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Appearance concerns in ophthalmic patients. *Eye*, 25(8), 1039-1044.

**Title:** Appearance concerns in ophthalmic patients

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**Short running title:** Appearance concerns in ophthalmic patients.

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27    **Abstract**

28    **Aims:** This study aimed to determine the psychosocial and appearance related  
29    concerns of a sample of ophthalmic patients by measuring a range of  
30    psychological, social and demographic factors.

31    **Methods:** Standardised psychological measures including anxiety, depression,  
32    appearance related distress, self discrepancy, appearance salience and valence  
33    were administered to 98 participants attending ophthalmic outpatient clinics in  
34    either London, Bristol, Sheffield or Bradford. Differences between groups were  
35    explored using t-tests and ANOVA, relationships between all variables were  
36    investigated using Pearson correlation coefficient.

37    **Results:** Although mean scores for psychological adjustment were within the  
38    normal range, some participants were experiencing considerable levels of  
39    generalized anxiety. Being older, male and being married or living with a partner  
40    was related to significantly better adjustment. Better adjustment was also related  
41    to a less visible area of concern, greater disguisability of the affected area, a  
42    more positive evaluation of their own appearance, less engagement in  
43    comparing themselves to others, greater feelings of being accepted by others,  
44    appearance being less important to their self concept and a smaller discrepancy  
45    between the persons ideal and actual appearance.

46    **Conclusions:** A majority of ophthalmic patients adjust positively to the demands  
47    placed upon them. By identifying the variables which are associated with  
48    successful adaptation, the specific psychological interventions and appropriate  
49    systems of support can be put in place to help those who are adversely affected.

50    **Key words:** disfigurement, psychological distress, outpatients, eye

## 51 **Introduction**

52 Patients with a wide variety of ophthalmic conditions often report concerns  
53 about the appearance of their eyes as well as issues relating to functional  
54 deficits<sup>1</sup>. The psychosocial impact of disfiguring eye conditions has been well  
55 documented, with 10-45% of outpatients experiencing clinical anxiety,  
56 between 3 and 18% clinical depression and between 45 and 46% raised  
57 levels of appearance related distress and social avoidance<sup>1</sup>. Approximately  
58 80% of patients with strabismus have been found to attribute problems in their  
59 personal life to their squint, with all patients adversely affected by the  
60 'cosmetic blemish of squint' and reporting problems making and maintaining  
61 friends<sup>2</sup>. Avoidance, concealment and behaviours indicating self  
62 consciousness such as reduced eye contact, eye rubbing, abnormal head  
63 posture, dark glasses, staying at home and avoiding situations which bring  
64 attention to their eye have also been described.

65

66

67 Nevertheless, there is significant variability in the ability of patients to cope with  
68 the challenges of a disfiguring eye condition and researchers have begun the  
69 task of identifying predictors of psychosocial adjustment. Contrary to the  
70 expectations of the lay public and many health care providers, important  
71 findings from research, clinical practice and personal accounts suggest that the  
72 extent, type and severity of a disfigurement are not consistently strong  
73 predictors of adjustment, although the visibility of the condition may exacerbate  
74 distress<sup>4</sup>. There is a consensus amongst researchers and practitioners that

individual adjustment is affected by a complex interplay of physical, socio-cultural and psychosocial factors<sup>4 5 6 7</sup> in which some factors contribute to distress, while others appear to 'buffer' a person against the stresses and strains of living with a disfigurement.

A number of factors have been thought to have a positive impact on psychosocial coping for patients with eye conditions. This includes advancing age<sup>8</sup>, perceived social support and levels of concern about appearance issues. Research from ophthalmic outpatient clinics reveal that higher anxiety levels are significantly related to greater worry about appearance, belief that the condition is more noticeable to others and a to less favourable perception of social support. Higher levels of depression were related to a greater worry about appearance and lower perceived social support<sup>1</sup>.

This study aims to take this work further by employing a range of validated psychosocial measures to identify the psychosocial and appearance related concerns of a range of disfiguring ophthalmic conditions. The variables included in this study aim to extend previous work, by measuring a range of psychological as well as social and demographic factors that may predict psychological adjustment. Identifying these predictors will facilitate the development of targeted psychosocial interventions and enable recommendations to be made regarding the provision of psychological support

in eye clinics. In addition this study includes outpatients from several geographic locations London, Bristol, Bradford and Sheffield.

## **Materials and Methods**

A total of 98 adult patients attending one of 4 ophthalmic outpatient clinics in London, Bristol and Sheffield or an ocular prosthetics clinic in London between 2007 and 2008 were recruited. All patients included in the study presented to the clinic with eye conditions which affected the appearance of their eyes. Such conditions include ptosis, thyroid eye disease, strabismus, ocular cancer and trauma.

