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

3

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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 deficits¹. 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 avoidance¹. 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 friends². 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 distress⁴. There is a consensus amongst researchers and practitioners that

75 individual adjustment is affected by a complex interplay of physical, socio-
76 cultural and psychosocial factors⁴⁵⁶⁷ in which some factors contribute to distress,
77 while others appear to 'buffer' a person against the stresses and strains of living
78 with a disfigurement.

79

80

81 A number of factors have been thought to have a positive impact on
82 psychosocial coping for patients with eye conditions. This includes advancing
83 age⁸, perceived social support and levels of concern about appearance issues.
84 Research from ophthalmic outpatient clinics reveal that higher anxiety levels are
85 significantly related to greater worry about appearance, belief that the condition
86 is more noticeable to others and a to less favourable perception of social
87 support. Higher levels of depression were related to a greater worry about
88 appearance and lower perceived social support¹.

89

90

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

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

101

102

103 **Materials and Methods**

104 A total of 98 adult patients attending one of 4 ophthalmic outpatient clinics in
105 London, Bristol and Sheffield or an ocular prosthetics clinic in London between
106 2007 and 2008 were recruited. All patients included in the study presented to
107 the clinic with eye conditions which affected the appearance of their eyes. Such
108 conditions include ptosis, thyroid eye disease, strabismus, ocular cancer and
109 trauma.

110

111

112 *Materials*

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

118 The questionnaire included six validated scales.

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

123 indicates clinical caseness, that were the individual to be examined by an
124 experienced mental health professional, it is highly likely that they would
125 be diagnosed to be suffering from an identifiable psychiatric disorder. The
126 HADS has shown adequate internal consistency over a range of studies
127 and good concurrent validity when compared to a range of other anxiety
128 and depression scales ($r=0.60$ to 0.80)¹⁰. It has been used to good effect in
129 studies with patients with facial disfigurements¹¹.

- 130 • The Derriford Appearance Scale short form (DAS24)¹², a shortened version
131 of the DAS59¹³ measures appearance related distress and dysfunction. It
132 has been widely used in research related to disfigurement. Total scores
133 range from 11-96 with lower scores representing lower levels of distress.
134 It has adequate internal consistency ($\alpha=0.92$), test retest reliability
135 ($r=0.82$), concurrent validity with the DAS59 ($r=0.88$) and convergent
136 validity with measures of anxiety, depression, social avoidance, social
137 distress, fear of negative evaluation, negative affect and shame ($r>0.45$).
- 138 • Physical Appearance Discrepancy Questionnaire (PADQ) based on the
139 work of Altabe & Thompson (1996)¹⁴, assesses how different the
140 participant feels they look from their ideal, as considered by themselves,
141 the media and friends & family. Scores range from 4-28 with higher scores
142 representing a greater discrepancy.
- 143 • The Valence of Appearance scale (CARVAL)¹⁵ measure how positively or
144 negatively the participant evaluates their own appearance, with higher
145 scores indicating a more positive evaluation. Scores range from 6-36.

- 146 • The Saliency of Appearance scale (CARSAL)¹⁵ measures the extent to
147 which appearance is important to a person. Higher scores indicate greater
148 saliency. Scores range from 6-36.
- 149 • The Iowa-Netherlands Comparison Orientation measure (INCOM)¹⁶
150 measures the individual differences in how often a person compares their
151 appearance to that of others. Higher scores indicate a higher frequency of
152 comparisons with others on the basis of appearance. Scores range from
153 11-55. The authors cite good psychometric properties of the scale.

154

155

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

162

163

164 ***Statistical analysis***

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

169

170

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.

