




The UK National Artificial Eye Questionnaire study: predictors of artificial eye wearers' experience part 1—comfort and satisfaction

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Abstract

Objectives To report associations with comfort and with appearance satisfaction in artificial eye wearers.

Methods Multicentre, observational, cross-sectional study, nationwide within the National Health Service England. The National Artificial Eye Questionnaire (NAEQ) was completed by 951 respondents. Multiple regressions assessed associations between the experiences of artificial eye wearers, routine management, changes over time, baseline and demographic parameters and their reported comfort, satisfaction with appearance and prosthesis motility.

Results Better comfort levels were associated with needing less lubrication ($\beta = 0.24$, $p < 0.001$), older age ($\beta = 0.17$, $p = 0.014$), less discharge ($\beta = 0.16$, $p < 0.001$), less frequent cleaning ($\beta = 0.16$, $p = 0.043$), and male gender ($\beta = 0.06$, $p = 0.047$). Greater satisfaction with the appearance of the artificial eye was associated with better perceived motility ($\beta = 0.57$, $p < 0.001$). Black ethnic origin predicted a lower satisfaction with the appearance ($\beta = -0.17$, $p = 0.001$). Greater satisfaction with the motility was associated with a better appearance rating ($\beta = 0.51$, $p < 0.001$), longer time of having an artificial eye ($\beta = 0.13$, $p < 0.001$), older age ($\beta = 0.11$, $p = 0.042$), and a shorter adjustment time ($\beta = -0.07$, $p = 0.016$). Of the testimonials concerning appearance aspects, the majority (21/45, 46.7%) were related to the effect on social interactions.

Conclusions The results suggest that more attention should be given to the “dry anophthalmic socket syndrome” as a key cause of discomfort. Young patients are concerned particularly about the motility of the artificial eye. Over time satisfaction with the artificial eye movement is likely to improve.

Introduction

The loss of an eye is a major life event. It requires adaption to monocular vision, including changes in perception due to the loss of binocular cues to depth and a reduction in visual field on the affected side [1]. In addition, there is a change in appearance, comfort and routine associated with wearing and maintaining an artificial eye [2]. Previous reports underscore the importance of keeping patients well informed

regarding outcomes, cosmesis and proper management of the prosthesis [3–5]. However, an evidence-based protocol for the ideal routine care and handling of an artificial eye is lacking [6, 7]. A consensus appears to be building around a protocol for managing discharge proposed by Pine et al. [8–10] Nonetheless, available data are mostly based on small discrete surveys [3–5, 11–13]. Furthermore, the effects of management and other aspects on the comfort levels experienced by patients has not been widely explored [2].

Evidence regarding the emotional, psychosocial, and quality of life (QOL) implications of artificial eye wear emphasised the importance of providing emotional support or counselling in order to maximise long term QOL [12, 13]. These patients were shown to have lower health-related QOL scores [3, 13], with perceptions of their social relationships negatively affected, whilst being prone to suffer from anxiety and depression [13]. Nevertheless, little was published regarding functional and/or vision related QOL aspects in these patients [2].

The UK National Artificial Eye Questionnaire (NAEQ) Study was devised to address the unmet need to establish

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Table 1 Multiple regression analyses for the predictive values of demographics, experience over time, aetiology, and prosthesis care regarding the comfort and satisfaction ratings, in 951 artificial eye wearers.

