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Psychological distress and coping following eye removal surgery

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Psychological distress and coping following eye removal surgery

Purpose: Psychological distress is reasonably well documented in people with facial disfigurement; however, in patients following eye removal surgery this has not been studied adequately. We hypothesised that lower distress levels would be associated with age and adaptive coping strategies and that women would be more likely to report higher levels of distress and, therefore, use maladaptive coping strategies.

Methods: This exploratory, cross-sectional study measured distress and coping in a sample of 56 post enucleation or evisceration patients. The Hospital Anxiety and Depression Scale and the Brief COPE measured distress and coping strategies.

Results: In all, 25.5% and 10.9% of the sample had high levels of anxiety and depression, respectively. Significant associations were found between levels of distress, coping strategies and demographic variables ($p < 0.05$). There were significant differences in coping strategies between those with higher and lower levels of distress ($p < 0.05$). Females reported higher levels of anxiety ($U = 202.5, p < .01$) and depression ($U = 229, p < .05$) than males. Those who experienced enucleation or evisceration aged between 20 and 39 reported significantly higher levels of depression compared with other age groups ($U = 68.5, p < .01$).

Conclusions: There was a relatively low level of distress across the whole sample, but we found high levels of distress in a considerable proportion (18.18%) of participants. Participants' coping strategies and levels of distress were correlated. Females and participants aged between 20 and 39 at time of eye removal were particularly vulnerable to distress.

Key words: anxiety, depression, eye loss, disfigurement, coping

Introduction

Eye removal surgery is performed to remove a diseased/injured eye, provide comfort or replace volume and allow for cosmetic and functional appearance.¹ The most common indications for eye removal surgery include intraocular malignancy, trauma, a blind painful eye, phthisis, prevention of ophthalmia, improvement of cosmesis, and microphthalmia.² Despite advances in medical and surgical interventions, complete resolution of altered appearance following facial surgery is rarely obtainable and patients commonly report related psychological consequences.

High levels of anxiety and depression are associated with altered appearance across a wide range of conditions including: facial palsy,³⁻⁵ Grave's ophthalmopathy,⁶⁻⁹ disfiguring eye conditions,¹⁰ facial burns,¹¹ and facial psoriasis.¹² However, the psychological reaction and distress experienced by those with disfigurements varies.¹³ Some research indicates that anxiety is high following an alteration in appearance,^{10, 14} and depression may be present,^{15, 16} while some studies indicate individuals do not appear to experience any psychological distress.¹⁶

Previous research regarding the psychological impact of injuries or eye conditions has mostly focused on consequences for vision, function and perceived attractiveness.⁷ More recently, ophthalmic research has explored the psychological impact experienced by patients and found that the presence of a pre-operative or disfiguring eye condition (e.g. ptosis, strabismus) is associated with higher levels of depression, anxiety, social phobia and decreased quality of life compared with general population norms.^{10, 17-20} James et al. (2011)¹⁹ found gender differences in ophthalmic patients with females reporting marginally higher levels of anxiety, depression and value placed on their appearance; and large differences in appearance-related distress and dysfunction were observed. Research indicates that corrective surgery can have benefits for physical and psychological functioning with post-operative

patients reporting lower levels of anxiety, social avoidance and disability at work; and increased quality of life and perception of their own attractiveness compared to pre-operative.^{17, 18} This research, however, is strabismus-specific and collected data over a relatively short period, post-operatively. To date, no research has examined how other ophthalmic patients cope post-operatively.

Coping is the cognitive and behavioural process used to master, tolerate, or reduce threats or stressors.^{21, 22} The coping concept involves perceiving a threat, appraising options and resources available, and selecting a response.²²⁻²⁴ The coping strategy employed will either improve functioning (adaptive coping) or maintain/increase levels of distress (maladaptive coping). In a prospective study, Nielsen & Knardahl (2014)²² found a reciprocal relationship between coping and distress, with baseline distress being positively associated with maladaptive coping, which in turn maintains existing levels of distress rather than increasing or reducing distress. Specific coping strategies are malleable which implies that strategies can be modified and developed, which could decrease levels of distress. Gender differences in coping have been observed with a meta-analysis finding that females were more likely to perceive stressors more severely and engage in emotion-focused coping, whereas men were more likely to engage in problem-focused coping.²⁵ To date, no research has explored coping in ophthalmic patients who have undergone eye removal surgery. This paper is the first to examine coping and distress in patients presenting with a range of pre-operative eye conditions following enucleation or evisceration, with data collected across a relatively longer time period, post-operatively.

