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Title: Factors associated with Quality of Life and Mood in Adults with Strabismus

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ABSTRACT

Background/Aims

To explore the factors associated with the mood and quality of life (QoL) of patients with strabismus due to undergo realignment surgery.

Methods

A cross-sectional study was undertaken with adult patients. Along with demographic, clinical and psychosocial process variables the Hospital Anxiety and Depression Scale and AS-20 QoL measures were administered. Regression models were used to identify the factors associated with QoL and mood.

Results

Of the 220 participants, 11% were experiencing clinical levels of depression and 24% clinical anxiety. This is in line with other forms of facial disfigurement but higher than other chronic diseases. Although mood and QoL were associated with age and diplopia it was beliefs and cognitions which were more consistently associated with well-being. This included feelings of social anxiety and avoidance, a belief that strabismus has negative consequences, poor understanding of strabismus, social support, fear of negative evaluation and the perceived visibility of their condition.

Conclusions

Psychosocial rather than clinical characteristics were identified as determinants of well-being in this population. It is important for clinicians planning surgery to be aware of these factors which could influence outcomes. Longitudinal studies need to

be conducted to explore the direction of causality before interventions to improve well-being are developed and evaluated.

INTRODUCTION

The face is the most prominent physical feature, and the eyes play an important role in perceived attractiveness and communication. Therefore, it is not surprising that along with the functional impact of strabismus, patients can experience significant psychological distress.

Adjustment to disfiguring conditions such as strabismus is thought to result from a complex interaction of physical, psychological and social factors, with some patients even expressing a willingness to trade in part of their life expectancy in return for being rid of strabismus and its associated effects.¹ There is however inconsistency regarding the impact of clinical variables. Some adults with large-angle misalignment report few psychosocial concerns, whilst others with 'minor' deviations experience significant problems.² The impact of the direction of deviation also remains unclear, with some studies suggesting no relationship between direction of deviation and QoL³, whilst others report that esotropic individuals rate themselves as coping better than exotropic patients.⁴ Whilst the presence of diplopia can lead to concerns about difficulties such as driving and walking² leading to poorer functional QoL,⁵ patients without diplopia predominantly report concerns about physical appearance, social relationships, difficulties in communication and eye contact² and experience poorer psychosocial QoL.⁵ These findings suggest that objective measures of ocular deviation in strabismus are not strong predictors of psychological well-being.

Clearly measuring QoL and mood, both in research and clinical practice, is important. However, without identifying the factors associated with psychological distress, the mechanisms through which these outcomes might be improved cannot be established. Research in other conditions including those that can alter appearance have found that the beliefs a patient has about their condition and its treatment, social interactions and support, along with how they view their appearance, all play an important role.^{6,7} While some of these factors may contribute to poor psychological well-being, others will act as 'buffers' against the stresses of living with strabismus. It is therefore vital that these factors are identified to enable the development of psychological provisions for those in need.

This study therefore aims to establish the psychosocial profile of patients with strabismus who are about to undergo realignment surgery, by identifying the factors associated with QoL and mood.

METHODS

Participants

Between November 2010 and April 2012 consecutive adult strabismus patients (≥ 17 years old) listed for strabismus surgery at Moorfields Eye Hospital, London were prospectively identified. Patients were consented into the study either on the day of being added to the waiting list or at their pre-operative assessment. All questionnaires were completed prior to surgery. Approval was obtained from the

North London Research Ethics Committee for the study.

Patients were excluded if they had significant co-morbidities (i.e. predominant treatment was for another illness), other facial or ocular abnormalities, identifiable psychosis, dementia, or other cognitive impairment, as identified in the patient records.

The data analysed in this article is part of a longitudinal study following patients post realignment surgery. The sample size was therefore initially powered to look at differences overtime in QoL. However, in order to perform the hierarchical regression analysis with the predictor variables outlined in Figure 1, with an effect size of 0.15 and $\alpha=0.05$, GPower 3.1.6 indicates a sample size of 217.

