$) or significant ($p = 0.045$). Similarly a comparison of the proportion of nondrivers to drivers in the two groups approaches but does not reach significance ($z = 1.91$; $p = 0.056$).

Relationship of Questionnaire Results to Demographic Results

The significant questionnaire scales were correlated with the demographic variables of the monocular group using both linear regression and multiple regression models. These analyses did not indicate a significant relationship between age of surgical removal of an eye, age vision was lost, time since surgery or time since vision was lost, or visual acuity and any of the NEI VFQ scales which differed statistically between the two groups. Only one relationship was statistically significant. Although there was no overall relationship of age and the Peripheral Vision Scale ($r = 0.040$, $p = 0.7728$), this was because of opposite trends in the two subgroups. With age the monocular group's NEI VFQ Peripheral Vision Scale scores improved ($r = 0.376$, $p = 0.0441$), while those for the binocular group declined ($r = -0.433$, $p = 0.0307$).

Discussion

Statistical analysis comparing the patient and control group scores on the 12 NEI VFQ subscales, the NEI VFQ Composite, and the SF-12 physical (PCS) and mental (MCS) component summary scores demonstrated statistically significant differences in 3 of the 15 measures: NEI VFQ Peripheral Vision, NEI VFQ Role Difficulties, and NEI VFQ Composite and approached significance in a fourth, the NEI VFQ Driving scale.. After a brief discussion of study limitations, we shall discuss each of these results.

Limitations of the Study and Characteristics of the Samples

All studies are limited by the study design, the measures taken and the characteristics of the sample. Our study was a prospective cross-sectional study. Thus measures were taken at a particular time and there is no direct access to what happened before or after that time. We

cannot look at the development of the differences between monocular and binocular subjects.

To fit the study comfortably into the clinic we selected a short general HRQOL measure, the SF-12 as well as the vision specific NEI VFQ. While both of these questionnaires are well represented in the literature no questionnaire adequately measures all functions. For example, commonly discussed deficits associated with the loss of an eye are stereopsis and the loss of peripheral field^{2, 14-16}. Stereopsis and the possible effects of its loss are not directly measured in the NEI VFQ. Inclusion of questions related to stereopsis and depth perception might have increased the difference between the groups.

Neither our binocular nor monocular population was selected randomly; hence they contain biases which may limit the generalizability of the results to other populations. Our sample of patients who had unilateral surgery to remove one eye is relatively small, 29. All had good cosmetic results and normal visual acuity in the remaining eye. Both groups were drawn from a largely rural environment which differentiates them from more urban populations. The educational levels of both groups was about high school level (Table 2). By selecting as a control group persons who accompanied patients to the clinic unintended biases may have been introduced.

The causes of surgery, the types of surgery (enucleation, evisceration, or exenteration) the ages at surgery, time since the surgery and social conditions varied. Because of the sample size we could not stratify the sample for post hoc analyses of these variables in detail. However, as noted in the results section correlations of many of these variables failed to indicate a relationship with NEI VFQ scale scores.

General and Mental Health—Analysis failed to show statistically significant differences between patient and control groups in the SF-12 physical and mental health summary and in the NEI VFQ General Health scores. This is significant in that these measures are indicative of the patients' general outlook and are excellent indicators of the patients' perceived general HRQOL.

Some support for the lack of a general health effect is found in a German study²⁴ in which the authors examined the time trade off utility values of the loss of an eye in a group of 23 patients with good visual acuity in the remaining eye who had good cosmetic results following surgical removal of an eye more than a year in the past. The utility values were much better than expected when compared to other medical conditions, suggesting that the loss of an eye had relatively minor impact on the perceived overall health of the subjects.

However, our results differs from a study of Korean patients²⁵ which used the Medical Outcomes Study Short Form 36 (SF-36) and found major differences between 48 normal volunteers and 134 patients who had surgery to remove an eye. Because the SF-12 is designed to be a shorter replacement of the SF-36 and is reported to provide very similar results^{26, 27}, it is difficult to explain the difference. The Korean study also examined several depression scales and social variables. The monocular patients expressed greater depression and more social concerns. The authors interpreted depressive symptoms and social concerns with appearance as being the major causes of the reduced SF-36 scores²⁵. We did not directly measure depression and social concerns other than on the SF-12 but there is some indication of these concerns on the NEI VFQ. Monocular patients indicated that the loss of vision had led to role difficulties (see Role Difficulties section below).