### *Materials*

The two measures of psychological well being included were the DAS24 and the HADS. The other intervening cognitive variables were selected on the basis that they are considered potentially modifiable through psychosocial intervention and from the experience of clinicians and research are associated with the extent of psychological adjustment.

The questionnaire included six validated scales.

- The Hospital Anxiety & Depression Scale (HADS)<sup>9</sup>, a valid and reliable 14-item self screening questionnaire for depression and anxiety in patients with physical health problems. Higher scores indicate greater levels of depression or anxiety and scores 11 > on either of the HADS subscales



indicates clinical caseness, that were the individual to be examined by an experienced mental health professional, it is highly likely that they would be diagnosed to be suffering from an identifiable psychiatric disorder. The HADS has shown adequate internal consistency over a range of studies and good concurrent validity when compared to a range of other anxiety and depression scales ( $r=0.60$  to  $0.80$ )<sup>10</sup>. It has been used to good effect in studies with patients with facial disfigurements<sup>11</sup>.

- The Derriford Appearance Scale short form (DAS24)<sup>12</sup>, a shortened version of the DAS59<sup>13</sup> measures appearance related distress and dysfunction. It has been widely used in research related to disfigurement. Total scores range from 11-96 with lower scores representing lower levels of distress. It has adequate internal consistency ( $\alpha=0.92$ ), test retest reliability ( $r=0.82$ ), concurrent validity with the DAS59 ( $r=0.88$ ) and convergent validity with measures of anxiety, depression, social avoidance, social distress, fear of negative evaluation, negative affect and shame ( $r>0.45$ ).
- Physical Appearance Discrepancy Questionnaire (PADQ) based on the work of Altabe & Thompson (1996)<sup>14</sup>, assesses how different the participant feels they look from their ideal, as considered by themselves, the media and friends & family. Scores range from 4-28 with higher scores representing a greater discrepancy.
- The Valence of Appearance scale (CARVAL)<sup>15</sup> measure how positively or negatively the participant evaluates their own appearance, with higher scores indicating a more positive evaluation. Scores range from 6-36.

- The Saliency of Appearance scale (CARSAL)<sup>15</sup> measures the extent to which appearance is important to a person. Higher scores indicate greater salience. Scores range from 6-36.
- The Iowa-Netherlands Comparison Orientation measure (INCOM)<sup>16</sup> measures the individual differences in how often a person compares their appearance to that of others. Higher scores indicate a higher frequency of comparisons with others on the basis of appearance. Scores range from 11-55. The authors cite good psychometric properties of the scale.

Participants were asked to state the area of the body they were most concerned about and asked to rate from 1 (extremely easy) to 7 (impossible) how difficult the participant felt it was to hide or disguise the aspect of appearance about which they were most concerned. Participants were also asked to rate their feelings of social acceptance; the extent to which the respondent felt accepted by their social group and society in general.

### ***Statistical analysis***

Differences between groups were explored using t-tests and ANOVA. The relationships between all variables were investigated using Pearson product-moment correlation coefficient. All tests were two tailed, with a significance level of  $p=0.05$ . The data was analyzed using SPSS version 14.

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171 ***Statement of ethics***

172 We certify that all applicable institutional and governmental regulations  
173 concerning the ethical use of human volunteers were followed during this  
174 research.

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176

177 **Results**

178 The mean age of participants was 52.79 years ranging from 18 to 87. 62% were  
179 female and 81% were white. Approximately 58% were married or lived with their  
180 partner. Having a disease or illness (16.3%) and getting older (16.3%) were the  
181 two main self reported causes of the condition leading to appearance concern.  
182 For 79% of participants the eyes were their main area of concern in regards to  
183 their appearance.

184

185

186 Table 1 displays the mean scores for all variables. The DAS24, anxiety and  
187 depression mean scores were within the normal range. However, standard  
188 deviations and ranges indicate that the variation in scores between participants  
189 was considerable with some patients experiencing considerable levels of  
190 generalized anxiety. The distribution of patients with anxiety and depression  
191 which was classified as either 'normal', 'moderate' or 'caseness' is illustrated in  
192 figure 1.