Hypotheses

We aimed to 1) identify if psychological distress was a feature in a sample of people following eye removal surgery and 2) investigate whether levels of distress (anxiety or

depression) were associated with coping, age, or gender. We hypothesised that lower distress levels would be associated with age and adaptive coping strategies (active coping, acceptance, humour, planning, positive reframing, religion, emotional support, instrumental support.). We also hypothesised that women would be more likely to report higher levels of distress and, therefore, use maladaptive coping strategies (self-distraction, self-blaming, venting, behavioural disengagement, substance use, denial).

Materials and Methods

Ethical approval (REC: 11/NW/0353) was obtained for this exploratory, cross-sectional, non-interventional study with all research adhering to the principles outlined in the Declaration of Helsinki. Eligible participants using a tertiary care ophthalmology centre were recruited consecutively at their routine clinic visit. All patients were routine review patients in the ocular prosthetic department. No patients attended early due to any perceived problems they had encountered. They were reviewed by experienced ocular prosthetists. Patients and ocular prosthetists did not make any adverse comments about their cosmesis. All patients had ocular prostheses in situ which were manufactured by hand by experienced ocularists to match the fellow eye. A control group was not included as there is no immediately comparable group for this population and only patient's with major eye conditions are invited for annual reviews in the UK. Inclusion criteria were: (1) patients who had lost an eye, regardless of aetiology or chronicity; (2) patients who had undergone eye removal surgery; (3) adults aged over 18 receiving ongoing management of their enucleated/eviscerated eye; and (4) patients who were fluent in English and, therefore, able to complete the measures. Patients with a previously enucleation and evisceration diagnosed psychiatric illness or currently receiving treatment for a psychiatric or psychological problem were excluded.

Measures

The brief COPE is a 28-item inventory of common coping strategies: active coping, planning, positive reframing, acceptance, humour, religion, use of emotional support, use of instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement, and self-blame.²⁶ Table 1 presents a brief summary of each coping strategy.²⁷ Each item is scored against a four-point scale ranging from “I haven’t been doing this at all” to “I’ve been doing this a lot”. Higher scores indicated higher use of the respective strategy. Though the brief COPE has not been specifically validated for use with populations who have undergone eye removal surgery, it has been validated for use with adults in the UK and has been shown to be reliable.^{26, 28} Cronbach’s alpha is used as an estimate of the reliability of a psychometric measure where a coefficient of more than nine indicates excellent internal consistency. Cronbach’s alpha for the Brief COPE in the present study was 0.934.

The Hospital Anxiety and Depression Scale (HADS)²⁹ is a well validated and used screening measure of anxiety and depression in patients with physical health conditions. It contains 14 four-point items with two seven-item subscales, one assessing anxiety (HADS A; e.g. “worrying thoughts go through my mind”) and the other assessing depression (HADS-D; e.g. “I have lost interest in my appearance”). Total scores for each subscale range from 0 to 28.³⁰ These scores are used to determine ‘caseness’ or clinical levels of anxiety and depression; none (0-7), possible (8-10), probable (11-21). Cronbach’s alpha for the HADS in this study was 0.91.

Additionally, clinical (date and reason for surgery) and demographic variables (age, gender, marital status, ethnicity, religion and employment status) were recorded.

Procedure

Following written informed consent, participants either completed the questionnaire in a

private room in the outpatient department following their follow-up outpatient appointment or at home, returning the questionnaire with a prepaid envelope.

Statistical analysis

Data were analysed with SPSS v22 (IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.), incorporating descriptive statistics, correlations, and group comparisons. Due to the lack of normal distribution across key variables, non-parametric tests were used throughout. Correlation analyses were conducted using Spearman's r . Group comparisons were conducted using the Mann-Whitney U test and the Kruskal-Wallis test.

