What do patients with strabismus expect post surgery? The development and validation of a questionnaire

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ABSTRACT

Aims To develop and validate a short questionnaire to assess patients' expectations about outcomes post strabismus surgery.

Methods Questionnaire items were extracted from previous literature and reviewed by a multidisciplinary team. A cross-sectional study was then undertaken with 220 adult patients due to undergo strabismus surgery. Participants completed the 17-item questionnaire. Scale structure was explored using principal component analysis (PCA), and the subscales analysed in relation to demographic and clinical characteristics and psychosocial well-being in order to establish validity.

Results PCA revealed a 3-factor solution for the Expectations of Strabismus Surgery Questionnaire (ESSQ): (a) intimacy and appearance-related issues, (b) visual functioning, (c) social relationships. This 3-factor solution explained 59.30% of the overall variance in the ESSQ. Internal consistency, content and nomological and concurrent validity were considered acceptable.

Conclusions Patients with strabismus have high expectations about their postsurgical outcomes. This questionnaire provides a useful tool to assess the expectations patients have about their surgery, whether these expectations change over time and how they impact on postsurgical outcomes.

BACKGROUND

Strabismus affects approximately 4% of the population,[1] and is an ocular motility disorder presenting as misalignment of the eyes, commonly known as a squint. Strabismus surgery can successfully realign the eyes, eliminate double vision and improve quality of life up to 18 months post surgery.[2 3] However, not all patients are satisfied post surgery despite good clinical outcomes.[4]

Evidence, across a wide range of conditions, suggests that patients' expectations about their health, disease course and treatment can influence a range of clinical outcomes.[5] Within ophthalmology, the literature is scarce, but that which does exist suggests that preoperative expectations, specifically in cataract surgery, play an important role in how satisfied a patient is post surgery.[6] Providing additional information about what to expect after cataract surgery has also been found to improve satisfaction, give patients a better understanding about what is happening to them and reduce anxiety post surgery.[7]

Appearance concerns are one of the major reasons that patients with strabismus seek surgery,[8] but little is known about what patients expect post strabismus surgery. Adult patients approaching surgery experience poor quality of life and clinical levels of anxiety and depression, unrelated to clinical measures,[9] raising concerns that these patients may hold unrealistic expectations about the outcome of their surgery. By accurately understanding patient expectations, surgeons will be able to identify patients who may have unrealistic expectations and address these prior to surgery,[10] in order to improve postsurgical outcomes.[11]

In order to explore patient expectations and how these impact on postsurgical satisfaction, systematically developed and validated scales are required.[10] This study, therefore, aims to develop and validate the Expectations of Strabismus Surgery Questionnaire (ESSQ).

METHODS

Patients

Between November 2010 and April 2012, consecutive adult patients with strabismus (≥17 years old) listed for strabismus surgery at Moorfields Eye Hospital NHS Foundation Trust, London, were prospectively identified. Patients were consented into the study either on the day of being added to the waiting-list or at their preoperative assessment. The questionnaires were given to the patient after they had received verbal and standardised written information about the procedure by their consultant ophthalmologist. This information covered the aims of surgery, the surgical procedure, the risks of surgery, that is, allergies, redness, scarring, overcorrection and undercorrection and finally the aftercare required. The patient then chose to either complete the questionnaire in the waiting-room or to take it home with a freepost envelope for return.

Analytical strategy

Questionnaire development took place in three phases:

Item generation and selection

Items were identified via a systematic search of the literature,[12] and inspection of vision-specific and disease-specific quality of life questionnaires. These items were reviewed by the research team consisting of three consultant ophthalmic surgeons, two health psychologists, an orthoptist and a person with strabismus, in order to establish content validity and any potential areas of omission.

Reduction of the items and questionnaire structure

Participants completed each of the items generated within phase 1 of the study. The questionnaire

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asked participants 'using the five point scale below, please rate how you expect surgery to change the various aspects of your life'. Responses were on a 5-point Likert scale, for which, 1 was 'made considerably worse', 2 'made worse', 3 'remain the same', 4 'improve' and 5 'considerably improve'. In order to establish the structure of the questionnaire, patient responses were subjected to a principal component analysis (PCA) using IBM SPSS Statistics V.21. Prior to performing PCA, the suitability of the data for factor analysis was assessed by inspecting the correlation matrices and by calculating the Kaiser–Meyer–Olkin value and Bartlett's test of sphericity.[13] If the Kaiser–Meyer–Olkin value was 0.6 or above, Bartlett's test of sphericity reached statistical significance and there were few coefficients below 0.3 in the matrices, this supported the factorability of the items.