193

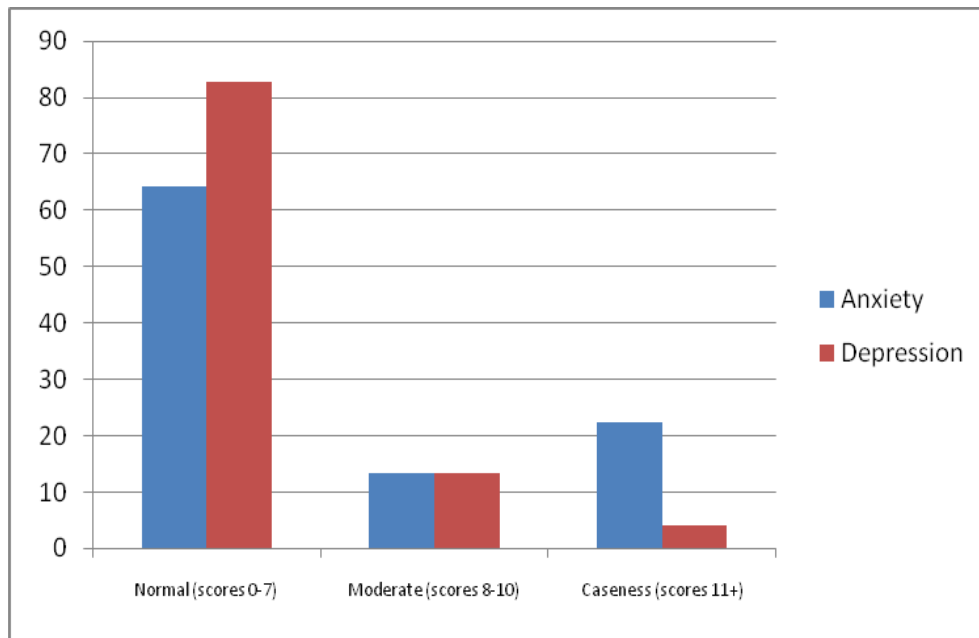
194 **Table 1. Descriptive Statistics for sample**

	<i>Group</i>	<i>N</i>	<i>Mean</i>	<i>Std. Deviation</i>
DAS24	Overall	98	37.80	13.03
	Female	62	41.11	12.97
	Male	34	31.10	10.56
Depression	Overall	98	4.44	3.31
	Female	62	4.84	3.60
	Male	34	3.55	2.51
Anxiety	Overall	98	7.16	4.57
	Female	62	7.86	4.70
	Male	34	5.66	4.04
Visibility	Overall	94	5.39	2.17
	Female	59	5.58	2.05
	Male	33	5.00	2.40
Disguisability	Overall	88	4.61	1.70
	Female	58	4.90	1.69
	Male	28	4.07	1.65
Self	Overall	96	30.08	10.77
discrepancy	Female	61	32.62	9.52
	Male	33	25.13	11.63
Salience	Overall	98	33.22	6.80
	Female	62	34.88	6.50
	Male	34	30.20	6.54

Social	Overall	98	35.72	6.89
Comparison	Female	62	36.89	5.67
	Male	34	33.34	8.39
Social	Overall	97	11.65	2.61
Acceptance	Female	61	11.52	2.49
	Male	34	12.06	2.70
Valence	Overall	98	21.95	7.66
	Female	62	23.89	7.43
	Male	34	18.35	7.04

195

196 The independent sample t-test showed no significant differences between men  
197 and women on scores of depression, visibility and social acceptance. There  
198 were significant differences on the DAS24  $t(93) = 3.808$ ,  $p=0.000$  (two-tailed),  
199 anxiety ( $t(93) = 2.282$ ,  $p=0.025$  (two-tailed), disguisability  $t(83) = 2.159$ ,  
200  $p=0.034$ , salience  $t(93) = 3.482$ ,  $p=0.001$ , social comparison  $t(50.47) = 2.201$ ,  
201  $p=0.032$  and valence  $t(93) = 3.515$ ,  $p=0.001$  with males scoring lower on all  
202 variables (Table 1). However, the effect size ranged from very small (0.008) to  
203 large (0.139).



**Figure 1. Classification of anxiety and depression by %**

A significant negative correlation was found between age and the DAS24  $r=-0.33$ ,  $n=95$ ,  $p<0.01$  and salience  $r=-0.22$ ,  $n=95$ ,  $p=0.03$ , with older participants experiencing less distress and dysfunction as a result of their appearance and considered appearance to be less important.

The relationships between the DAS24, HADS and all other variables are displayed in Table 2. The DAS24 was correlated significantly with all other variables, in the expected directions. The largest correlations were found between the DAS24 and overall discrepancy and valence. Depression and anxiety were found to significantly correlate with overall discrepancy and valence, ranging from 0.24 to 0.43. Small significant correlations were also found between anxiety and visibility and anxiety and salience.