However, overall our population appears less affected by depression or social concerns than the Korean population, perhaps due to cultural differences. In our sample, the monocular

patients actually had higher quality of life scores on all three of the general health scales as compared to the normal control subjects. Therefore, a simple increase in sample size would be unlikely to have reversed the effect at a statistically significant level.

Peripheral Vision—Peripheral vision is evaluated on the NEI VFQ using a single question: Because of your eyesight, how much difficulty do you have noticing objects off to the side while you are walking *along*? The greatest difference between the monocular and binocular control groups was on the peripheral vision subscale.

Loss of an eye results in a field loss of 20 to 30 percent along the horizontal meridian visual field depending on facial structure,^{14-16, 31, 32}. This value assumes that one is facing straight ahead and looking at a distant fixation point. However, depending on eye and head position visual field reduction can be as great as 50%³³. The loss of visual field and resultant loss of exteroception and visuomotor coordination¹ continued to affect perceived vision-specific quality of life even after a mean duration of 23 years. It is unclear whether the difficulty seeing things to the side while walking resulted in greater accidents or a higher incidence of falls in monocular individuals as these questions were not directly asked. However, there are some suggestions that this may be true in the personal accounts of those who have lost an eye¹⁴⁻¹⁶. It is also unclear whether patients with acquired monocular vision might benefit from periods of orientation and mobility training as broader scanning strategies are commonly recommended to compensate for visual field reduction^{14-16, 34}.

Our data indicate that as monocular patients age, their concern about their peripheral vision loss declines (i.e., their peripheral vision scores improve). This may represent some compensatory learning or comparison to their binocular peers who are progressively more concerned about peripheral vision. If it is related to learning, it is not related to age of surgery or vision, or to time since surgery or vision loss.

Role Difficulties—The two questions in the NEI VFQ scored for the Role Difficulties subscale are: Do you accomplish less than you would like because of your vision? Are you limited in how long you can work or do other activities because of your vision?

Difficulties of monocular patients in role difficulties are well supported in the literature. Coday et al's found that half of their sample expressed difficulty participating in sports and hobbies in which they had previously taken part²⁴. Linberg et al reported 32% of respondents felt the loss of an eye had affected their involvement in recreation and 16 % said it affected home activities²³. Fatigue partially accounts for difficulties monocularly blind children have in reading and completing school tasks⁵.

Discussion of role difficulties is also important in the work place. Although 23%²³ and 22%²⁴ of monocular patients report that the loss of an eye has adversely affected their job performance, only 6% reported an actual change in job status²⁴. Augsburger et al reported that none of the patients in their enucleation group ceased working because of changes in their perceived visual functioning²⁰. Just 2.5% reported that they stopped working because of a subjective decrease in visual functioning in another study¹⁹.

NEI VFQ Composite—The NEI VFQ composite score is a mean of the vision targeted subscale scores, but excludes the general health question. As such, it summarizes the vision specific changes in quality of life on all of the other subscales. Each vision scale has a lower mean value for the group which had an eye surgically removed than the binocular group, though these reductions are not always statistically significant (Figure 1). This general difference is best represented by the statistical difference shown in the NEI VFQ composite score.

The NEI VFQ composite score reduction is consistent with earlier reports²²⁻²⁴. Many monocular patients (33.6%) reported permanent changes in their lives²². A German study of 23 enucleated patients and a normal reference group of 507 controls²⁴ also reported that the NEI VFQ composite score was reduced in the monocular group. Although the authors indicated that individual scales were reduced they did not report the specific reductions or their statistical significance.

Earlier studies report the patient's eventual ability to adapt to monocular life but with varying degrees of difficulty and concern^{22, 23}, especially early on in the adaptive period⁶⁻¹³. The NEI VFQ composite scores in this study and the German study²⁴ provide evidence that patients who lose an eye perceive the presence of long-term functional costs even after they have made the initial adjustments noted by others^{22, 23}.

Driving—The questions comprising the NEI VFQ Driving subscale are: IF CURRENTLY DRIVING: How much difficulty do you have driving during the daytime in familiar places? How much difficulty do you have driving at night? How much difficulty do you have driving in difficult conditions, such as bad weather, during rush hour, on the freeway, or in city traffic.

Although the differences between the monocular patient and normal binocular groups only approached statistical significance, we feel it is important to discuss the topic of driving for two reasons. First, the loss of peripheral visual field has led to the suggestion that monocular individuals should have increased difficulties driving and might be less safe on the road. Second, the lack of difference between the two groups on the driving subscale was in part a consequence of scoring lack of driving as missing data. As noted, two of the 29 monocular patients (6.9%) were not driving. Studies of patients enucleated to treat ocular melanoma report similar percentages, 2 of 46 (4.3%)²⁹ and 7 of 56 (12.5%)³⁰, of patients that gave up driving because of subjective changes in their visual functioning following enucleation.