Results

Sample characteristics

Table 2 summarises the demographic characteristics of the sample. Fifty-six patients completed the questionnaire pack. Of the participants, 88.5% had eye removal surgery due to chronic causes (blind painful eyes, phthisic eye, eye disease, born without eyes) and 11.5% had surgery as a result of acute causes (trauma, surgery to remove tumour). The majority classified themselves as White British (85.2%), two thirds (65.5%) were married or cohabiting and the rest were single (18.2%), divorced (7.3%), widowed (7.3%) or separated (1.8%). The majority of participants identified themselves as Anglican (58.5%) with the remaining including; Roman Catholic and Sikh.

Levels of distress

Participants were split into non-case, possible case, and probable cases, consistent with the literature. However, due to the small number of participants in the possible ($n = 16$) and

probable ($n = 4$) across HADS-A and HADS-D case groups, these were collapsed into the “case” group. Table 3 summarises “caseness” for HADS-A and HADS-D.

Correlational analysis

Correlations greater than 0.4 were considered statistically meaningful correlations. There were significant correlations between brief COPE and HADS subscales (Table 4). HADS-A was significantly positively associated with active coping, planning, positive reframing, instrumental support, emotional support, self-distraction, self-blaming, venting, behavioural disengagement, substance use and denial coping strategies. Likewise, HADS-D was significantly positively correlated with using religion, planning, positive reframing, instrumental support, self-distraction, self-blaming, venting, behavioural disengagement, substance use and denial coping strategies.

Participants’ age was not significantly correlated with HADS score. However, age was significantly negatively correlated with self-distraction, active coping, positive reframing, emotional support and substance use as coping strategies. The age when participant’s eye was removed was not related to anxiety or coping scores, although, there was a significant correlation with the depression score indicating that being older when receiving eye surgery was linked to higher levels of depression.

Comparative analysis

There were significant group differences in coping strategies between those classified as HADS “cases versus non-cases”. Clinically anxious people were significantly more likely to employ active coping ($U = 133.5, p < .01$), planning ($U = 125.5, p = .001$), self-blaming ($U = 116, p < .001$), positive reframing ($U = 110.5, p < .001$), instrumental support ($U = 169, p < .05$), venting ($U = 162, p < .05$), behavioural disengagement ($U = 109, p < .001$), emotional support ($U = 177.5, p < .05$), substance use ($U = 168.5, p < .01$) and denial ($U = 98.5, p < .05$).

.001) coping strategies compared to non-anxious people. Clinically depressed people were significantly more likely to employ planning ($U = 73, p < .05$), self-blaming ($U = 53, p < .01$), positive reframing ($U = 61.5, p < .05$), behavioural disengagement ($U = 35, p = .001$) and denial ($U = 57.5, p < .05$) coping strategies compared to non-depressed people.

Female participants reported significantly higher levels of anxiety ($U = 202.5, p < .01$) and depression ($U = 229, p < .05$) compared with male participants. Females were also significantly more likely to employ active coping ($U = 229, p < .05$) and venting strategies ($U = 230.5, p < .05$), whereas males were more likely to use humour ($U = 218.5, p < .05$).

Mood did not differ significantly between age groups. There were, however, significant age group differences in active coping, $\chi^2(2) = 11.18, p < .01$, and self-distraction, $\chi^2(2) = 7.23, p < .05$, coping strategies. Participants aged 20 to 39 were significantly more likely to employ active coping ($U = 47.5, p < .01$)($U = 45, p < .01$) and self-distraction ($U = 69, p < .05$)($U = 64.5, p < .05$) coping strategies than older participants.

There were significant group differences in levels of depression, $\chi^2(2) = 9.76, p < .01$, and coping strategies based on age at eye removal. Participants who underwent eye removal surgery between the ages of 20 and 39 reported significantly higher levels of depression than those younger than 20 at age of eye removal ($U = 68.5, p < .01$) and were significantly more likely to self-blame ($U = 23, p < .05$) than those who were 39 or older at the time of surgery. There were no significant group differences between patients with acute or chronic reason for surgery in terms of levels of anxiety ($U = 109.5, p = .41$), depression ($U = 80.5, p = 0.9$), and coping strategies used ($p > .05$).