Predictors (variables)	Category	Comfort rating ^a		Appearance rating		Motility rating	
		Partial <i>r</i> (β)	<i>p</i>	Partial <i>r</i> (β)	<i>p</i>	Partial <i>r</i> (β)	<i>p</i>
		Multiple R squared ^c = 0.21		Multiple R squared ^c = 0.42		Multiple R squared ^c = 0.38	
Age	≥ 66	0.17	0.014	NI		0.22	0.0007
	>50–65	0.04	0.54			0.12	0.045
	>30–50	0.01	0.92			0.11	0.042
	<i>18–30</i>						
Gender	<i>Female</i>			NI		NI	
	Male	0.06	0.047				
Aetiology	Trauma	NI		NI		NI	
	<i>Congenital</i>						
	<i>Tumour</i>						
	<i>Other</i>						
Ethnicity	White	0.01	0.82	−0.04	0.49	NI	
	Black	−0.06	0.16	−0.17	0.001		
	Asian	0.02	0.71	−0.04	0.42		
	<i>Other</i>						
Total length of prosthesis time (years)		0.01	0.88	0.01	0.90	0.13	<0.0001
Length of current prosthesis time (years)		0.02	0.53	−0.05	0.42	−0.03	0.50
Time taken to adjust (years)		NI		NI		−0.07	0.016
Prosthesis cleaning frequency		0.12	0.043	0.00	0.98	0.03	0.58
Prosthesis cleaning method	Water	NI		NI		NI	
	Soap						
	<i>Other</i>						
Prosthesis removal frequency		0.00	0.95	0.08	0.26	0.03	0.56
Time since last polishing (years)		NI		−0.08	0.21	0.00	0.96
Rating degree of beneficial effect after polishing prosthesis		NI		0.01	0.73	0.05	0.073
Lubrication frequency		0.24	<0.0001	0.07	0.10	0.05	0.082
Lubrication modality	Drops	NI		0.05	0.42	NI	
	<i>Ointment</i>						
	<i>Other</i>			0.08	0.20		
Comfort rating				0.01	0.76	0.02	0.44
Discharge rating ^b		0.16	<0.0001	0.02	0.69	0.06	0.078
Discharge location ^d	<i>Visible</i>						
	Not visible	0.05	0.15	0.02	0.59	0.05	0.079
Motility rating				0.57	<0.0001		
Appearance rating						0.51	<0.0001

Values in boldface mark a significant independent predictive value of the parameter ($p < 0.05$).

Categories in italics mark the reference category.

NI—Not included in the multiple regression (univariate $p > 0.1$).

^aComfort—Average score of all items rated in this parameter related category.

^bDischarge—Average score of frequency and severity rating items.

^cMultiple regression (general linear model) R^2 .

^dDischarge visible externally during the day versus discharge not externally visible (no discharge, or builds up on the eyelashes only in the morning, or builds up only inside the socket).

an organised, wide-reaching, and comprehensive database in order to substantialise information pertaining to patient education and expectation management [4]. Part 1 of the current study aims to assess how demographics, aetiology,

length of wear, adjustment time, discharge levels, polishing and routine care may associate with the overall satisfaction with the comfort and the appearance of an artificial eye. The associations of these parameters with

visual function and QOL aspects will be addressed in Part 2. Personal testimonials relating to comfort and appearance aspects are herein discussed. Testimonials related to mental health, visual function and quality of life will be covered in Part 2.

Subjects and methods

Study design and recruitment

This national, observational and cross-sectional questionnaire study was granted approval by the National Research Ethics Service. A Health Research Authority approval was granted for each participating recruiting site, totalling 40 sites, nationwide within the National Health Service (NHS) England. The study was included on the National Institute for Health Research Clinical Research Network Portfolio and received support accordingly.

The NAEQ was available to patients 18 years of age or older attending NHS eye services or maxillofacial prosthetic services. Questionnaires were anonymous, and self-filled. All completed questionnaires were placed into a secure box (at each site) and collected to one central location (Queen Victoria Hospital, East Grinstead).

Recruitment for the study started in July 2017 and ended in April 2019, with final recruitment of 951 AE respondents. All completed questionnaires were included in the data analysis.

Questionnaire

The 37 items questionnaire (NAEQ) was constructed by a panel consisting of experienced maxillofacial prosthetists and oculoplastic specialists. Questions covered demographics, aetiology, length of prosthesis use, polishing, cleaning regime and modality, lubricant regime and modality, comfort, discharge, motility, and appearance. The NAEQ is fully disclosed in Supplement 1. The questionnaire allocated one (last) optional item for free-text testimonials to be filled by the respondent.