Measures

Demographics

Data were collected on age, gender and ethnicity.

Clinical Measures

All participants underwent a full orthoptic assessment at their pre-operative visit.

This included previous ocular history, direction and size of deviation, and the presence of diplopia. Deviation was assessed by cover test and the angle measured with alternate prism cover test. The angle used for analysis was the largest of near

and distance angle. Diplopia was assessed during motility testing and was classified according to being present (in any position) or not.

Psychosocial Measures

Participants completed a series of psychosocial measures. The choice of measures was based on the framework of adjustment to strabismus developed by the research team (Figure 1) an adaption of the model outlined by the Appearance Research Collaboration.⁸ Where possible existing validated measures were used.

Predisposing factors	Intervening psychosocial processes			Primary Outcomes
Demographic & clinical variables	Beliefs & cognitions	Appearance specific beliefs & cognitions	Social support	Psychosocial well-being
(BLOCK 1)	(BLOCK 2)	(BLOCK 3)	(BLOCK 4)	(DV)
Gender Age Ethnicity Affected eye Classification Disease history (incl. duration) Treatment history Visual acuity Experience of double vision Direction & size of deviation	Illness perceptions Treatment perceptions Fear of negative evaluation	Social anxiety & avoidance Concern about appearance Perceived visibility Salience Valence	Family Friends Significant others	Anxiety Depression QoL

DV – dependent variables

Figure 1. Framework outlining the process of psychological adjustment to strabismus

Beliefs and cognitions

Revised Illness Perception Questionnaire (IPQ-R)⁹: The IPQ-R is a widely used, validated measure of patient beliefs about their condition and was adapted for strabismus by the authors. The timeline, consequences, personal control and coherence subscales were included. High scores on the timeline and consequences subscales indicate strongly held beliefs about the chronicity and the negative consequences of strabismus. High scores on the coherence and personal control subscales represent a personal understanding of strabismus and positive beliefs about its controllability.

Treatment Representations Inventory (TRI)¹⁰: The 27-item TRI assesses patients' treatment cognitions relating to four subscales; treatment value, treatment concerns, decision satisfaction and cure. All items were adapted to ask about realignment surgery. High scores on the treatment value and cure subscales indicate positive beliefs about the value and curative effect of treatment. High scores on the decision satisfaction subscale indicate greater satisfaction with treatment, and high scores on the treatment concerns subscale indicate more concerns regarding treatment.

Fear of Negative Evaluation (FNE) scale¹¹: This validated 12-item FNE scale measures the extent to which an individual is concerned by the opinions of others. Higher scores indicate greater fear.

Appearance-Related Processing

Social anxiety & avoidance: The Derriford Appearance Scale (DAS24)¹² is a 24-item scale measuring the impact of appearance-related distress on social anxiety and social avoidance. Higher scores represent greater distress. The scale also includes an

introductory question asking participants to report if they are concerned about any aspect of their appearance, yes or no. This information was extracted and analysed as an additional variable, labelled 'concern about appearance'.

Perceived Visibility of Strabismus : Patients were asked to rate the visibility of their strabismus, using a seven-point Likert scale ranging from 1 (not at all visible) to 7 (extremely visible).

Salience of Appearance scale (CARSAL)¹³: The CARSAL is a 7-item questionnaire measuring the extent to which physical appearance is important to a person. Higher total scores indicate greater importance.

Valence of Appearance scale (CARVAL)¹³: The CARVAL is a 6-item questionnaire that measures how a patient evaluates their own physical appearance. Higher total scores indicate a more negative self-evaluation.

Social Support

Multidimensional Scale of Perceived Social Support (MSPSS)¹⁴: The MSPSS is a 12-item, validated measure of subjective levels of social support from family, friends and significant others. Higher scores indicate greater levels of social support.

