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Citation: McBain, H. B., Ezra, D. G., Rose, G. E. & Newman, S. P. (2014). XThe psychosocial impact of living with an ocular prosthesis. Orbit, 33(1), pp. 39-44. doi: 10.3109/01676830.2013.851251

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Link to published version: https://doi.org/10.3109/01676830.2013.851251

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McBain, H.B, Ezra, D.G., Rose, G.E, Newman, S.P. & The Appearance Research Collaboration. (2014). The psychosocial impact of living with an ocular prosthesis. *Orbit*, 33(1), 39-44.

Long/short title: The psychosocial impact of living with an ocular prosthesis

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ABSTRACT

Objective: Many patients are satisfied with their ocular prosthesis, but some describe problems with social interactions, body image and self-esteem. Although both clinical practice and research suggest that the severity of a disfiguring condition does not predict distress, there has been little research with patients living with an ocular prosthesis. The objective was to explore the psychological impact of living with an artificial eye or cosmetic shell and determine the relationship between psychological well-being and clinical and psychosocial factors.

Methods: A cross-sectional study between March and September 2008 at the ocular prosthesis clinic of Moorfields Eye Hospital, UK. The primary outcome measures were mood as measured by the Hospital Anxiety and Depression Scale (HADS) and appearance-related social anxiety and social avoidance, as measured by the Derriford Appearance Scale (DAS24).

Results: Mean scores on the HADS and DAS24 were within normal range, but a considerable proportion of participants were experiencing significant levels of distress. Psychosocial adjustment was unrelated to most clinical and demographic variables, but was associated with a series of cognitive processes.

Conclusions: Psychological variables, rather than clinical or demographic factors, are associated with how a patient adjusts to wearing an ocular prosthesis. Such factors might be amenable to change through psychosocial intervention.

Key words: disfigurement, ophthalmology, anxiety, depression, prosthesis

Introduction

Ocular prostheses are used in the management of a wide variety of acquired and congenital disease, often after evisceration, enucleation or orbital exenteration. Despite the disfiguring nature and difficult management of such conditions, the psychological consequences of living with an ocular prosthesis are poorly understood.

The eyes are important for inter-personal communication.(1) All artificial eyes have somewhat limited motility and orbito-facial prostheses have none, thus affecting eye contact during personal interactions. Nonetheless, patients frequently express high levels of satisfaction with the shape, colour, mobility, fixation and comfort of an ocular prosthesis.(2) Satisfaction has been found to be greater for those who feel that their artificial eye is imperceptible to others and this is unrelated to type of surgery or orbital implant.(3) Although research suggests that adjusting to life with an ocular prosthesis can happen within the first 6 months(4) for about 40% of patients this can take 2 years or more.(5)

Early research has emphasized the importance of psychological outcomes after enucleation.(5;6) Quality of life (QoL) has been found to be severely affected(7;8) and although research has shown that patients with an ocular prosthesis exhibit levels of anxiety and depression that are within the normal range,(8-10) the prevalence of clinical anxiety or depression is over 28%. Higher levels of anxiety and depression have been linked to older age, being married, having children and the belief that the prosthesis highly influences social and interpersonal relationships.(8) In contrast Wang and colleagues(10) found that before orbital implant

insertion 49% of participants exhibited clinical levels of anxiety and this dropped to 10% after treatment.

Whilst previous reports have considered the extent of psychological adjustment for individuals living with an ocular prosthesis this study represents not only a detailed investigation of two important psychological outcomes, mood and social avoidance. It also aims to explore the relationship between these variables and clinical, demographic and intervening psychological processes. Identification of these process variables is of clinical importance as these factors might be amenable to intervention, thereby providing avenues to improve the psychosocial well-being of such patients.

The primary aim of this study was to determine the psychosocial well-being of patients wearing an ocular prosthesis and, secondarily, to determine the relationship between these measures and clinical, demographic and cognitive processes.

Materials and methods

SETTING

A cross-sectional study was undertaken with participants recruited in an outpatient clinic at Moorfields Eye Hospital, London. Participants either completed the questionnaire at the hospital or at home, the questionnaires containing a number of demographic and psychosocial questions.

ETHICS

The study was performed according to the Declarations of Helsinki.

PATIENTS AND STUDY POPULATION

Patients attending the ocular prosthetics clinic at Moorfields Eye Hospital, London were approached to take part in the study; they were considered eligible for recruitment if aged over 17 years and living with an ocular or orbital prosthesis. Ninety-eight participants were recruited into the study and completed questionnaires were received from 39 (39.79%) participants.