Eigenvalues, screeplot and parallel analysis were inspected to identify the number of factors within the questionnaire. Forced factor solutions were then conducted to attain the total variance explained by the proposed structures. To aid interpretation of these solutions, an oblimin rotation was performed to identify if there was a simple structure to the solutions.[14] The final step was to go back to the research team to assess whether the structure was theoretically meaningful and possessed good content validity.

Missing data

There was a total of 0.6% missing data across the dataset. Levels of missing data were analysed and judged to be missing completely at random (χ^2=1227.94, df=1293, p=0.90). Missing data was managed using multiple imputation methods in IBM SPSS V.21. Ten-scale level imputation iterations were used to eliminate bias. It has been suggested that between 3 and 10 imputations are sufficient, particularly for datasets with minimal missing data (Rubin, 1987). All analyses were performed on each of these 10 datasets and then pooled to give a final result.

Validity and reliability

Internal consistency was checked using Cronbach's alpha, with values above 0.7 considered acceptable.[15] Content validity was established via a review of the items and structure of the questionnaire by the research team and patient. Nomological validity and concurrent validity were established via exploration of the associations between the ESSQ and a series of demographic, clinical and psychosocial measures. Along with the items generated in phase 1, all participants completed the following self-report questionnaires.

The Derriford Appearance Scale

The Derriford Appearance Scale (DAS24)—a measure of appearance-related social anxiety and social avoidance—is widely used in research related to disfigurement.[16] Total scores range from 11 to 96 with lower scores representing lower levels of distress.

Perceived visibility

Participants were asked to rate how visible they felt their squint was to other people on a 7-point Likert scale from 1 (not at all visible) to 7 (extremely visible).

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) is a widely used, validated 14-item questionnaire measuring anxiety and depression in people with physical health problems.[17] Total scores range from 0 to 21, with higher scores indicating greater levels of anxiety or depression.

Table 1 Demographic and clinical characteristics of the sample

	n (%)
Age, mean (SD)	45.17 (17.35)
Female	118 (53.60)
White	178 (80.90)
Age of onset, mean (SD)	21.06 (23.99)
Comitance	
Concomitant	129 (58.60)
Incomitant	91 (41.40)
Classification	
Primary	31 (14.10)
Residual	37 (16.80)
Secondary	14 (6.40)
Secondary (iatrogenic)	12 (5.50)
Consecutive	38 (17.30)
Neurogenic	49 (22.30)
Mechanical	35 (15.90)
Other	4 (1.80)
Worse eye visual acuity—LogMAR conversion*, mean (SD)	0.43 (0.73)
Best eye visual acuity—LogMAR conversion*, mean (SD)	−0.06 (0.12)
Deviation in primary position (PD)	
Esotropia	63 (28.4)
Exotropia	80 (36.0)
Hypotropia	23 (10.4)
Hypertropia	40 (18.0)
Esophoria or exophoria	14 (6.3)
Size of deviation in primary position (PD), mean (SD)	34.19 (19.58)
Double vision	
No	96 (43.60)
Yes	124 (56.40)
Previous treatment history	
Strabismus surgery	112 (50.90)
Botulinum toxin therapy	94 (42.70)
Prism therapy	50 (22.70)

*Visual acuity. Visual acuity measured as Snellen's acuity, but converted into LogMAR scale for statistical analysis. LogMAR values ranged between −0.20 and 2.1. The score of 2.2 LogMAR being assigned to vision of counting fingers, hand movements, perception of light and non-perception of light.

The Adult Strabismus Quality of Life Questionnaire

The Adult Strabismus Quality of Life Questionnaire (AS-20) is a validated strabismus-specific quality of life instrument.[18] The scale consists of 20 items with four subscales: self-perception, interaction, reading and general quality of life.[19] Scores range from 0 to 100, with higher scores indicating better quality of life.