Primary outcome measures

Hospital Anxiety & Depression Scale (HADS)¹⁵

The HADS is a widely used, validated 14-item questionnaire measuring anxiety and depression in patients with physical health problems. Higher scores indicate greater levels of anxiety or depression. For each subscale, scores of 0-7 are in the 'normal' range; scores of 8-10 suggest moderate levels of anxiety or depression; and scores of

≥11 are highly indicative of clinical anxiety or depression, meaning that if the individual was examined by a mental health professional, it is highly likely that they would be diagnosed with an identifiable psychiatric disorder.¹⁶

*Adult Strabismus Quality of Life Questionnaire (AS-20)*¹⁷

The AS-20 is a validated, strabismus-specific QoL instrument. The measure has a composite scale and two subscales; functional and psychosocial QoL, with higher scores indicating better QoL. The normal threshold score has been set at 84 for overall, 93 for psychosocial and 70 for functional QoL.¹⁸

Data Analysis

Levels and patterns of missing data were analysed using Little's Missing Completely at Random (MCAR) test. If data were MCAR one multiple imputed dataset rather than using pooled analysis is feasible.¹⁹ Constraints and rounding were used to ensure that the imputed scale level data was meaningful.

A series of hierarchical multiple regression was conducted to identify the unique predictors for mood and QoL ($p < 0.05$). The variables were added into the hierarchical regression based on the framework outlined in Figure 1. Prior to this analysis the independent variables were examined for multicollinearity, linearity and homoscedasticity. Statistical significance was set at.

RESULTS

Participants

Two hundred and twenty (76.92%) of the 286 participants who consented to take part in the study returned completed questionnaires.

Missing data

Of the 7770 data points 0.9% was missing, with complete data for 185(83.3%) participants. No participant had >50% missing data. Analysis was conducted on 1 imputed dataset as MCAR was non-significant ($\chi^2=339.467;df=398;p=0.985$).

Descriptive statistics

Of the 220 completed questionnaires, there was an almost even distribution of males and females, the majority were white and between the ages of 17 and 88 years. A majority of participants had concomitant strabismus and for most the eyes deviated outwards. All other clinical and psychosocial outcomes are detailed in Table 1.

Table 1. Descriptive statistics for clinical, demographic and primary outcome measures

		n(%)	Range	M(S.D)
Age (years)			17-88	45.17(17.35)
Gender	Male	102(46.40)		
	Female	118(53.60)		
Ethnicity	White	178(80.90)		
	Black African/Caribbean	12(5.50)		
	South Asian	15(6.80)		
	Other	15(6.80)		
Comitance	Concomitant	129(58.60)		
	Incomitant	91(41.40)		

Classification§	Primary Residual Secondary Secondary (Iatrogenic) Consecutive Neurogenic Mechanical Other	31(14.10) 37(16.80) 14(6.40) 12(5.50) 38(17.30) 49(22.30) 35(15.90) 4(1.80)		
Disease duration (years)			0-88	24.35(19.904)
Age of onset (years)			0-76	21.06(23.99)
Previous surgery	No Yes	108(49.10) 112(50.90)		
Total no of previous strabismus surgeries			1-6	0.96(1.26)
Previous Botulinum toxin type A therapy	No Yes	126(57.30) 94(42.70)		
Prism therapy for diplopia	No Yes	170(77.30) 50(22.70)		
Worse eye visual acuity - LogMAR Conversion†			-0.2–2.2	0.43(0.73)
Best eye visual acuity - LogMAR Conversion†			-0.2–2.2	-0.06(0.12)
Deviation in primary position	Esotropia Exotropia Hypotropia Hypertropia Esophoria & Exophoria	63(28.4) 80(36.0) 23(10.4) 40(18.0) 14(6.3)		
Deviation in primary position				34.19(19.58)
Diplopia	None in any position Diplopia in any position	96(43.60) 124(56.40)		
Anxiety	Normal Moderate Caseness	121(55.00) 47(21.40) 52(23.60)	0-18	7.20(4.40)
Depression	Normal Moderate Caseness	171(77.70) 26(12.80) 23(10.50)	0- 19	4.84(4.11)
AS20 Function	Below normal threshold Above normal threshold	149(67.70) 71(32.30)	0-100	54.99(23.37)
AS20 Psychosocial	Below normal threshold Above normal threshold	183(83.20) 37(16.80)	5-100	56.32(28.48)