Discussion

This is the first study to examine distress and coping in ophthalmic patients following enucleation or evisceration. Compared to those with visible differences or other ophthalmic

patients there were relatively low levels of psychological distress,²⁰ as measured by HADS anxiety or depression, in the sample as a whole (81.82%).³¹ A considerable proportion (18.18%), however, reported markedly higher levels of anxiety and depression than other populations using HADS. Levels of distress in this population may have been underestimated as we excluded individuals with previous or known psychiatric/psychological problems. We identified a need to routinely assess for distress (anxiety and depression) in this population in order to provide specific, evidenced-based support for those who need it. We suggest using the HADS as it is a relatively simple questionnaire, well-used in medical out-patient populations and with good face validity. Clinicians should be alert to the possibility that patients may be masking anxiety or depression in consultations. They should be encouraged to ask patients, both male and females and particularly those aged 20 to 39 at time of eye removal, to what extent distress is a problem for them.

The hypothesis that high levels of distress (anxiety and depression) would be associated with maladaptive coping was partially supported.²² Both anxious and depressed “cases” versus “non-cases” reported different coping strategies, however, neither adaptive nor maladaptive coping strategies were a feature of high anxiety or low mood and use of religion was low in both groups. The lack of differentiation between coping strategies and poor association with distress indicates that the brief COPE may not be sufficiently sensitive or specific for use in this population. Further qualitative research may identify the specific drivers of distress for these patients and the coping strategies associated with its management. Females report greater psychological distress, arising from appearance differences in society than males.³²⁻³⁴ Consistent with the literature, we also found significant gender differences in levels of distress with females reporting higher levels of anxiety and depression compared to males. Our prediction that females would employ less positive coping was not supported as the only significant differences indicated that females used more active coping and venting,

whereas males used more humour coping strategies. However, more recent research indicates that males also experience appearance-related concern but tend to express this differently than females.³⁵ As a result, the extent and severity of appearance concern is often masked by reluctance or inability to discuss with others. Clinicians should encourage appearance-related discussions with men during consultation.

The hypothesis that levels of distress and coping strategies would be associated with age was partially supported. Age alone was not associated with distress. There were, however, significant age group differences in coping with participants aged 20 to 39 being more likely to employ self-distraction and active coping compared to younger and older participants. Additionally, results indicated that individuals who undergo enucleation or evisceration surgery aged 20 to 39 years may be particularly vulnerable to psychological distress. This vulnerability may be accounted for by a greater predisposition to depression in this age group combined with a conflicted self-identity during a time of great importance in its development.^{36, 37} Surprisingly, there was no difference in levels of distress and coping based on cause of surgery (acute or chronic).

Limitations

This study is the first to use validated measures (brief COPE, HADS) and systematically investigate distress and coping strategies in general ophthalmic patients following enucleation or evisceration. However, it has limitations. The measures used were generic and may not be sensitive or specific enough, in particular, we do not recommend that the brief COPE is used in future research concerning this population. This area of research is in need of a patient reported impact and outcome measure for use in clinical practice and this study could inform its development.

The sample size was small and the patient group heterogeneous as recruitment was a challenge due to the infrequency of enucleation and evisceration. Practical considerations meant that all participants were recruited consecutively from secondary care from one specialist centre. In this case, recruitment from secondary care was appropriate as it is typical for enucleation and evisceration patients to attend regular check-ups and it eliminated the effect of several clinicians. However, recruitment from a specialist centre that utilises a holistic approach may not be typical of other centres and it is possible patients will have better outcomes compared to those receiving care at other non-specialist institutions. Additionally, all patients in the sample had prosthesis: levels of distress may vary for those without. Thus, levels of distress in this population may be underestimated in the current sample and there is a need for further research across service provision and subgroups using more sensitive measures.

Furthermore, time since surgery was variable in this sample, this, along with the cross-sectional design of the study, limited determination of causality and we recommend a prospective longitudinal design study to capture change over time following surgery.

Conclusion

We have shown distress is high in a small but important proportion of patients who have experienced enucleation or evisceration. Surgical ophthalmology services typically treat the physical and functional aspects of eye removal surgery exclusively with little consideration of psychological and social consequences, as evidenced by the lack of on-going psychological support for this patient group. This study highlights the need for service development to include a psychological assessment and appropriate referral for those who need it via an established care pathway.