MATERIALS

How people adjust to living with a visible difference is multifaceted and current models that aim to understand this process fail to capture these complexities. A number of psychosocial variables that are potentially amenable to change have been identified and developed into a framework by the Appearance Research Collaboration (ARC). This framework aims to capture the range of experiences of those affected by a visible difference, along with indentifying a number of factors that might predict adjustment (Figure 1). Using this framework data were collected on the following variables:

Predisposing factors

Gender, age, ethnicity, current living arrangements (i.e. living alone, living with friends/family, living with partner), age of acquisition, duration of prosthesis wear (from first fitting), aetiology and type of prosthesis.

Intervening cognitive processes

<u>Dispositional style</u>

Levels of optimism were measured using the four-item version of the Life Orientation Test-Revised(11). Questions include 'I am always optimistic about my future'. Responses are on a five-point Likert scale, ranging from 1 (strongly agree) to 5 (strong disagree). Total score ranges from 4-20, with higher scores indicating a more optimistic outlook.

Socio-cognitive factors

Satisfaction with Social support

Quality of social support was assessed using the four-item version of the Short Form Social Support Questionnaire(12) which asks how satisfied a person is with different types of support including practically and socially.. Quality ratings ranged from 1 (very satisfied) to 6 (very dissatisfied), with total scores ranging from 4-24. Higher scores represent a greater satisfaction with one's social network.

Feelings of social acceptance

Two items, with a seven-point Likert scale ranging from 1 (not at all) to 7 (completely), were used to assess the extent to which the respondent felt accepted by their social group and by society in general. Total scores range from 2 to 14, with higher scores indicating greater subjective feelings of acceptance.

Fears of Negative Evaluation (FNE) scale(13)

This 12-item scale examines the extent to which an individual is concerned by other people's opinion of them. Questions include 'I am afraid that other people will find fault with me' and 'If I know someone is judging me, it has little effect on me'. Scores range from 12 to 60, with high scores indicating a greater fear of negative evaluation.

Netherlands Comparison Orientation Measure (NCO)(14)

The NCO comprises 11 items, rating how often the respondent compares themselves wit others. Questions include 'I am not the type of person who compares often with others' and 'I always like to know what others in a similar situation would do'. Responses range from 1 (strong disagree) to 5 (strongly agree), and higher scores indicating a greater level of social comparison.

Appearance-related cognitions

Disguisability

Participants were asked to rate how difficult they felt it was to disguise this area of concern, on a Likert scale ranging from 1 (extremely easy) to 7 (impossible).

The Valence and Salience of Appearance Scales (CARVAL, CARSAL)(15)

The CARVAL is a 6-item questionnaire that measures how a participant evaluates their own appearance (valence), with higher scores indicating a more negative evaluation. Questions include 'My body and face look pretty much the way I would like' and 'I don't like the way I look'. CARSAL measures the extent to which appearance is part of a person's working self-concept or how important it is to them (salience), with higher scores indicating that appearance forms a greater part of their self-concept or is more important to them. Questions include 'I am usually conscious of my appearance' and 'For me, my appearance is an important part of who I am'. Responses range from 1 (strongly agree) to 6 (strongly disagree) for each item (total ranging from 6 to 36).

Physical Appearance Discrepancy Questionnaire (PADQ)(16)

The PADQ evaluates the discrepancy between how a person thinks they look and how they (or others) would ideally like them to look. Questions include 'How different from your ideal appearance do you think you look?' and 'How different are you from the way your friends think

you should look?'. The scale consists of 8 items, each, with responses ranging from 1 (not at all different) to 7 (extremely different), and a higher score indicating greater discrepancy.

Primary outcome measures

The Derriford Appearance Scale short form (DAS24)(17;18)

The DAS24, a 24-item version of the DAS59,(19) is a measure of social anxiety and social avoidance in relation to appearance. Questions include 'How distressed do you get when you see yourself in the mirror/window?' and 'How distressed do you get when going to social events?'. The total score ranges from 11 to 96, with lower scores representing low levels of social anxiety and social avoidance.

The Hospital Anxiety & Depression Scale (HADS)(20)

The HADS is a validated, reliable 14-item self-screening questionnaire for depression and anxiety, for use in patients with physical health problems. Questions include 'I still enjoy the things I used to enjoy' and 'I can laugh and see the funny side of things'. Scores range from 0 to 21, with higher scores indicating greater levels of depression or anxiety. For both subscales, a score of 0–7 is regarded as being in the 'normal' range, 8–10 is suggestive of moderate levels of anxiety or depression, and greater than 10 indicates a high likelihood that such a patient would receive a diagnosis of clinical anxiety or clinical depression.