Testimonials

Overall, 168 artificial eye wearers have filled 193 free-text comments, covering various aspects of their experience. These free-text testimonials were grouped according their related category: Care and comfort (21/193, 10.9%); Appearance (45/193, 23.3%); Mental health and attitudes (41/193, 21.2%); Quality of life and visual function (57/193, 29.5%); Suggestions and requests (29/193, 15.0%). All comments, grouped by category, are detailed in Supplement 2.

Data analysis and statistical methods

Ordinal numeric values from the survey items were scored so that a high score represents better functioning or patient satisfaction. Each item was then converted to a 0 (lowest possible score) to 100 (highest possible score) scale, representing the achieved percentage of the total possible score. The comfort and discharge scores were each averaged across the multiple items in the questionnaire related to these parameters.

Data were analysed with StatSoft Statistica software, version 10 (StatSoft, OK, USA). Spearman (r) coefficients were calculated for correlation between continuous parameters. Analysis of variance was used for comparison of averages between groups. To test for independent predictive values of the different parameters, as well as to control for the multiple comparisons, all variables reaching a P value ≤ 0.1 in the univariate analysis were included in multiple regressions (general linear model). The regression models are presented with their respective whole model R^2 and regressors' partial r ($Beta$ coefficient). A two-sided P value of <0.05 was considered statistically significant.

Results

Of the 951 respondents, 503 (52.9%) were male; 58 (6.1%) were 18–30 years old, 160 (16.8%) were 31–50 years old, 278 (29.2%) were 51–65 years old, and 444 (46.7%) were over 65 years old.

The factors shown by multiple regression analyses to be correlated with comfort rating, satisfaction with prosthetic appearance, and satisfaction with prosthetic motility, and their relative contributions to the overall prediction of each outcome (β -coefficients), are recorded in the Table 1. The univariate analyses are detailed in Supplement 3.

Comfort level

The following five factors, presented in descending order of their relative contribution in the multiple regression model (β -coefficients), were the significant independent predictors of a better (higher) comfort rating: a negative correlation with increased frequency of lubrication ($\beta = 0.24$, $p < 0.001$), a positive correlation with older age ($\beta = 0.17$, $p = 0.014$), a negative correlation with increased amount of discharge ($\beta = 0.16$, $p < 0.001$), a negative correlation with increased frequency of cleaning ($\beta = 0.16$, $p = 0.043$), and a positive correlation with male gender ($\beta = 0.06$, $p = 0.047$).

Specifically, individuals who reported greater comfort relied on less frequent lubricant use (Table 1, Supplement 3). The next predictor of better comfort ratings was older age (66 years and older) when compared with the

youngest age group (18–30 years; Table 1, Supplement 3). Less discharge and lower frequency of prosthesis cleaning were the next predictors of better reported comfort (Table 1, Supplement 3). Lastly, male gender was a weak, however significant, predictor of better reported comfort (Table 1, Supplement 3).

Testimonials relating to comfort and care

Free-text comments relating to comfort and care constituted the lowest proportion (only 21/193 total comments, 10.9%) of all aspects covered in the artificial eye wear experience (Supplement 2). Of the testimonials in this category, nine (42.9%) were related to maintenance and care, including removal, cleaning, drops or ointments, and polishing. Seven comments (33.3%) were related to comfort, including pain, dryness, temperature, and other sensations. Five (23.8%) comments were made regarding discharge.

Satisfaction with appearance and motility

Only two factors, presented in descending order of their relative contribution in the multiple regression model (β -coefficients), were the significant independent predictors of a greater satisfaction with the general appearance of the artificial eye: a positive correlation with better perceived motility ($\beta = 0.57$, $p < 0.001$), and a negative correlation with Black ethnic origin ($\beta = -0.17$, $p = 0.001$).

The following four factors, presented in descending order of their relative contribution in the multiple regression model (β -coefficients), were the significant independent predictors of a greater satisfaction with the motility of the artificial eye: a positive correlation with a better general appearance rating ($\beta = 0.51$, $p < 0.001$), a positive correlation with a longer time of having an artificial eye ($\beta = 0.13$, $p < 0.001$), a positive correlation with older age ($\beta = 0.11$, $p = 0.042$), and a negative correlation with a longer adjustment time ($\beta = -0.07$, $p = 0.016$).