**Table 2. Pearson's correlation coefficients between outcomes and all other variables**

	DAS	Depression	Anxiety
Visibility	0.22 <sup>1</sup>	0.12	0.20
Disguisability	0.31 <sup>1</sup>	0.13	0.15
Salience	0.42 <sup>1</sup>	0.12	0.27 <sup>1</sup>
Social Comparison	0.34 <sup>1</sup>	0.03	0.15
Overall discrepancy	0.54 <sup>1</sup>	0.43 <sup>1</sup>	0.31 <sup>1</sup>
Social Acceptance	-0.48 <sup>1</sup>	-0.11	-0.15
Valence	0.55 <sup>1</sup>	0.37 <sup>1</sup>	0.24 <sup>1</sup>

<sup>1</sup> p<0.05

## Discussion

This study aimed to determine the psychosocial and appearance related concerns of a sample of ophthalmic patients. Scores on the DAS24 suggest that participants were experiencing distress and dysfunction in relation to their appearance, with scores higher than that of the general population<sup>17</sup> but lower than previous studies of patients attending ophthalmic outpatient clinics<sup>1, 18</sup>. Interestingly, nearly 40% of participants reported levels of distress and dysfunction in relation to their appearance that were higher than population

norms. This confirms previous findings in ophthalmic outpatients with disfiguring eye disease<sup>1</sup> and suggests that this is a pervasive issue for patients which could be an important motivating factor for consulting with ophthalmologists and surgeons.

Similarly, although mean scores for anxiety and depression suggest that many participants were in the normal range, these mean scores were higher than that of a non-clinical sample<sup>19</sup>, and similar to those of pre-operative strabismus patients<sup>18</sup> but lower than previous reports of other ophthalmic outpatient clinics dealing with disfiguring disease<sup>1, 20</sup>. Although the majority of participants fell below the clinical cut off scores on the HADS, over 22% of the population displayed 'caseness' levels of anxiety. This is slightly lower than previously reported<sup>1</sup> but is nevertheless indicative of a high level of unmet need in this population.

Although female participants were found to experience greater levels of general anxiety, reported higher levels of distress and dysfunction in relation to their appearance, placed more value on their appearance, compared their appearance more often with others and evaluated their appearance more negatively than males, the differences in mean scores were marginal. An exception to this pattern is in relation to appearance related distress and dysfunction in which large differences between men and women were reported. This is consistent with the disfigurement literature<sup>21</sup>.



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258 As has been found in studies involving clinical patients and the general  
259 population<sup>17 21</sup> older age was related to appearance being less important and  
260 lower levels of appearance related distress and dysfunction .These higher  
261 levels reported by the younger responders may be a reflection of the perception  
262 that appearance is considered more important for relationships and social  
263 activity, hence the significantly higher scores for appearance salience in this  
264 study.

265

266

267 The correlations between adjustment, visibility and disguisability suggest that  
268 those patients who perceive their disfigurement to be highly visible and  
269 experience difficulties disguising this feature, exhibit increased levels of general  
270 anxiety and appearance related distress and dysfunction. This is in line with  
271 previous research which suggests that participants who believe their disfiguring  
272 condition is more noticeable to other people are more likely to experience  
273 increased levels of anxiety<sup>1</sup>.

274

275

276 Our study is limited by the fact that data on clinical diagnosis was not collected  
277 and therefore analysis looking at the impact of specific conditions was not  
278 possible. It is feasible that other chronic conditions and their resultant symptoms  
279 and treatment may have impacted upon psychological adjustment, future

research would therefore benefit from capturing this data. Furthermore, participants are those attending for hospital appointments and therefore actively seeking treatment. As highlighted in a recent review<sup>22</sup> this maybe because these patients are experiencing greater levels of appearance related distress, have worse visual function or because they or their primary care provider is unaware of the treatment options. Further research is needed to identify what type of patient seeks treatment for disfiguring eye conditions.

These findings should be interpreted by clinicians with some caution as there was considerable variability in scores from patients indicating that it is not always the case that markers such as being male, older, with a less visible and more disguisable condition will buffer a patient from distress about their appearance. Surgical decision making and assessment for psychological support for example, should still consider each patient's concerns and expectations on a case by case basis, rather than relying on gender, age, visibility or perceived disguisability of the condition as reliable indicators of unmet need.

In summary, this study found that although many participants were coping successfully with concerns about their appearance, there were substantial numbers of patients experiencing high levels of distress and dysfunction in relation to their appearance. This study also identified a number of psychosocial

variables related to adjustment including the importance placed on appearance, how a person views their own appearance, feelings of social acceptance, how often a person compares their appearance to others and the discrepancy between how a person feels they look in reality compared to their ideal self. These factors help us better understand how patients positively adjust to their disfiguring eye condition. These findings are of clinical importance as they offer an opportunity for clinical intervention and are now being used to develop structured psychological interventions to improve successful psychological adjustment and address the unmet needs of ophthalmic outpatients with disfiguring conditions.

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