The safety of monocular drivers³⁵⁻³⁹ (and pilots⁴⁰⁻⁴³) has been well documented. However, monocular drivers retain concerns regarding their driving performance well after their initial adaptive period to monocular life; 39% of previous drivers felt their driving status was adversely affected by the loss of one eye²³. Specifically concern was expressed about night driving, judging distances, parking and backing up²³. An increased awareness expressed by these concerns may help explain the safe driving of those monocular patients who continue to drive.

Conclusion

Patients who have undergone surgical removal of one eye report that they have a HRQOL which is comparable to that of a group of normal binocular subjects of similar age. The absence of differences between monocular and normal binocular groups' general physical and mental health related scores suggests that despite the patients' loss of an eye, they have generally adapted well to their monocular blindness.

However, despite their general good quality of life and successful adaptation, these patients experience continued reductions in their vision specific quality of life. In addition to a generalized reduction in vision specific quality of life, they report specific problems with seeing objects in their peripheral visual fields and feel that they accomplish less or are limited in the length of their participation in work or other activities. There was some evidence that these difficulties led a higher number of them to cease driving.

These successful adaptations occur in the absence of formal education or rehabilitation programs. The possibility exists that adaptations to the effects of loss of an eye from trauma or disease would be more successful, faster, or less emotionally disturbing if these patients participated in a more formal rehabilitation program such as exists in some Veterans Administration facilities⁴³.

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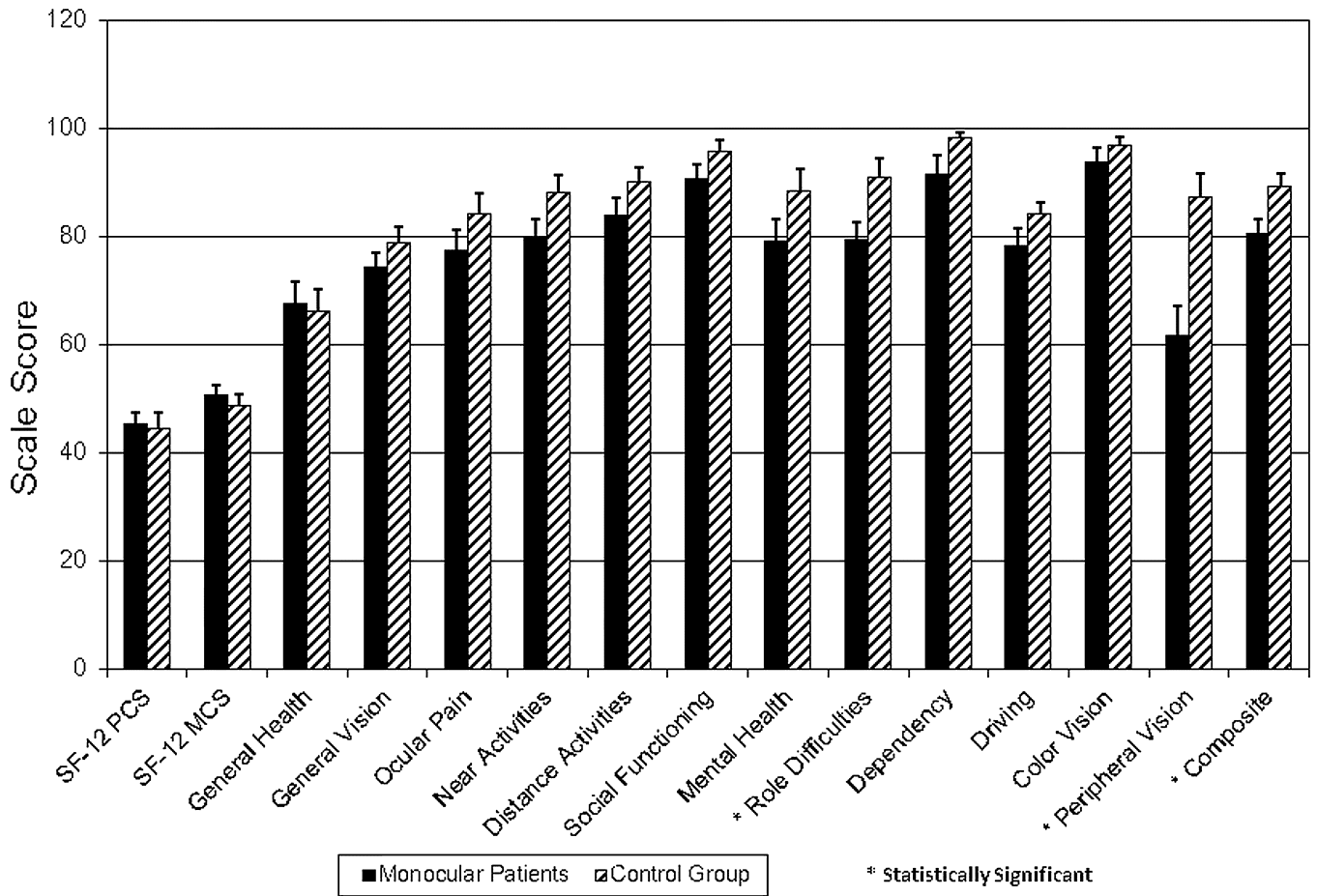