§Secondary refers to a squint occurring following the loss or impairment of vision. Secondary (iatrogenic) refers to squint occurring secondary to sight saving surgery e.g. retinal detachment surgery; †Visual acuity. Visual acuity measured as Snellens 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

Disease duration and age of onset varied quite considerably, from those who were born with the condition to many who had developed strabismus more recently. Approximately half had undergone previous realignment surgery and many had also received Botulinum Toxin A and prism therapy. Realignment surgery was being performed for cosmetic reasons in 44% of cases.

Mean scores for participants on the AS-20 subscales were below the normal threshold score, indicating that they have a poorer quality of life and large standard deviations indicate wide variability. Using normative scores over 67 and 83% of the population score below normal on functional and psychosocial QoL respectively. The proportion of patients with clinical anxiety in this sample was 23.87% and clinical depression 10.36%. Sixteen (7.2%) participants experienced both clinical anxiety and depression.

Predictors of Mood and Quality of Life

A series of multiple hierarchical linear regressions were conducted in order to establish the variables significantly associated with anxiety, depression and QoL. Variables were entered into the regression using the blocks outlined in Figure 1.

Anxiety

After entry of all variables the final model explained 40% of the variance in anxiety (Adjusted $R^2=0.40$, $F_{(40,178)}=4.53$, $p<0.0001$). Beta coefficients indicated that IPQ coherence, TRI Treatment concerns, FNE, DAS24 and social support from friends and family all made significant contributions to the final model. More anxiety was

associated with a poorer understanding of strabismus, more concerns about treatment, greater fear of negative evaluation, greater social anxiety and social avoidance, less support from friends but more support from family.

Depression

After entry off all variables the final model explained 52% of the total variance in depression (Adjusted $R^2=0.52$, $F_{(40,178)}=7.01$, $p<0.001$). Age, IPQ coherence, DAS24 and social support from both family and friends all made a significant contribution to the level of depression experienced by participants. Greater levels of depression were associated with being older, having a poorer understanding of strabismus, greater social anxiety and social avoidance, less support from friends but more support from family.

Functional Quality of Life

The final model for functional QoL explained 48% of the variance (Adjusted $R^2=0.48$, $F_{(40,178)}=6.36$, $p<0.001$). Disease classification, the presence of diplopia, IPQ consequence, FNE and DAS24 all made a significant contribution. Suggesting that poorer functional QoL is associated with mechanical strabismus (as compared to residual and consecutive strabismus), having diplopia, believing that strabismus has negative consequences, greater fear of negative evaluation and greater social anxiety and social avoidance.

Psychosocial Quality of Life

The final model for psychosocial QoL explained 79% of the variance (Adjusted $R^2=0.79$, $F_{(40,178)}= 22.39$, $p<0.001$). IPQ consequence, visibility, DAS24 and salience all made a significant contribution as indicated by the standardized β coefficients. Indicating that poorer psychosocial QoL is associated with a belief that strabismus has negative consequences, a more visible squint (as perceived by the patient), greater social anxiety and social avoidance and placing a high value on appearance.

Table 2 provides an overall summary of the predictors of psychosocial well-being in this population.

Table 2. Summary of results from the hierarchical linear regressions

	Anxiety $\beta(p)$	Depression $\beta(p)$	Functional QoL $\beta(p)$	Psychosocial QoL $\beta(p)$
Age	-	0.25(<0.01)	-	-
Classification	-	-	0.19(<0.04)*	-
Diplopia	-	-	-0.24(<0.01)	-
IPQ Coherence	-0.14(0.02)	-0.15(0.01)	-	-
IPQ consequences	-	-	-0.34(<0.01)	-0.15(0.01)
TRI Treatment Concerns	0.23(<0.01)	-	-	-
FNE	0.25(<0.01)	-	-0.17(0.02)	-
Visibility	-	-	-	-0.40(<0.01)
DAS24	0.24(0.01)	0.44(<0.01)	-0.28(<0.01)	-0.31(<0.01)
CARSAL	-	-	-	-0.11(0.02)
Social Support Family	0.26(<0.01)	0.18(0.02)	-	-
Social Support Friends	-0.25(<0.01)	-0.27(<0.01)	-	-