Specifically, rating of higher satisfaction with the motility of the artificial eye was a very strong predictor of a better general appearance rating. Vice versa, a better general appearance rating was the strongest predictor of a higher satisfaction with the motility (Table 1, Supplement 3). The only other significant predictor of appearance rating was ethnic background. That is, Black ethnic origin predicted a lower satisfaction with the appearance of the artificial eye (Table 1, Supplement 3).

The next strong predictor of better motility ratings was age over 30 years when compared with the youngest age group (18–30 years; Table 1, Supplement 3). Age was not associated with the general appearance rating (Supplement 3). Next, a longer length of time of having an artificial eye predicted higher satisfaction with the motility, however,

was not a significant predictor of general appearance (Table 1, Supplement 3). Lastly, a shorter self-reported adjustment time to the artificial eye was a weak, however significant, predictor of greater satisfaction with the motility (Table 1, Supplement 3).

Testimonials relating to satisfaction with appearance

Comments relating to appearance of the artificial eye constituted the second most prevalent (45/193 total comments, 23.3%) aspect in the reported artificial eye wear experience (Supplement 2). Of the testimonials in this category, the majority (21, 46.7%) were related to the effect of the appearance on social interactions. This included comments regarding stigma, tolerance of facial disfigurement, fitting in at school, staring, eye contact, romantic relationships, attractiveness, self-consciousness, and implications on self-confidence. Fourteen (31.1%) comments included assertions of degree of satisfaction with the appearance. These include statements such as that “it looks great”, “aesthetics has been much better”, as well as comments regarding the size, colour fit, and match with the fellow eye. Five comments (11.1%) were on other general aspects of appearance including, for example, eyelid sag due to prosthesis weight and change of facial appearance. Five (11.1%) comments were made stressing the motility aspect of the prosthesis. Of note, only one of these conveyed a positive perception, specifically acknowledging the superior motility of a hollow artificial eye.

Discussion

Much attention has been given to socket discharge experienced by prosthetic eye wearers, which has been shown to be a major cause for patients’ concern [2, 3, 5, 6, 11]. Surprisingly, in the current survey the discharge levels were only third-most predictive regarding the perceived overall comfort, the most predictive aspect being the frequency of applying lubrication. Furthermore, personal testimonials specifically stressing discharge issues accounted for less than a quarter of the comfort-related category. Both these variables, lubricants use and discharge, plausibly represent different facets of an uncomfortable *dry anophthalmic socket*.

A healthy, comfortable socket requires a healthy tear film together with a sustained wettability of the ocular prosthesis [14, 15]. Unfortunately, there is less tear production in the anophthalmic socket [16, 17]. It has been shown that symptomatic patients with reduced basic tear secretion require lubricants to improve symptoms [16]. Fett et al. evaluated the need for additional lubrication in 200

anophthalmic patients and found that 23% required supplementation [18].

Punctal occlusion also improved discharge and comfort, with no significant change in bacterial flora [19]. Jang et al. [20] showed that artificial eye wearers are particularly prone to meibomian gland dysfunction (MGD), a contributor to a dry, discharging socket. It has been thus advocated that greater attention should be made towards identifying, providing information, and advising treatment for MGD in symptomatic patients. Furthermore, patients should be informed regarding the potential impact of diet, systemic medication, home and work environment on tear evaporation [14].

In the current study, 33% of the respondents indicated that they rely on lubricants on at least a daily basis. We assume that more frequent lubricant use implies a dry socket, however it should be noted that we do not have evidence to support a dry anophthalmic socket syndrome directly. Nevertheless, some of the questions in the questionnaire are very similar to questions of the Ocular Surface Disease Index. [21] With regards to responses across the questions relating to comfort in different environmental exposures (wind, seasonal change, at work, at home, watching TV, and driving; Supplement 1), the highest proportions were reported for discomfort when exposed to windy conditions. Approximately 20% responded that they experience discomfort all, or most of the time, in windy conditions, implying the exacerbating effect of wind on tear evaporation. Interestingly, this would seem to be opposite to the expected tearing response in a normal eye when exposed to evaporative conditions. It could be speculated that this might be related to loss of the reflex lacrimation usually brought about by the corneal reflex.