Figure 1. Comparison of SF-12 and NEI VFQ subscores for Monocular Patients and the Binocular Control Group. The means of the monocular and normal binocular control groups are presented for each subscale. The error bars represent the standard errors of the means. An asterisk marks a scale which showed a statistically significant difference between the two groups. Measures of general physical and mental health indicate that the monocular patients have a quality of life at least as good as the normal binocular subjects. However, their visual specific quality of life is reduced on every scale of the NEI VFQ, although not always at a statistically significant level. This universal reduction in vision specific quality of life is reflected in a statistically significantly reduced composite score.

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Table 1

Characteristics of One-Eyed Patients

Patient #	Age At Test	Age Vision Lost	Age at Surgery	Time since Surgery	Time Since Vision Loss	Sex	Education (Years)	Normal Eye	Visual Acuity
1	62	37	42	20	25	f	7	Right	20/20
2	66	53	53	13	13	m	13	Left	20/25
3	42	1	1	41	41	f	14	Right	20/20
4	43	19	19	24	24	f	12	Left	20/25
5	60	25	25	35	35	f	12	Right	20/25
6	20	2	2	18	18	m	12	Right	20/25
7	49	25	47	2	24	f	9	Right	20/25
8	74	73	73	1	1	m	18	Left	20/25
9	47	27	27	20	20	f	15	Right	20/20
10	51	3	3	48	48	f	12	Right	20/20
11	63	1	3	60	62	f	12	Left	20/30
12	56	53	53	3	3	f	12	Left	20/20
13	37	1	1	36	36	m	16	Left	20/20
14	41	1	1	41	41	m	13	Left	20/20
15	69	55	55	14	14	m	8	Left	20/20
16	58	54	57	0.5	4	f	12	Right	20/30
17	43	15	15	28	28	m	9	Left	20/20
18	40	1	1	39	39	f	14	Right	20/25
19	72	7	23	49	65	f	12	Left	20/20
20	56	51	51	5	5	f	12	Right	20/40
21	29	26	26	3	3	m	16	Left	20/20
22	53	8	8	45	45	m	9	Left	20/20
23	33	0	14	19	33	m	14	Right	20/20
24	77	6	31	46	71	m	3	Left	20/20
25	43	39	41	2	4	m	9	Left	20/20
26	63	22	24	39	41	m	16	Left	20/40
27	45	35	35	10	10	m	14	Right	20/20

Patient #	Age At Test	Age Vision Lost	Age at Surgery	Time since Surgery	Time Since Vision Loss	Sex	Education (Years)	Normal Eye	Visual Acuity
28	35	8	12	23	27	m	12	Left	20/20
29	51	19	51	0.5	33	m	12	Right	20/20
Mean±SD	50.98±14.17	23.00±21.20	27.38±21.28	23.62±18.01	28.03±19.33		12.03±3.10		

SD = standard deviation

Table 2

Summary of Subject Characteristics

	Monocular Subjects	Binocular Subjects	p
Age	50.98±14.17	49.46±13.80	NS
Sex			0.0201
Male	16	6	
Female	13	19	
Education (years)	12.03±3.10	12.36±2.04	NS
Marital Status			NS
Single	6	3	
Married	14	15	
Widowed	5	3	
Divorced	3	2	
Unanswered	1	2	
Visual Acuity (logMAR)	0.06±0.09 (20/23)	0.05±0.08 (20/22)	NS

Mean ± SD; SD = standard deviation. Values in parentheses are the Snellen equivalents of the mean LogMAR acuities.