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Tables

Table 1: Coping strategies in the brief COPE (adapted from Litman)²⁷

Coping style	Coping strategy	Typified by
Adaptive	Acceptance	Learning to accept the problem
	Active coping	Taking steps to eliminate the problem
	Emotional support	Seeking sympathy from others
	Humour	Making light of the problem
	Instrumental support	Seeking advice from others
	Planning	Thinking about dealing with the problem
	Positive reframing	Reframing the stressor in positive terms
	Religion	Using faith for support

Maladaptive	Behavioural disengagement	Giving up trying to deal with the problem
	Denial	Refusing to believe the problem is real
	Self-blaming	Attributing the occurrence of a stressful event to oneself
	Self-distraction	Distracting oneself from a stressor by thinking about or engaging in other activities
	Substance use	Using alcohol or drugs to reduce distress
	Venting	Wanting to express feelings

Table 2: Descriptive statistics for clinical and demographic variables and HADS scores.

	n (%)	M (SD)	Range
Total	55		
Age (Years)		53.46 (16.23)	20 - 88
Gender			
<i>Male</i>	34 (61.8)		
<i>Female</i>	21 (38.2)		
Employment			
<i>Employed</i>	28 (51.9)		
<i>Unemployed</i>	26 (48.1)		
Age at eye removal surgery (years)		22.31 (18.55)	2 - 77
Time since eye removal surgery (years)		32.35 (22.69)	3 – 79

Table 3: Level of psychological distress according to HADS score

	HADSA (%)	Median (IQR)	HADSD (%)	Median (IQR)
Non-Case	41 (74.5)	3 (5)	49 (89.1)	1 (3)
Case	14 (25.5)	11.5 (5)	6 (10.9)	12 (4)

Table 4: Spearman's rho correlations between demographic variables, brief COPE subscales and HADS subscales.

	Years Since Surgery	Eye Removal Age	HADS A	HADS D	Self-distraction	Active Coping	Religion	Acceptance	Humour	Planning	Self-blaming	Positive reframing	Instrumental support	Venting	Behavioural Disengagement	Emotional Support	Substance Use	Denial			
Age	.49*	.14	-.25	.02	-	-	-.03	-.12	-.19	-.25	-.09	-.29*	-.14	-.08	-.1	-.28*	-.29*	-.24			
	*				.33*	.42*															
Years Since Surgery		-.68**	-.21	-.23	-.22	-.15	.05	.1	-.04	-.02	.02	-.1	-.07	.06	.05	-.26	-.14	-.2			
Eye Removal Age				.07	.39**	-.04	-.24	-.05	-.19	-.08	-.18	-.05	-.26	-.07	-.16	-.13	-.01	-.02	.06		
HADS A					.62**	.42**	.5**	.23	.20	.2	.52*	.57*	.49**	.51**	.4**	.5**	.49**	.47**	.6**		
HADS D						.36**	.22	.27*	.21	-.06	.37*	.5**	.27**	.34**	.35**	.46**	.25	.34**	.6**		
Self-distraction							.65*	.33*	.48**	.25	.63*	.5**	.55**	.47**	.67**	.36**	.55**	.46**	.52*		
Active Coping								.36*	.44*	.29*	.73*	.55*	.69**	.65**	.58**	.4**	.61**	.27	.55*		
Religion											.44**	.05	.52*	.43*	.46**	.3*	.42**	.4**	.41**	.15	.47*
											*	*									*

Acceptance	.34*	.44*	.33*	.51**	.28*	.88**	.13	.26	.12	.26
Humour		.2	.31*	.31*	.33*	.22	.09	.21	.19	.18
Planning		.66*	.85**	.75**	.63**	.54**	.67**	.35**	.62*	*
Self-blaming			.61**	.61**	.5**	.56**	.41**	.31*	.66*	*
Positive Reframing				.63**	.63**	.44**	.56**	.31*	.55*	*
Instrumental Support					.46**	.48**	.76**	.37**	.57*	*
Venting							.33*	.41**	.16	.46*
Behavioural Disengagement								.5**	.59**	.69*
Emotional Support									.5**	.51*
Substance Use										.45*

$p < .05^*$

$p < .01^{**}$