STATISTICAL ANALYSIS

Data was analyzed using SPSS v.16 (SPSS Inc, Chicago, Illinois). Scores for different groups were compared using one-way ANOVA, with an α-risk of 0.05. The relationship between pairs of variables was investigated using the Pearson product-moment correlation coefficient.

Results

Completed questionnaire were received by 39 patients (18 female, 46%) and of these 37 (95%) indicated that the appearance of their eyes caused them some concern. Demographic and other group characteristics are summarised in Table I.

All psychometric measures show good internal consistency, with Cronbach's alphas greater than 0.7. Table II displays descriptive statistics for all variables. Although mean scores for anxiety and depression are within the accepted normal range, the results suggest that 18% (n=7) of the patients were experiencing clinical depression and 18% (n=7) clinical anxiety; this included 3 participants who were experiencing both clinical anxiety and depression. Although scores for appearance-related social anxiety and social avoidance (mean 37.5, standard deviation 14.7, standard error of mean 1.96) are within the normal range, 21% (n=8) of patients reported considerable levels of social anxiety and avoidance in relation to their appearance.

Appearance-related social anxiety and avoidance

The DAS24 correlated significantly with social acceptance ($r = -0.46$, $p = 0.01$) and valence ($r = 0.55$, $p = 0.02$), There were no significant associations between the DAS24 and any other demographic, clinical or psychosocial variable.

Anxiety and depression

The pattern of correlations for anxiety and depression differed: anxiety was correlated significantly with disguisability ($r = 0.46$, $p = 0.01$), self-discrepancy ($r = 0.48$, $p < 0.01$), valence (r

= 0.45, p = 0.01) and salience (r = 0.45, p = 0.01). Depression significantly correlated with social acceptance (r = -0.46, p < 0.01), self-discrepancy (r = 0.52, p < 0.01), optimism (r = -0.50, p < 0.01) and valence (r = 0.58, p < 0.01). As compared with those living with someone (friends, family or a partner), those living alone experienced significantly higher levels of depression (living alone 10.4, living with someone 7.00; $F_{(1, 66.06)} = 5.37$, p = 0.02), with a large effect size (Cohen's d = 0.99). There were no significant associations between anxiety or depression and any other demographic, clinical or psychosocial variable.

Discussion

Contrary to the expectations of many healthcare professionals and consistent with research in other areas(21) this study suggests that the psychological well-being of those living with an ocular prosthesis is not related to duration of prosthetic wear, age of acquisition, gender, current age or type of prosthesis. Rather poor psychological well-being was related to having a pessimistic outlook and the beliefs a patient has about their appearance and how accepted they feel by society. This study also highlights the importance of instrumental support, as those participants living with a partner, family or friends had lower levels of depression than those living alone. The identification of these underlying cognitive processes is of importance as clinicians can now identify patients who are experiencing considerable levels of psychological distress and target these potentially modifiable cognitive processes through psychological intervention, thus potentially improving the well-being of this population.

Levels of anxiety and depression were within the normal to moderate range, some patients had scores indicating a possible clinical diagnosis of anxiety or depression. The proportion of such

patients was considerably higher than would be expected in the general population,(22) and greater than that reported by Wang and colleagues(10) in a study post insertion of a secondary hydroxyapatite orbital implant but considerably lower as compared to a group of Korean anophthalmic patients.(8) The degree of appearance-related social anxiety and avoidance is somewhat higher than that of the general population,(17) and patients post orbital implant insertion.(10) Suggesting that this population experience considerable generalised anxiety and depression and also anxiety specific to social situations and hence use techniques and strategies to hide their appearance and avoid social interaction.

This investigation has some limitations that need to be acknowledged. The study was exploratory, cross-sectional, and with a modest sample size. Over 40% of the sample failed to return a completed questionnaire, potentially biasing the results of the study. It may be that either appearance was a greater concern for those who chose not to participate or they may have been experiencing greater levels of anxiety or depression. Generalization to other ocular prosthetics patients should be made with caution, as only patients attending for prosthetics fitting were recruited. Thereby excluding long-term prosthetics wearers not being followed up in clinic; such patients might either be very happy with their prosthesis, or perhaps silently bearing a considerable psychological burden. The cross-sectional nature of this investigation precludes an examination of how individuals change over time and adjust to their prosthesis. Furthermore, although a number of specific cognitive processes have been found to significantly correlate with psychological well-being, any causal relationship between these factors and adjustment remains unclear. Future work might benefit from exploring the role of other clinical measures of prosthetic performance, such as visual acuity and field in the remaining eye, comfort of the prosthetic, or discharge from the socket.