Age, ethnicity, disease duration, age of onset, previous ocular and treatment history at baseline were obtained from patients' clinical records. Examination included the assessment of the direction and size of deviation at near (1/3 m) and distance (6 m) using the alternate prism cover test and assessment of binocular functions. For multiplanar deviations, the largest angles, targeted for surgical correction, be that at near or distance, were recorded for analysis. Pearson's correlation coefficients were used to explore the relationship between the ESSQ and all other continuous variables, and either independent samples t tests or analysis of covariance (ANOVA) to explore differences between

Table 2 Responses and item loadings for the Expectations of Strabismus Surgery Questionnaire

	Mean (SD)	Made considerably worse n (%)	Made worsen (%)	Remain the same n (%)	Improve n (%)	Considerably improve n (%)	Factor loadings		
							F1	F2	F3
The appearance of my eyes	4.24 (0.79)	2 (0.91)	1 (0.46)	33 (15.07)	90 (41.10)	93 (42.47)	0.80		
My double vision*	3.90 (0.90)	1 (0.48)	2 (0.97)	81 (39.13)	53 (25.60)	70 (33.82)		0.80	
My vision	3.84 (0.90)	2 (0.91)	2 (0.97)	90 (41.10)	59 (26.94)	66 (30.14)		0.82	
How embarrassed I feel when people look at me	3.94 (0.82)	1 (0.46)	0 (0.00)	75 (34.25)	78 (35.62)	65 (29.68)	0.87		
My confidence	4.05 (0.76)	1 (0.46)	0 (0.00)	52 (23.74)	101 (46.12)	65 (29.68)	0.77		
The appearance of my face	3.90 (0.81)	2 (0.91)	0 (0.00)	71 (32.27)	91 (41.36)	56 (25.45)	0.83		
The position of my head	3.77 (0.82)	1 (0.46)	1 (0.46)	94 (43.32)	72 (33.18)	49 (22.58)		0.57	
My ability to read	3.68 (0.80)	1 (0.46)	0 (0.00)	110 (50.23)	66 (30.14)	42 (19.18)		0.78	
My depth perception	3.61 (0.76)	1 (0.46)	0 (0.00)	115 (53.00)	68 (31.34)	33 (15.21)		0.67	
My ability to concentrate	3.59 (0.73)	1 (0.46)	1 (0.46)	110 (50.46)	78 (35.78)	28 (12.84)		0.73	
My headaches/eye pain	3.55 (0.75)	2 (0.91)	0 (0.00)	117 (53.92)	71 (32.72)	27 (12.44)		0.56	
My ability to form intimate relationships	3.40 (0.67)	1 (0.46)	0 (0.00)	148 (67.89)	48 (22.02)	21 (9.63)	0.56		
My ability to meet new friends	3.39 (0.62)	1 (0.46)	0 (0.00)	143 (65.90)	59 (27.19)	14 (6.45)			−0.48
My ability to obtain/keep a job	3.25 (0.56)	1 (0.46)	0 (0.00)	162 (77.88)	34 (16.35)	11 (5.29)			−0.65
My relationship with my doctor/ophthalmologist	3.21 (0.52)	1 (0.46)	0 (0.00)	175 (81.02)	31 (14.35)	9 (4.17)			−0.40
My relationship with my friends	3.16 (0.45)	1 (0.46)	0 (0.00)	183 (84.33)	29 (13.36)	4 (1.84)			−0.87
My relationship with my family	3.08 (0.33)	1 (0.46)	0 (0.00)	197 (90.78)	18 (8.29)	1 (0.46)			−0.83
Eigenvalue							5.04	3.57	1.47
Variance explained in %							29.67	21.02	8.62

*For those with clinical diplopia, n=0, 1, 8, 34, 60, respectively.

groups on the ESSQ subscales. Using Šidák correction for multiple comparisons, a significance level of $p<0.002$ was set.

RESULTS

Sample characteristics

Of the 286 (93.77%) who consented to take part in the study, 220 (76.92%) completed questionnaires were returned. Table 1 details the demographic and clinical characteristics of the sample.

Item generation and selection

Sixteen items were generated from the systematic search of the literature[9] and relevant quality of life questionnaires. Inspection of the items by our patient representative and research team led to the inclusion of an additional item relating to the ability of people to obtain or maintain their job role.

Reduction of the items and questionnaire structure

On inspection of the individual items, the data indicated that 42.47% of the sample expected a considerable improvement in the appearance of their eyes as a result of surgery, and 33.82% a considerable improvement in their double vision. Less than 2% of the sample expected worsening of their current state (table 2).

The items were subjected to a PCA on confirmation that the data were suitable for factor analysis. PCA revealed the presence of four components with eigenvalues above 1. Inspection of the screeplots indicated significant breaks after the fifth component for the ESSQ. Results from the parallel analysis, however, showed only three components with eigenvalues exceeding the corresponding criterion values for a randomly generated data matrix of the same size (17 variables×220 participants). Therefore, a forced 3, 4 and 5-factor solution was undertaken. The data presented here are the results of the 3-factor solution as this was assessed as being both statistically and theoretically superior to the 4 and 5-factor solutions.