A recent study of Rokohl et al. [22] assessed symptoms and signs of the dry anophthalmic socket syndrome using standardised dry eye questionnaires. They report that most (63%) anophthalmic patients have significantly more subjective dryness complaints on their anophthalmic side compared to the healthy fellow eye, even in absence of tear deficiency and clinical MGD [22]. Taken together, the current study adds support to the possibility that a key factor to comfort with an ocular prosthesis is addressing the dry socket with its associated contributors and manifestations.

It should be noted that the emphasis here given on the dry anophthalmic socket as a major cause of discomfort does not exclude the importance of discharge as a cause of discomfort. Both aspects are important and related. It was previously shown that there is a positive association between the incidence of discharge experience and cleaning frequency [6] and between the incidence of discharge experience and concerns about discharge [2]. The research to date showing high levels of concern about discharge are limited to those whose study populations mainly cleaned

their prosthetic eyes frequently and consequently had high (>81%) incidences of discharge [3, 23–26]. Similarly, in the current study population, 47.5% indicated that they clean their artificial eye at least once daily (including 14.6% that clean twice daily, and 1% that clean on an hourly basis). The majority of the participants indicated that they experience discharge (16.9% on a monthly basis, 9.8% twice weekly, 39.2% daily, 8.6% twice daily, 12.1% hourly). The majority (63.3%) have additionally responded that the discharge they experience is only mild or light, while 21.4% responded that the discharge is moderate (thick), and severe (requiring antibiotics) in 2% of cases. Similarly to these previous reports, we found a significant positive correlation between the frequency of cleaning and the reported level of discharge ($r=0.20$, $p<0.0001$). Of note, the regression analysis results add that higher cleaning frequency is also correlated with more discomfort, and this association is independent of the degree of discharge.

Appearance seems to be one of the most preoccupying issues in the artificial eye experience. It accounted for approximately a quarter of testimonials submitted in this survey. Not surprising, as the main function of an artificial eye is to reinstate facial harmony by offering the best possible cosmetic match [15, 27]. Specifically, the implication on social interactions was the predominant issue emphasised. This is the same for other visible disfigurements, in which the most common difficulties fall within the area of social interaction [28, 29].

Pine et al. [2] identified that among 217 prosthetic eye wearers, disguisability was an important factor, with particular concern when reduced motility or disruption of facial symmetry were perceived. Participants were more concerned with how they appeared to others compared with how they appeared to themselves [2]. In the study of Song et al. [5] satisfaction with the ocular prosthesis was linked with economic status, other people's response, and insertion of a motility peg. The results of the current study imply that the motility and the general satisfaction with the appearance of the artificial eye are almost inseparable aspects, as evident by the particularly strong reciprocal correlation between these two rating items in the questionnaire. Alternatively, it may represent the limitation entailed in trying to measure these two aspects as separate entities via self-report. Nevertheless, in the context of social interactions, it is expected that prosthesis movement in concert with the companion eye is highly related to its ultimate function of disguisability.

The fact that respondents of Black ethnic origin rated lower satisfaction with the appearance of the artificial eye seems to be a novel association. It would be difficult to determine what the reason for this ethnic disparity is, as we lack important objective data to validate these self-reported perceptions, or socio-demographic data which could be a

confounding factor. However, there are known racial differences in ocular baselines [30–32], the prognosis of several ophthalmic diseases [33–35] as well as surgical outcomes [36–38]. Furthermore, in general there is evidence to suggest that there may be amplified scar formation in dark skinned individuals [39]. However, it remains unclear as to the presence of any racial differences in complications relating to the anophthalmic socket and associated aesthetic sequelae.