175

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

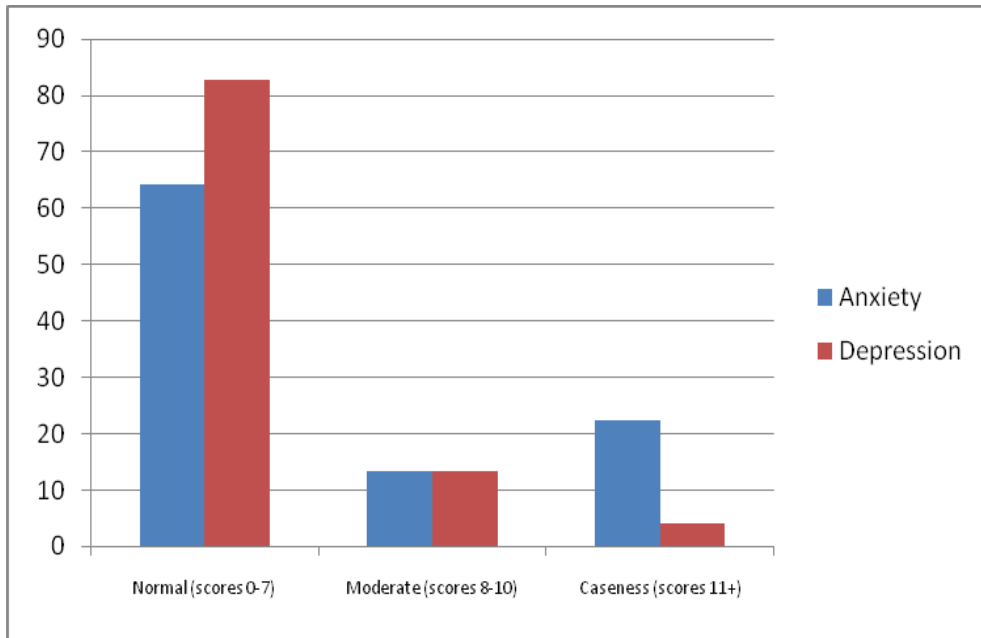
194 **Table 1. Descriptive Statistics for sample**

	<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 discrepancy	Overall	96	30.08	10.77
	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).



204

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

206

207 A significant negative correlation was found between age and the DAS24 $r=-$
 208 0.33, $n=95$, $p<0.01$ and salience $r=-0.22$, $n=95$, $p=0.03$, with older participants
 209 experiencing less distress and dysfunction as a result of their appearance and
 210 considered appearance to be less important.

211

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

219

220 **Table 2. Pearson’s correlation coefficients between outcomes and all**
 221 **other variables**

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

222 ¹ p<0.05

223

224 **Discussion**

225 This study aimed to determine the psychosocial and appearance related
 226 concerns of a sample of ophthalmic patients. Scores on the DAS24 suggest that
 227 participants were experiencing distress and dysfunction in relation to their
 228 appearance, with scores higher than that of the general population¹⁷ but lower
 229 than previous studies of patients attending ophthalmic outpatient clinics^{1, 18}.

230 Interestingly, nearly 40% of participants reported levels of distress and
 231 dysfunction in relation to their appearance that were higher than population

232 norms. This confirms previous findings in ophthalmic outpatients with
233 disfiguring eye disease¹ and suggests that this is a pervasive issue for patients
234 which could be an important motivating factor for consulting with
235 ophthalmologists and surgeons.

236

237

238 Similarly, although mean scores for anxiety and depression suggest that many
239 participants were in the normal range, these mean scores were higher than that
240 of a non-clinical sample¹⁹, and similar to those of pre-operative strabismus
241 patients¹⁸ but lower than previous reports of other ophthalmic outpatient clinics
242 dealing with disfiguring disease^{1, 20}. Although the majority of participants fell below the
243 clinical cut off scores on the HADS, over 22% of the population displayed
244 'caseness' levels of anxiety. This is slightly lower than previously reported¹ but
245 is nevertheless indicative of a high level of unmet need in this population.

246

247

248 Although female participants were found to experience greater levels of general
249 anxiety, reported higher levels of distress and dysfunction in relation to their
250 appearance, placed more value on their appearance, compared their
251 appearance more often with others and evaluated their appearance more
252 negatively than males, the differences in mean scores were marginal. An
253 exception to this pattern is in relation to appearance related distress and
254 dysfunction in which large differences between men and women were reported.
255 This is consistent with the disfigurement literature²¹.

256

257

258 As has been found in studies involving clinical patients and the general
259 population^{17 21} 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 anxiety¹.

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

280 research would therefore benefit from capturing this data. Furthermore,
281 participants are those attending for hospital appointments and therefore actively
282 seeking treatment. As highlighted in a recent review²² this maybe because these
283 patients are experiencing greater levels of appearance related distress, have
284 worse visual function or because they or their primary care provider is unaware
285 of the treatment options. Further research is needed to identify what type of
286 patient seeks treatment for disfiguring eye conditions.

287

288

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

298

299

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

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

314

315

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323

324

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330

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338

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