The forced 3-factor solution explained a total of 59.30% of the overall variance in the ESSQ (table 2). All components showed a number of strong loadings, and most variables loaded substantially onto one component. The three components represented (a) intimacy and appearance-related issues, (b) visual functioning and (c) social relationships. The communalities were >0.3, which suggested that all items fitted well within their corresponding factor.

Domain scores were then created by calculating a mean of the items within that subscale (table 3). The questionnaire and scoring instructions can be found as online supplementary materials.

Validity and reliability

Internal reliability of all subscales was acceptable with Cronbach's alpha ranging from 0.76 to 0.89. All other measures were also checked for internal reliability, and were deemed acceptability, with Cronbach's alpha ranging from 0.82 for the HADS depression subscale to 0.95 for the AS-20 psychosocial subscale.

The statistically significant ($p<0.05$) Pearson correlation coefficients between the ESSQ subscales and demographic, clinical and psychosocial factors were between 0.15 and 0.57 (table 4). Independent sample t tests, for the two-group comparisons, and ANOVAs, for analysis comparing more than two groups,

Table 3 Summary data for the Expectations of Strabismus Surgery Questionnaire subscales

	Possible range	Actual range	M (SD)	No. of items
Intimacy and appearance-related issues	1–5	1–5	3.92 (0.64)	5
Visual functioning	1–5	2–5	3.69 (0.60)	7
Social relationships	1–5	1–5	3.22 (0.38)	5

M, mean.

revealed a number of statistically significant between-group differences (table 5).

DISCUSSION

This study aimed to develop a questionnaire, using classical test theory, to measure patients' expectations of their poststrabismus surgery outcomes. Item selection was undertaken using a variety of methods, including data from a published literature review,[12] a review of validated vision and strabismus-specific quality of life questionnaires and from a variety of contributors across different disciplines. The exploratory PCA presented three distinct domains, in which, convergent validity and reliability were evident by the high loadings within each factor, relatively high Cronbach's alpha and simple structures. These three domains represented: (a) intimacy and appearance-related issues, (b) visual functioning and (c) social relationships, reflecting the domains found within a number of strabismus-specific quality of life questionnaires.[18 20]

The individual items of the ESSQ indicated that patients expected surgery to lead to considerable improvements,

Table 4 Correlations between Expectations of Strabismus Surgery Questionnaire subscales and demographic, clinical and psychosocial outcomes

	Intimacy and appearance-related issues	Visual functioning	Social functioning
Age (years)	−0.15	0.32*	−0.05
Disease duration (years)	0.17	−0.25*	−0.05
Age of onset (years)	−0.25*	0.43*	0.003
No. of previous surgeries	0.12	−0.19	0.05
Size of deviation in primary position (PD)	0.21	−0.27*	−0.02
Worse eye visual acuity —LogMAR	0.04	−0.45*	−0.15
Best eye visual acuity—LogMAR	−0.08	−0.12	−0.05
Perceived visibility	0.55*	−0.24*	0.22*
Anxiety	0.16	0.03	0.24*
Depression	0.04	0.29*	0.29*
DAS24	0.36*	−0.07	0.36*
AS-20 self-perception	−0.59*	0.22	−0.32*
AS-20 interaction	−0.49*	0.14	−0.41*
AS-20 reading	0.09	−0.51*	−0.28*
AS-20 general	−0.12	−0.31*	−0.28*

*<0.002.
AS-20, Adult Strabismus Quality of Life Questionnaire; DAS24, Derriford Appearance Scale.

Table 5 Differences between categorical participant characteristics on Expectations of Strabismus Surgery Questionnaire subscales