The results of this study are, nevertheless, of clinical importance. The proportion of patients with clinical anxiety or depression highlights a need to identify such patients and implement referral pathways for appropriate management. This identification of patients needing psychological care might be best achieved by using validated measurement tools such as the HADS or DAS24.

Successful adaptation to an artificial eye appears to be associated with a number of underlying beliefs held by the patient, rather than clinical aspects of their condition. The identification of these factors provides a better understanding of the distress experienced by patients living with an ocular prosthesis and offers a potential therapeutic opportunity through psychological interventions such as cognitive behavioural therapy.

Declarations of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Acknowledgements

Funding for the study was provided by the Healing Foundation in association with the Welton foundation and the Worshipful Company of Tin Plate Workers. The authors would like to acknowledge the ARC Advisory Committee, in particular, Olivia Giles, Pam Warren & Luke Wiseman for their input into the ARC research programme.

Appendix

Members of the Appearance Research Collaboration (ARC);

James Byron-Daniel, Rodger Charlton, Alex Clarke, Sally-Ann Clarke, Diana Harcourt, Elizabeth Jenkinson, Antje Lindenmeyer, Tim Moss, Rob Newell, Krysia Saul, Andrew Thompson, Eleanor Walsh, Paul White, Emma Williams, Hayley McBain, Stanton Newman.

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Predisposing factors		Intervening cognitive processes		Primary outcomes
		Dispositional style Optimism		
Age Gender Ethnicity Living status Age of acquisition Duration of wear Type of prosthesis Aetiology		**Socio-cognitive factors** Satisfaction with Social Support Feelings of Social Acceptance Fear of Negative Evaluation Social Comparison **Appearance-related cognitions** Perceived disguisability Salience Valence Appearance self-discrepancy		Appearance-related social anxiety & social avoidance Anxiety Depression

Figure 1. Framework of psychological adjustment to disfigurement

Table I. Characteristics of study population (n=39)		
Gender	Female n(%)	18 (46.2)
Current age	Mean (range)	50.3 years (19-87 years)
Living status	Living with partner, family or friends n(%)	32(82.1)
Ethnicity	Caucasian n(%)	29(74.4)
Reason for prosthesis wear	Trauma n(%)	22(56.4)
	Malignancy n(%)	11(28.2)
	Congenital anomaly n(%)	4(10.3)
	Illness or disease-related n(%)	2(5.1)
Type of prosthesis	Full prosthesis n(%)	28(71.8)
	Cosmetic shell n(%)	11(28.2)
Age of acquisition	Mean (range)	31.62 years (0 – 73 years)
Duration of prosthesis wear	Mean (range)	18.6 years (1 month – 71 years)

Table II. Descriptive statistics for each variable

Variable	Mean (SD)	Possible range
Optimism	14.7 (2.6)	5 - 20
Satisfaction with social support	21.0 (4.0)	4 - 24
Social acceptance	11.8 (2.5)	5 - 14
FNE[a]	34.7 (11.2)	16 - 60
Social comparison	34.8 (8.7)	14 - 54
Disguisability	4.2 (1.6)	1 - 7
Valence	21.1 (8.6)	7 - 36
Salience	31.7 (7.2)	13 - 42
Self discrepancy	29.0 (13.0)	8 - 56
DAS24[b]	37.5 (14.7)	11 - 88
Anxiety	6.9 (3.7)	1 - 21
Depression	7.6 (3.3)	4 - 21

[a] Fear of Negative Evaluation
[b] Derriford Appearance Scale 24

Table III. Pearson's Correlation Coefficient (r) between primary outcome measures and all other variables

	DAS24[b]	Anxiety	Depression
Current age	-0.20	-0.11	-0.12
Duration of prosthesis wear	-0.07	-0.14	-0.22
Age of acquisition	-0.12	0.04	0.10
Optimism	-0.32	-0.36	-0.50*
Satisfaction with social support	-0.44	0.07	-0.23
Social acceptance	-0.46†	-0.28	-0.46*
FNE[a]	0.33	0.36	0.29
Social comparison	0.25	0.20	0.06
Disguisability	0.25	0.46†	0.30
Self discrepancy	0.28	0.48*	0.52*
Valence	0.55†	0.45†	0.58*
Salience	0.35	0.45†	0.15

[a] Fear of Negative Evaluation
[b] Derriford Appearance Scale 24
* denotes p<0.01, † denotes p<0.05

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