Finally, longer time of having the prosthetic eye, a shorter adjustment time to the prosthetic eye, and older age were associated with greater satisfaction with the motility of the artificial eye. The fact that longer time of prosthetic eye experience was not also independently associated with the general appearance satisfaction may reflect a genuine tendency to accept the limitations of the attainable motility with an artificial eye, while the expectation to attain a good cosmetic match (e.g. in terms of size, colour, etc.) persists. Furthermore, perhaps over time patients adjust their expectations regarding what is considered a satisfactory motility range. Arguably, saccadic movement could be enough in the context of conversational eye contact, while extreme gaze duction, although ideal, is not necessarily crucial. This finding is in partial agreement with the report of Pine et al. among 63 prosthetic eye wearers, as they found that concerns regarding both appearance and motility of the prosthetic eye diminished over time [3]. The finding that a shorter self-reported adjustment time correlated with greater satisfaction with the motility could perhaps imply less socket related problems, which could plausibly influence motility range. However, objective evidence to support this speculation were not explored.

Pine et al. [2] also reported that older prosthetic eye wearers were less concerned about their appearance. They postulated that older adults' priorities may move away from their outward appearance as they become more focused on physical functioning [2, 40]. They also suggest that coping with disfigurement, particularly in the social context, improves with age, as the sense of identity or self-esteem are more established [2, 41]. The current study adds that there is a possibility that motility is more of a concern to young patients, while age was not independently associated with the general appearance satisfaction.

This study has limitations. Firstly, all data are self-reported via an anonymous questionnaire, and there is lack of examination or clinical history data to verify objective measures. Such objective evidence could have supported a claim of causal relationship between the various self-reported ratings of routine management, discharge, satisfaction with appearance, and the prosthesis motility. Currently, therefore, the reported associations cannot be determined to be causal. Furthermore, whether the patients' prosthesis wear experience is related to the type of surgery

and presence and volume of an implant could not be answered due to this study's methodology. Lastly, these data relate to acrylic artificial eyes, which is the overwhelmingly predominant type of prosthesis used in the UK. Therefore, it cannot be generalised to glass prosthesis.

In conclusion, the NAEQ study encompasses a vast array of aspects of prosthetic eye wear in the largest cohort of patients to date. As such, it allowed meaningful analyses of associations with the various experiences of prosthetic eye wear as opposed to only analysing discrete aspects. This could advance not only obtaining substantial information about these experiences in order to provide to patients, but also offer some predictive capacity to be able to anticipate problems and adjustment issues, ultimately employing resources where they could influence outcome most. Within the limitations discussed, the current results suggest the following key points:

- More attention should be given to the “dry anophthalmic socket syndrome” as a key cause for discomfort. While the “discharging socket” is an important predictor of discomfort, it may be one of the causative facets, perhaps not the predominant one.
- More frequent cleaning of the prosthesis is correlated with both more discharge and more discomfort, independently. These observations support previous evidence establishing a link between discharge severity and cleaning frequency, and add that excessive cleaning may cause discomfort, regardless of the effect on discharge. It was previously proposed that the prosthetic eye cleaning regime should be individualised, while setting a time limit within which the prosthesis should remain in the socket before it is removed for cleaning (a conservative estimate of this limit might be 6 months) [8].
- The current study underscores the intimate relationship between a good prosthetic eye movement and the overall satisfaction with its appearance.
- It seems that young patients are particularly concerned about the motility of the artificial eye. Fortunately, they could be counselled, as these data imply, that over time their satisfaction with the artificial eye movement is likely to improve.

Summary

What was known before

- Previous reports underscore the importance of keeping patients well informed regarding outcomes, cosmesis and proper management of an artificial eye.
- There is no consensus regarding the ideal routine care and handling of an artificial eye.

- Available data are mostly based on small discrete surveys.

What this study adds

- This National Artificial Eyes Questionnaire study encompasses a vast array of experiences of the artificial eye wear.
- Part 1 reports predictors of satisfaction with the perceived comfort and appearance.
- A dry socket rather than a “discharging socket” seems a key cause for discomfort.
- Young patients are concerned particularly about the motility of the artificial eye.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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