	Intimacy and appearance-related issues	Visual functioning	Social functioning
Gender			
Male	3.75 (0.64)*	3.72 (0.59)	3.22 (0.41)
Female	4.05 (0.56)	3.69 (0.58)	3.21 (0.29)
Comitance			
Concomitant	4.02 (0.64)	3.48 (0.57)*	3.22 (0.39)
Incomitant	3.76 (0.55)	4.03 (0.44)	3.20 (0.29)
Previous surgery			
No	3.81 (0.67)	3.78 (0.61)	3.18 (0.40)
Yes	4.01 (0.55)	3.63 (0.55)	3.24 (0.30)
Previous prisms			
No	3.98 (0.62)	3.59 (0.57)*	3.22 (0.36)
Yes	3.67 (0.56)	4.07 (0.47)	3.18 (0.31)
Previous Botox			
No	3.82 (0.64)	3.79 (0.61)	3.19 (0.38)
Yes	4.03 (0.57)	3.59 (0.53)	3.24 (0.31)
Diplopia			
No	4.10 (0.62)*	3.39 (0.53)*	3.21 (0.36)
Yes	3.71 (0.55)	4.03 (0.45)	3.21 (0.34)
Occlusion			
No	3.78 (0.63)*	3.83 (0.59)*	3.18 (0.36)
Yes	4.22 (0.46)	3.39 (0.46)	3.29 (0.33)
Deviation in primary position			
Esotropia	3.97 (0.60)	3.69 (0.58)	3.24 (0.32)
Exotropia	4.06 (0.66)	3.43 (0.55)	3.24 (0.44)
Hypotropia	3.71 (0.50)	4.05 (0.56)	3.15 (0.28)
Hypertropia	3.67 (0.54)	3.95 (0.44)	3.12 (0.20)
Esophoria or Exophoria	3.80 (0.59)	4.06 (0.45)	3.23 (0.33)

*<0.002.

primarily in relation to the appearance of their eyes as well as vision and more specifically double vision. Less than 2% of the sample expected worsening of their current status. Research, however, does suggest that only 24% of patients with strabismus are successfully realigned post surgery according to clinical criteria;[21] while 38% are classified as partial successes or failures.[22] This might be because the patient requires prism therapy or a patch that was not necessary prior to surgery. They still have a large deviation, or are experiencing double vision, visual confusion or other related visual symptoms that may have developed after surgery.[22] Of the 124 participants with diplopia prior to surgery in this study, 1% expected their double vision to worsen, 7% expected their diplopia to remain the same and all others expected their double vision to improve. Research does, however, suggest that double vision can remain in approximately two-thirds of patients up to 6 months post surgery, with almost one-fifth of patients with horizontal residual deviations still finding diplopia problematic in daily life.[23] This highlights a possible discrepancy between what the patients expect in relation to their double vision prior to surgery and what may actually happen. This potential discrepancy could contribute towards poor quality of life or poor satisfaction post surgery,[6] and is particularly pertinent considering that patients appear to be more successfully aligned according to clinical criteria as opposed to quality of life outcomes.[4 24]

Intimacy and appearance-related concerns was the domain in which both men and women expected the most significant

improvements post surgery. Women did, however, report higher expectations that surgery would improve intimacy and appearance-related issues than men, as did those who were younger at age of onset. This included expectations about increased confidence and a reduction in feelings of embarrassment as a result of the way they looked, along with the ability to engage in intimate relationships. These expectations are not unsupported since surgery has been found to improve self-esteem and interpersonal relationships, and more so in women than men.[25] In contrast, the current study also found that older participants with late-onset strabismus and shorter disease duration expected significant improvements with regard to double vision and the ability to read and concentrate. This compliments research suggesting that women and younger people with a visible difference express greater levels of distress than men and older adults with a visible difference.[26]

Across all three domains, higher levels of anxiety and depression were associated with greater expectations about postsurgical outcomes. Similarly, poorer quality of life was associated with significantly higher expectations, particularly in relation to intimacy and appearance-related issues and social functioning. Although the direction of causality is unknown due to the cross-sectional nature of the data collection, this suggests that patients experiencing poorer psychological well-being prior to treatment place a high value on having surgery, and view it as an important route to improving their lives. Not meeting these high expectations may then contribute to poorer satisfaction post surgery.[6] Therefore, identifying mechanisms by which unrealistic expectations may be altered could be vital. This could be achieved by improving psychological well-being presurgery, although at present, this hypothesis is purely speculative and would require further exploration, or by targeting unrealistic expectations directly, through the use, for example, of patient decision-making aids.[11]

There are potential weaknesses to this study. The initial stage of item generation was undertaken using published literature rather than using qualitative semistructured interviews with patients. These methods may have elicited more specific and patient-centred expectations. The items were, however, reviewed by a patient with strabismus as was the structure of the questionnaire, and the strabismus-specific quality of life questionnaires from which items were generated were developed from qualitative interviews with patients.

This study has led to the development of a questionnaire that provides a structured approach to assessing patients' expectations about the psychological, appearance-related, functional and social improvements they anticipate post surgery. Further longitudinal work is required in order to assess whether these expectations change over time, and how they impact on psychosocial well-being post strabismus surgery. This then will provide a basis on which to support patients during this important decision-making process.

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