*standard β coefficients for group with the lowest value

DISCUSSION

This study aimed to assess the QoL and mood of patients with strabismus due to undergo realignment surgery and identify the factors associated with poor psychosocial well-being. In this sample the proportion of patients living with clinical

anxiety or depression was approximately 10 times greater than that of the general population.²⁰ These figures reflect the experience of people living with a facial disfigurement²¹ and more general ophthalmic conditions⁷ but are higher than those with chronic conditions such as rheumatoid arthritis²² and diabetes.²³ The considerable number of patients approaching surgery with a potentially diagnosable psychiatric condition is of concern.

In comparison to other research, participants in this study report levels of QoL which are akin to the population.²⁴ However, contrary to the expectations of many healthcare providers these findings suggest that clinical variables alone fail to explain the majority of variance in QoL and mood.

This analysis suggests that beliefs, cognitions and social support are more consistent predictors of mood and QoL. Beliefs about illness and treatment are constructed by patients so that they are able to make sense of their condition and associated symptoms. Patients, who feel strabismus has major and serious consequences on their life, are concerned about the possible physical and psychological side effects of having surgery and **have a poor understanding of their condition as a whole and find the symptoms puzzling,** experience poorer QoL and mood. Similar findings are reported for other disfiguring conditions.^{25;26} The anticipation of receiving an offensive reaction is not unfounded given that negative attitudes towards people with strabismus appear to emerge in early childhood. These prejudices can have a negative effect on socialisation²⁷ and in the long-term employability.²⁸ It is therefore

unsurprising that patients experience social anxiety and use techniques to hide their strabismus and avoid social situations.

The importance of perceived visibility in QoL suggests that clinical measures of misalignment may not best represent how patients see themselves or how they feel others see them. Social support also appeared to play an important role in both QoL and mood, however, not always in the expected direction. Whilst support from friends was perceived as positive and resulted in improved QoL and mood, support from family had the reverse effect. Higher levels of support from family members were associated with greater anxiety and depression. Social support has been shown to act as a buffer to the consequence of stressful life events. In the case of strabismus this appears to be provided by friends, who may offer the necessary resources for successful adjustment.

The present study has some limitations. Although this study was cross-sectional and therefore it is not possible to draw conclusions about the direction of causality, a small follow-up study has suggested continual improvements in psychological adjustment up to 1 year post realignment surgery.²⁹ The participants within the current study are now being followed post-surgery in to understand these relationships further in a much larger sample.

This study presents unique insight into the experience of a large number of patients with strabismus due to undergo realignment surgery. Patients report significant deficits in QoL and the proportion living with clinical anxiety or depression is

considerably higher than the general population and those with a long-term condition. Describing the QoL and mood of the population in isolation however does little to explain the mechanisms through which these outcomes may be improved. By exploring the factors associated with mood and QoL this study goes beyond that of previous research; suggesting that rather than clinical and demographic characteristics socio-cognitive factors are better predictors. The considerable number of patients approaching surgery with a potentially diagnosable psychiatric condition is of concern and therefore by following these patients post-surgery it will be possible to identify if it is these patients who experience poorer psychological outcomes after realignment. As the factors identified as important are potentially amenable to change, interventions to alter cognitions and beliefs such as cognitive behavioural therapy may be an appropriate method through which psychological well-being can be improved. The longitudinal analysis will shed further light on these relationships and provide a more robust understanding of what cognitions and beliefs should be targeted in order to improve the outcome for patients after realignment surgery.

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COMPETING INTERESTS

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